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# Report of the interim evaluation of the Consumer Dementia Research Network

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# Report of the interim evaluation of the Consumer Dementia Research Network

## **Keywords**

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## Abbreviations

AA	Alzheimer's Australia
AAR	Alzheimer's Australia Research Ltd
ACAT	Aged Care Assessment Team
CDRN	Consumer Dementia Research Network
CHSD	Centre for Health Service Development, University of Wollongong
DCRC	Dementia Collaborative Research Centre
DoHA	Commonwealth Department of Health and Ageing
HREC	Human Research and Ethics Committee
NCAC	National Consumer Advisory Committee
NHMRC	National Health and Medical Research Council
NQDCI	National Quality Dementia Care Initiative
NQDCN	National Quality Dementia Care Network
SPN	Service Provider Network

## Key Messages

### Overview

The key focus of this report is the interim evaluation of the Consumer Dementia Research Network (CDRN), which has been operating since September 2010. The CDRN represents an innovative approach to consumer engagement within the fields of dementia research and knowledge translation. This formative evaluation report reviews the activities of the CDRN in its first year of operation, preliminary impacts for consumers, providers and to a lesser extent the broader health and aged care system. It also seeks to capture the key strategic issues facing the network in the future.

### Major Evaluation Findings

The CDRN has generated an impressive list of achievements and short term impacts in its first year of operation. The evaluation of the CDRN has been framed using an evaluation framework that considers impacts and outcomes across three levels – consumers, providers and the system. These impacts are in evidence primarily through the activities of the members of the CDRN. They have successfully determined priorities for knowledge translation projects and through a rigorous assessment and review process identified two projects for funding. The network will allocate further funding of Round 2 projects in February/March 2012. The CDRN has established a relationship, which is crucial, with the leads of the three Dementia Collaborative Research Centres (DCRCs).

The network has several key achievements that demonstrate the increasing capacity of its members to work with researchers and service providers. This has included contributing a consumer perspective to research projects, providing presentations to service providers and presenting at major research and health forums. Several members have been invited to have ongoing roles with research teams through their membership of consultative committees.

At the broader health and aged care system level – the need for members to develop capacities and experience with their role in the network, has been the focus. For system change to occur this will require time and a two-way investment between the research community and the CDRN. To date the major opportunity to influence dementia research at a system level has come through preliminary work with the National Health and Medical Research Council (NHMRC). The NHMRC has a key role in supporting the major attitudinal shift that will be required on the part of researchers through demonstrating that the research community values consumer input through championing the contribution and providing tangible support for the work of the CDRN.

### Key Strategic Issues

The CDRN faces a range of strategic issues in the future. These issues require deliberation, discussion and action plans. The issues are listed below:

- Ensuring ongoing funding
- Engaging researchers
- Clarifying future roles
- Cooperating with the Service Provider Network
- Relating to State and Territory AA associations
- Contributing appropriately to the policy process
- Managing a national network
- Maintaining member engagement
- Planning for succession
- Evaluating success

### Conclusion

The CDRN is a new initiative that has genuinely applied the key principles of consumer engagement through its structure and operations to date. It is however still evolving and requires ongoing stewardship and investment if it is to achieve its potential. The CDRN has a clear path



forward for the year ahead; decisions about the network's ongoing sustainability beyond that period will be the subject of further discussions.

The purpose of the network is to support consumers in having an active role in research and knowledge translation and to use their experience and expertise in dementia care to inform the research process and contribute to better care practice and outcomes. These efforts will hopefully improve outcomes for consumers, providers and the broader health and aged care system in the future, leading to new stories of person-centred care, timely diagnosis and best practice treatment and support for the many families that will face dementia in the future.

*“You hear your own story all over again and it is desperate and it is lonely and isolated in the midst of service providers. I wonder why? Can't we support people to cope with this and keep their loved one at home with the support that is needed? It seems that the world of cancer does this way, way better – far in excess of what we have in place for dementia.”*

The following recommendations are based on an underlying premise that there is a need to build on what has been learnt so that there is ongoing improvement of the CDRN. They have been clustered into strategic recommendations (those fundamental to the ongoing viability of the network) and operational recommendations (those identifying process improvements for the network).

### **Strategic Recommendations**

It is recommended that:

1. The NHMRC builds upon the infrastructure established by AA through providing ongoing funding for the CDRN beyond June 2013 as demonstration of the government's commitment to sustained, planned and supported consumer engagement in research.
2. The relationships with the DCRCs and researchers continue to be developed with opportunities identified for joint planning and action that will stimulate consumer engagement in all stages of the research process.
3. The leadership for the CDRN provided by the AA National Office and Board is maintained as further investment is needed to ensure the sustainability of the network.
4. The report of the interim evaluation of the CDRN is disseminated widely both within government, research, aged and health care sectors to foster greater debate and awareness about consumer involvement in research.

### **Operational Recommendations**

It is recommended that:

5. The CDRN reviews its Terms of Reference and membership with priority given to recruiting an additional member with dementia. To maintain continuity the current Chairperson of the network is invited to continue in the role for another 12 months.
6. The ongoing role of the CDRN following the conclusion of the selection process for Round 2 of the NQDCN is clarified and documented through a work program for the ensuing 12 month period. The impacts of strategic developments in the sector are considered by the CDRN in discussions about the network's role.
7. The AA National Office clarifies its expectations and the desired relationship between the CDRN and the Service Provider Network.

8. The CDRN identifies mechanisms through which it might improve communication between and engagement of the AA State and Territory Associations.
9. The CDRN reviews the support needs of all members on an annual basis with consideration given to holding face-to-face meetings twice per year when the work of the network requires this and pending the identification of additional funding.

## 1 Introduction

This is the third progress report relating to the evaluation of the National Quality Dementia Care Initiative (NQDCI), which is being conducted by the Centre for Health Service Development, University of Wollongong on behalf of Alzheimer's Australia (AA). The focus of this report is the Consumer Dementia Research Network (CDRN), which has been operating since September 2010.

The CDRN represents an innovative approach within the field of consumer engagement in dementia research. While there has been an increase in consumer participation in research in recent years, the CDRN is one of the first major initiatives to include in its membership people with dementia as well as carers. In Australia, it is also one of the few examples of consumer engagement in every step of the research and knowledge translation process. The network aims to have a more direct and dynamic interaction with related research agendas and processes. An interim evaluation of the CDRN's operations has been commissioned to reflect on progress to date and to identify opportunities for improvements.

### 1.1 Aims of this report

This report aims to provide a formative evaluation of the CDRN, through describing key activities and short term impacts, and exploring any incentives and barriers encountered and unintended consequences. Formative evaluation uses the results of the evaluation to inform the ongoing development and improvement of the program. This is called evaluation for learning ('how can we learn and get better as we go?'). Consequently this review seeks to capture the lessons learned which may assist in the ongoing development of research, service and policy agendas, priorities and practices. While there has been much activity to report on, it is too early in the program to determine whether the CDRN's overall objectives have been met, or whether the achievements made are sustainable. This is summative evaluation which seeks to ascertain whether and to what extent the program was implemented as intended and the desired/anticipated results achieved. The purpose is to ensure accountability and value for money with the results of the evaluation informing any future planning decisions, policy and resource allocation. This is called evaluation for judgement ('how did we do?') and will be the subject of subsequent reports.

The intended audience for this report includes a diverse range of stakeholders, for example, the personnel of the AA National Office, the NQDCI Executive Committee and the Board of AA. Summary findings and/or the full report will also be made available to members of the CDRN, to assist with future planning.

### 1.2 Terms of reference for the CDRN

The terms of reference for the CDRN state that the purpose of the network is:

*'...to support consumers in having an active role in research and knowledge translation. Consumers will use their experience and expertise in dementia care to inform the research process and contribute to better care practice and outcomes.'*<sup>1</sup>

Its principal functions include involvement with the National Quality Dementia Care Network (NQDCN) and the Dementia Collaborative Research Centres (DCRCs). The primary consumer role with the NQDCN is focused on establishing priority driven knowledge translation projects that will improve the uptake of evidence into practice and ultimately the care of people with dementia. The involvement with the three DCRCs is about providing a consumer perspective on dementia research. This may include network members advising on consumer priorities for research and providing information and advice to researchers on how to improve their interactions with consumers. This role has also been extended to other research organisations such as the NHMRC and/or government committees.

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<sup>1</sup> The full terms of reference of the Consumer Dementia Research Network are included in Appendix 1.

## 2 The Evaluation Framework

### 2.1 CDRN evaluation structure

The evaluation of the CDRN has been framed using the Centre for Health Service Development (CHSD) evaluation framework. This considers impacts and outcomes across three levels – consumers, providers and the system; and asks the following six key questions: What did you do? How did it go? Can you keep it going? What has been learnt? Are your lessons useful for someone else? Who did you tell? A brief explanation of these six areas is provided below.

**Figure 1 CHSD evaluation framework**

What did you do?	How did it go?	Can you keep it going?	What has been learnt?	Are your lessons useful for someone else?	Who did you tell?
<b>Level 1 Impact on, and outcomes for consumers (including carers, families, friends, communities)</b>					
Direct care delivery	Impact on consumers Carer impact	Sustainability assessment	Capacity building assessment	Generalisability assessment	Dissemination
<b>Level 2 Impact on, and outcomes for providers (professionals, volunteers, organisations)</b>					
Professional development	Impact on service providers	Sustainability assessment	Capacity building assessment	Generalisability assessment	Dissemination
<b>Level 3 Impact on, and outcomes for the system (structures, processes, networks and relationships)</b>					
Governance Policy development	System level impacts External relationships	Sustainability assessment	Capacity building assessment	Generalisability assessment	Dissemination

#### 2.1.1 What did you do?

This question is essentially about program delivery (implementation) and encompasses what was done and how it was done. Through interviews with key stakeholders, CDRN members and project documentation we have explored the activities of the CDRN and lessons learnt about implementation of the network.

#### 2.1.2 How did it go?

The CDRN is a component of the NQDCI which as a whole is aiming to have an impact at the level of the consumer, provider and health and aged care system. The focus of the CDRN in this first year of operation has been predominantly at the level of the consumer. Therefore the impact on consumers and to lesser extent providers is discussed. Whilst preliminary reflection is included about system impacts, it is too early in the life of the network to evaluate impacts at this level.

#### 2.1.3 Can you keep it going?

The various definitions of sustainability coalesce around two main ideas - sustainability of the direct improvements made as part of an initiative; and the sustainability of the techniques and approaches learnt as part of the initiative as well as any indirect benefits. Evaluation of sustainability is closely aligned with the issue of capacity building (e.g. increased capability and

skills, increased resources) and any changes in structures and systems that ‘anchor’ or embed changes and facilitate sustainability. Due to the short life of the CDRN, sustainability is not a major focus of this interim evaluation; however issues that may impact on sustainability of the network in the future are highlighted.

#### 2.1.4 What has been learnt?

Within the context of the CDRN, specifically the aims of the network, capacity building has two main components:

- Developing the capacity of the network as a whole to ensure the CDRN can fulfil its terms of reference and that consumers have an active role in research and knowledge translation; and
- Other activities to improve the ongoing capacity of AA to strengthen consumer engagement.

#### 2.1.5 Are your lessons useful for someone else?

As one of the three major initiatives of the NQDCI, the CDRN aims to capture information, knowledge and experiences from the network’s activities in dementia research that can be applied in different contexts. This issue is best examined by looking at the contribution of the CDRN to the achievements of the NQDCI over time.

#### 2.1.6 Who did you tell?

The issue of dissemination (who else learnt about the CDRN?) is closely linked to the issue of generalisability (are the lessons useful for someone else?). The capacity of the CDRN to communicate about its successes throughout the wider health and aged care sector is important. This includes formal and informal mechanisms and processes for disseminating improvements.

### 2.2 Evaluation of the engagement processes of the CDRN

The evaluation design of the CDRN has been incorporated within the overall NQDCI Evaluation Framework. As noted in Version 2 of the Framework<sup>2</sup>, there are no simple assessment processes available to capture the issues surrounding consumer engagement in research, and no optimal benchmarks for evaluating the effectiveness of public participation/consumer engagement processes. Instead, the literature reveals a series of key attributes which are considered important to ensuring effective consumer engagement, which we have synthesised into the following eight ‘key domains’ to shape the evaluation of the CDRN:

1. **Leadership and culture** – who initiates/drives the engagement process and its outcomes?
2. **Role clarity / governance** – were participants and stakeholders clear about expectations of their contribution?
3. **Resources** – were participants and the engagement process provided with adequate resources, e.g. financial, information?
4. **Participation** – what were the participation patterns of members?
5. **Capacity building** – did participants feel they developed their skills?
6. **Support** – what supports were provided to participants to facilitate their active engagement?
7. **Communication** – what processes were used and to what effect?
8. **Recruitment and selection** – issues relating to the selection process; representativeness; and whether consumers were engaged as individuals or as representatives of particular groups.

To obtain an understanding of the engagement processes of the CDRN, we are using a ‘mixed methods’ approach. This includes collection of quantitative data – such as numbers of people participating, engagement and communication patterns and blog/list-server activity. In addition, there is a strong qualitative component, including interviews with CDRN members as well as key stakeholders such as representatives of Alzheimer’s Australia from National, State and Territory offices and representatives of the research, service delivery and/or policy sectors.

<sup>2</sup> Centre for Health Service Development (2011) *National Quality Dementia Care Initiative Evaluation Framework – Version 2*.

## 2.3 Evaluating impacts and outcomes of the CDRN

The key domains we are using to shape the evaluation of the CDRN predominantly focus on engagement processes. However, our overall evaluation approach also captures information regarding the expectations and experiences of CDRN members, as well as the patterns of their participation. The data have been collected from a range of stakeholders, and through a variety of processes as outlined in Table 1.

This information is building an understanding of the achievements and short term impacts of the CDRN on research priorities and processes, the barriers and enablers to effective consumer participation, and whether there were any unintended consequences (positive or negative) for members, providers or the broader research sector.

As this report is an 'interim evaluation' of the CDRN it is primarily concerned with formative rather than summative evaluation findings.

**Table 1** Data sources used in the interim evaluation of the CDRN

Data source	Method	Framework levels: impact and outcomes
CDRN members	Surveys and interviews Participation at national meetings – observations, feedback of members, evaluation forms and worksheets CDRN documentation	Level 1 (consumer) Level 2 (provider)
Alzheimer's Australia - National Office - State and Territory Associations	Interviews Email communications	Level 1 Level 2 Level 3 (system)
Key stakeholders - Policy, service provider, research, independent experts	Interviews Participation in meetings – observations, feedback, evaluation forms	Level 2 Level 3

We will seek to replicate a range of data collection processes throughout the evaluation period at different points in time, to track developments within the CDRN, as well as the network's engagement with relevant policy, research and service provider groups.

## 2.4 Additional questions raised by the CDRN

In keeping with the theme of consumer-driven research priorities, CDRN members were invited to identify issues they wanted included within the evaluation. This was explored in the May 2011 workshop in Brisbane, during a session facilitated by the national evaluation team. The session included an outline of the overall approach to the evaluation of the Initiative, and more specifically, the CDRN, and concluded with a group activity which asked members to write down a key question they wanted answered within the evaluation. In total, 27 questions were posed, which were grouped into the following five key themes:

- impact on research;
- impact on knowledge translation;
- impact on people with dementia;
- support for members; and,
- individual member contributions and roles.

The full list of the questions members raised is included as Appendix 2. All questions were reviewed in conjunction with representatives of AA. It was encouraging for the national evaluation team to see the resonance with the issues raised by the CDRN and those already being captured within the evaluation framework, however not all issues were within the scope of the evaluation.

Support for members, and individual member contribution and roles are captured in the key domains of 'Participation' and 'Support'. The impacts on research and knowledge translation will be discussed in our analysis in Section 4 and Section 5 of this report.

As the CDRN has only been in operation for a little over one year clearly only short term impacts can be discussed. One of the desired outcomes of the CDRN, which is to ultimately improve the care of people with dementia, requires a longer trajectory. It will be difficult to establish the influence of the CDRN in relation to efforts to improve the care of people with dementia. This is due to the multiple influences upon care of people with dementia and the difficulty of determining attribution. The evaluation framework for the CDRN fits within a model where it is reasonable to measure 'contribution' rather than 'attribution' and this approach will continue to underpin the evaluation.

## 3 Methods

### 3.1 Ethical considerations

In our early thinking about the evaluation of the CDRN, we had envisaged that the data to be collected directly from members would be undertaken by the project staff within the AA National Office with de-identified data being provided to the national evaluation team for analysis. As the evaluation progressed, it became clear that there would be value in the national evaluation team, as an independent party, collecting the data itself. Accordingly, we revised our application to the University of Wollongong Human Research Ethics Committee (HREC) to provide for our interviewing of key stakeholders, including CDRN members.

In our application to the HREC, we indicated our recognition of the issues pertaining to obtaining consent to participation in research of people with cognitive impairment, as outlined in the 'National Statement on Ethical Conduct in Human Research'.<sup>3</sup> Our application noted that all members of the CDRN, which comprises carers of people with dementia as well as people with early stage dementia, have self-nominated to join the CDRN, and actively participate in its activities and deliberations. Further, their capacity to contribute to decision-making has been demonstrated through their participation in the activities and ongoing communication mechanisms which are part of the CDRN. We cited the engagement we had already had with members of the CDRN, and their strong interest in contributing to the evaluation of the CDRN primarily because of its potential to better inform consumer participation mechanisms both now and into the future. We also noted that some of the CDRN members with a diagnosis of dementia had indicated their concern to us that their voices be heard first hand in the evaluation, and not only through carer feedback.

Our application to the HREC noted that the AA National Office had also indicated its preference for us to undertake the interview and/or survey processes which form part of the evaluation. Our independence from the management of the CDRN ensures that decisions by members to participate or not, and their responses, in no way could be perceived as compromising their ability to contribute to the overall activities of the CDRN. Our amended ethics application was approved in late August 2011.

### 3.2 Data collection

This interim evaluation of the CDRN has been shaped using data from a range of sources. The majority of the data collection tools have been developed and/or adapted by the national evaluation team.

These include:

- Participant feedback forms for the September 2010 summit and May 2011 workshop;
- Interview tool for use by the Manager of the CDRN to establish support needs and satisfaction levels of members;
- Exit interview template for use with members resigning from the CDRN;
- Reflective practice checklist (incorporated within the national evaluation team interview template);
- Communication and issues log to monitor key themes emerging among members;
- Audit tool for review of key stakeholder websites;
- Survey tool for use with CDRN members; and
- Semi-structured interview tool for use with CDRN members.

In addition, tools developed for other aspects of the NQDCI evaluation have also incorporated questions regarding the impact of the CDRN, including:

- The report template and site visit template used with NQDCN projects; and

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<sup>3</sup> National Statement on Ethical Conduct in Human Research 2007 – Updated 2009, Chapter 4.5 available at <http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e72.pdf> pp65-66 ; accessed 24 November 2011.



- The interview schedules used with stakeholders such as DCRC leads, AA State and Territory Associations, Service Provider Network (SPN) members, and Department of Health and Ageing (DoHA) representatives.

A description of the data and information collected to inform this interim evaluation report follows. For convenience, general comments are included where pertinent.

### **3.2.1 CDRN communications**

The email communications between the Manager of the CDRN, Dr Ellen Skladzien and members are a key source of material for the evaluation of the CDRN at the level of consumers (Level 1 of the evaluation framework). Members of the CDRN are provided with regular email communications which include summaries of CDRN working group activities, updates on related NQDCI activities, requests for CDRN involvement in research and other initiatives, as well as reminders of upcoming events. Members of the national evaluation team are also provided with a copy of these communications, for information, and these have proved to be a useful resource. They provide a means of tracking the CDRN's activities, and the corresponding level and nature of engagement with external agencies.

Following feedback from members regarding their communication preferences, the Manager of the CDRN instituted monthly teleconferences to provide verbal updates, which are supplemented with bimonthly email communications. These teleconferences have been scheduled monthly since mid 2011, however participation has been variable, with smaller than expected numbers of attendees.

### **3.2.2 Survey of CDRN members**

A web-based survey was conducted with members of the CDRN during late October and early November 2011. This survey was administered using SurveyMonkey®, an online survey tool. All 25 CDRN members were emailed an introductory message including a participant information sheet and consent form on 21 October 2011. A reminder email was sent on 28 October 2011 to those members who had not yet responded, to improve the response rate. The survey collection was closed on 1 November 2011.

In total, all 25 CDRN members who received the survey attempted to complete it. The data were then assessed for their quality, usability and consistency to ensure a robust analysis could be performed. Following this, it was found that a total of 24 (96%) surveys could be used in the final analysis. The collated results of this survey are included in their entirety in Appendix 3.

### **3.2.3 Interviews of CDRN members**

All 25 CDRN members were invited to participate in a semi-structured interview to probe issues relating to their involvement in the network and additional perceptions relating to the impact of the network and future sustainability. Interviews with 21 members were completed within the time period available. All interviews were recorded with summary notes simultaneously documented. Approximately 500 minutes of interview data were collected. These interviews were analysed thematically and coded by using the NVivo software. A broad cross section of members participated from all States and Territories.

### **3.2.4 Interviews of key stakeholders**

Over the course of the evaluation interviews will occur with key stakeholders to identify the impact of the NQDCI overall, and its individual elements (CDRN, SPN and NQDCN). In terms of the CDRN evaluation, these interviews are the major data collection tool to identify the processes and short term impacts of the CDRN for service providers (Level 2 of the Framework).

The interviews with key stakeholders were conducted during November and early December 2011. Given the imperative of this first round of interviews was the review of the CDRN, and the limited

exposure of the network to some stakeholder groups, it was decided that the initial round of interviews would target those groups with which the CDRN had had some interaction or involvement. A broader range of stakeholders will be included in the interviews scheduled to be conducted during 2012. A summary of completed interviews is provided in Table 2. This report only features results that pertain to the activities of the CDRN.

**Table 2 Stakeholder interviews**

Stakeholder	Organisations invited	Participant responses
Alzheimer's Australia including National Office and State and Territory associations	4	5
DCRC leads	3	2
Other: Policy, independent experts	2	1

### 3.2.5 Exit interviews of resigning members

An exit interview template was developed by the national evaluation team for administration by the Manager of the CDRN upon the resignation of CDRN members. The interview template includes a series of questions which seek to identify the reasons for joining the CDRN, members' expectations, experiences and their reasons for resigning.

The aim of the questions was to better identify the attributes which enable people to contribute, as well as barriers to participation. In addition, the template included a series of questions for the Manager of the CDRN to complete, as an opportunity to reflect on the experiences of the former member and whether there were lessons that might inform the future engagement of CDRN members.

There have been four members resign from the CDRN to date, with exit interview data being completed for two of these. All four members verbally provided the main reasons for their resignation which can be summarised as: competing personal and professional commitments; ill health; a desire to 'move on' from identifying as a carer and the absence of a policy focus within the network.

### 3.2.6 NQDCN documentation

The identification of priority areas for the knowledge translation projects to be funded under the NQDCN and selection of projects has been a core activity of the CDRN to date. Documentation associated with the NQDCN – project proposals, selection material, project reports and site visit templates – are sources of information that will contribute to assessing the impact of the CDRN over time with regard to both service providers and the broader health and aged care system as part of the overall NQDCI evaluation.

The CDRN has already contributed significantly to the NQDCN, in terms of identifying priority areas for knowledge translation projects, selecting projects, as well as clarifying and facilitating a broader understanding of their definition of knowledge translation as a means to improve care for people with dementia and carers.

It is too early to establish the overall impact of the CDRN on the NQDCN project outcomes. The data are available to identify key processes which have enhanced network members' ability to influence the selection and development of the projects. A brief summary is included in Table 3 below. Between 2 and 25 CDRN members have been involved in the various activities across the period September 2010 to December 2011 with consistent majority participation of members in the project selection processes.

**Table 3** *CDRN involvement in knowledge translation projects*

Stage and Activity		Time-frame
<b>Establishment</b>		
	Identifying priority areas	September 2010
<b>Round 1 NQDCN</b>		
	Development of project concepts	September – October 2010
	Project selection processes	Expressions of Interest: November 2010 Full proposals: February 2011
	Participation on steering committees	November 2011 ongoing
<b>Clarifying knowledge translation activities</b>		
	Participation in NHMRC workshop	July 2011
<b>Round 2 NQDCN</b>		
	Working groups to clarify project concepts	March – July 2011
	Project selection processes	December 2011 – February 2012

### 3.2.7 Website reviews

A range of organisations have been identified that AA believes are likely to be engaged in various aspects of the NQDCI and more particularly the CDRN. These organisations are currently involved in either the National Quality Dementia Care Initiative Executive Committee or the Service Provider Network formed to support the Initiative, which is why these websites were selected for audit. The websites of these organisations were reviewed in December 2011 by searching for the acronym 'CDRN' and organisational title 'Alzheimer's Australia', (refer to Table 4 below).

**Table 4** *Audit of websites of potential partner organisations*

Organisation	Website	Search Results
Alzheimer's Australia and State and Territory Associations	<a href="http://www.fightdementia.org.au/">http://www.fightdementia.org.au/</a>	68 hits generated for the term CDRN, predominantly linked to NQDCI page (60 hits) with 8 results directed to an AAR Dementia Grant form which is no longer accessible. Also searching NQDCI brought up the following two documents: Alzheimer's Australia National Quality Dementia Care Initiative Funding Application Template and NQDCI Proposal Template.
Dementia Collaborative Research Centres	<a href="http://www.dementia.unsw.edu.au/">http://www.dementia.unsw.edu.au/</a>  <a href="http://www.hlth.qut.edu.au/nrs/research/associated_centres_and_programs/dementiacentre/">http://www.hlth.qut.edu.au/nrs/research/associated_centres_and_programs/dementiacentre/</a>  <a href="http://www.anu.edu.au/">http://www.anu.edu.au/</a>  <a href="http://www.dementiaresearch.org.au/">http://www.dementiaresearch.org.au/</a>	<p>No hits were generated for the term CDRN; 18 hits for the term Alzheimer's Australia – several references in these 18 hits to the NQDCI and associated references to the CDRN, occurred on various pages throughout the DCRC (Assessment and Better Care) website.</p> <p>No hits were generated for the term CDRN; with 184 results for 'Alzheimer's Australia', and no hits for the acronym 'NQDCI' on the DCRC (Consumers and Carers) website.</p> <p>The Dementia Collaborative Research Centre – Early Diagnosis and Prevention (DCRC – Early Diagnosis and Prevention) does not have a dedicated website at ANU (<a href="http://www.anu.edu.au/">http://www.anu.edu.au/</a>).</p> <p>The website <a href="http://www.dementiaresearch.org.au/">http://www.dementiaresearch.org.au/</a> is a page appearing to unify the Centres on one website – it is still under development so currently mirrors the DCRC (Assessment and Better Care)</p>

Organisation	Website	Search Results
		website.
BUPA Aged Care	<a href="http://www.bupaagedcare.com.au/">http://www.bupaagedcare.com.au/</a>	No search function, so pages were reviewed by scanning for the search terms 'CDRN' and 'Alzheimer's Australia'. The 'Partnerships' page ( <a href="http://www.bupaagedcare.com.au/about-us/partnerships">http://www.bupaagedcare.com.au/about-us/partnerships</a> ) lists the partnership with AA to deliver the NQDCI, with reference to consumers' role. Further references to AA identified.
HammondCare	<a href="http://www.hammond.com.au/">http://www.hammond.com.au/</a>	No search function, so pages were reviewed scanning for the search terms 'CDRN' and 'Alzheimer's Australia'. No specific reference to the CDRN. On the 'Resources' page, it is recommended to visit the AA home page for more general information on dementia.
ACH Group	<a href="http://www.ach.org.au/">http://www.ach.org.au/</a>	Searching for 'CDRN' and 'Alzheimer's Australia' returned no results. However, viewers are directed to Alzheimer's Australia for more information, for example on dementia risk reduction strategies and early intervention.
Helping Hand Aged Care	<a href="http://www.helpinghand.org.au/">http://www.helpinghand.org.au/</a>	Searching 'CDRN' and 'Alzheimer's Australia' returned no results.
Resthaven Incorporated	<a href="http://www.resthaven.asn.au/">http://www.resthaven.asn.au/</a>	Searching 'CDRN' returned no results. Searching 'Alzheimer's Australia' returned 29 hits. These related mainly to the Postgraduate Research Scholarship in Dementia Care, established in conjunction with AA, and directing website users to the AA homepage for more information on certain issues.
Bright Water Care Group	<a href="http://www.brightwatergroup.com/">http://www.brightwatergroup.com/</a>	Searching 'Alzheimer's Australia' and 'CDRN' returned no results.
Frontier Services	<a href="http://www.frontierservices.org/">http://www.frontierservices.org/</a>	Searching 'Alzheimer's Australia' and 'CDRN' returned no results.
Commonwealth Department of Health and Ageing	<a href="http://www.health.gov.au/">http://www.health.gov.au/</a>	Searching 'CDRN' returned no results. Searching 'Alzheimer's Australia' returned 387 matches with documents. Those relating to the CDRN and NQDCI are as follows: <ul style="list-style-type: none"> <li>• NQDCI is mentioned in document titled 'Outcome 4: Aged Care and Population Ageing'.</li> <li>• The Address to Alzheimer's Australia 14th National Conference (Brisbane, May 2011) by Minister Butler also refers to the CDRN and NQDCI.</li> </ul>
Royal District Nursing Service	<a href="http://www.rdns.com.au/">http://www.rdns.com.au/</a>	Searching 'CDRN' and 'NQDCI' returned no results. Searching 'Alzheimer's Australia' returned one reference to a staff profile of a member of the RDNS who was a past President of AA Victoria.
Northern Health – Bundoora Extended Care Centre	<a href="http://www.nh.org.au/bundoora-extended-care-centre/w1/i1001208/">http://www.nh.org.au/bundoora-extended-care-centre/w1/i1001208/</a>	Searching 'CDRN' and 'NQDCI' returned no results. Searching 'Alzheimer's Australia' returned 30 matches none of these matches directly linked to the AA web-site or contained any detailed information relating to AA.

### 3.2.8 Communications and issues logs

The summary record of communications from the Manager of the CDRN to the members of the CDRN is referred to as the communications log. Originally this was described as a listserv. A listserv is an electronic mailing list of people who wish to receive specified information from an

identified source (in this case the AA National Office) and in relation to a specific topic (the NQDCI).

The communications log provides information regarding opportunities for participation in activities by CDRN members and the major communication issues conveyed by AA to the network. In addition the communications log provides an indication of the frequency of communication and the level of ongoing interaction that is needed to support consumer engagement initiatives such as the CDRN. One on one emails between representatives of the AA National Office and individual members of the CDRN have not been included in this communications log, only emails to all members have been recorded.

Subjects covered in this communications log are summarised below, further discussion about communication within the CDRN is included in later sections of this report.

Between July 2010 and November 2011 there were approximately 102 email communications from the Manager of the CDRN to the CDRN membership, averaging around 1.5 emails per week, (noting that the launch of the CDRN occurred in September 2010 with the first face to face meeting of members). Looking at the distribution of emails over time, peaks in use are evident. In April/May 2011 a high level of use was reported, which mainly related to the lead up to, and follow-up from, the 14th Alzheimer's Australia National Conference (held in Brisbane from 17 to 20 May) and associated CDRN meeting. In September 2011 another peak in communication was evident, which was largely accounted for by a number of requests for participation in surveys and projects, as well as requests for feedback on NQDCI tender documents and DCRC proposals.

As can be seen in Table 5 below, the most emails recorded in the communications log related to requests for various types of participation. Membership was another frequent subject of communication, including issues of recruitment and resignation. Other email communications related to general matters, CDRN meetings, distribution of related information, and NQDCI matters.

**Table 5** *Summary of communication log activity to CDRN members*

Subject matter	Examples	Number of emails
Request for participation	Research initiatives, consultations, policy developments and workshop or conference presentations	31
Membership issues	Recruitment, resignations, request for assistance by members	24
General matters	Regular CDRN updates on activities and requests for involvement	16
CDRN meetings	Agenda setting, background reading, follow-up actions	12
Related information	New initiatives, news items	10
NQDCI	Working groups, draft project descriptions, selection of proposals	9
<b>Total</b>		<b>102</b>

Additionally, an online forum / chat room was established, and was expected to be a main venue for CDRN communication. However this proved unsuccessful, whilst still operational it continues to be underused by members. Many members reported that they were not familiar with this communication mechanism and felt more comfortable with the use of email and telephone.

A separate issues log was also kept alongside the communications log. This data collection tool aimed to assist the Manager of the CDRN track issues that required attention and resolution over time. Twenty two issues were recorded in this log from December 2010 to November 2011, with actions and outcomes also reported for each issue.

Most of these issues related to:

- Individual support needs of CDRN members;

- Changes in CDRN membership;
- Resource issues relating to participation; and
- Responses to other stakeholders.

### 3.2.9 National summit/meeting evaluations and observations

The national evaluation team has attended both national meetings of the CDRN, as observers and on occasion participants. The inaugural National CDRN summit was held in September 2010, prior to the finalisation of our contract with AA to undertake the national evaluation. Consequently, our attendance at the meeting was in an observer capacity only. It was, however, an extremely valuable opportunity for us to meet the CDRN members and key stakeholders, and gain a better understanding of the sorts of evaluation questions and data collection processes that would be most relevant for this element of the overall NQDCI program evaluation. At the time, we were able to assist the team from the AA National Office to develop a simple workshop evaluation form for members to complete, which has since proved to be a template for subsequent meetings. This tool has provided us with some valuable baseline data, in particular regarding expectations of the members and stakeholders, against which we can compare subsequent data as the evaluation progresses.

The second national workshop of the CDRN was held in May 2011, and this provided the national evaluation team with the opportunity to work collaboratively with the CDRN members and the Manager of the CDRN to test some of the principles underpinning the evaluation. This is in keeping with our overall approach to the evaluation, which is to assist individuals and organisations build capacity in their evaluation skills. Similarly, it is consistent with the general principles underpinning the CDRN, which is to enable consumers to have a voice in the direction and evaluation of activities that relate to them.

The major focus of our engagement with the CDRN at the second meeting was to present the overall evaluation approach. In particular, we sought members' feedback on the key domains identified in the literature which have been adopted to assess the engagement processes of the CDRN. The meeting also provided the national evaluation team an opportunity to observe the processes, interactions and dynamics of the group, and compare these against our observations from the inaugural meeting. A summary of data collected through these face to face meetings is provided in Table 6.

**Table 6** *CDRN meeting data sources*

Meeting	Data sources
<b>Inaugural Summit</b>	
	Workshop evaluation form Minutes and actions arising
	Informal feedback from CDRN members and key stakeholders in attendance
	Observations of the national evaluation team
<b>2<sup>nd</sup> National Workshop</b>	
	Workshop evaluation form
	Activity – Key domains; barriers and enablers
	Activity – Note to evaluators re: unintended consequences
	Activity – Exercise: What questions do you want answered in the evaluation?
	Minutes and actions arising
	Informal feedback from CDRN members and key stakeholders in attendance
	Observations of the national evaluation team

### 3.2.10 CDRN member telephone survey – AA National Office

An unanticipated source of data was the de-identified information provided by the Manager of the CDRN following her telephone conversations with each member of the CDRN during early 2011. The spreadsheet included summary points only from these conversations. The telephone conversations followed a structured interview template addressing operational issues, processes, levels of engagement and barriers and enablers to participation. Twenty two members were interviewed: 4 former carers; 15 carers; 2 people with a diagnosis of dementia; and 1 other (status not recorded).

### 3.2.11 Joint AA/NHMRC knowledge translation in dementia workshop

An unexpected development of the overall NQDCI has been the convening of a workshop by the National Health and Medical Research Council (NHMRC), in conjunction with Alzheimer's Australia. The workshop was intended both to build capacity and understanding of knowledge translation within the sector, as well as to feed into the development of project concepts for the second round of NQDCN project funding. The workshop evaluations have been incorporated into this interim evaluation report.

The workshop arose out of conversations between the NHMRC and AA National Office following the outcomes of the project selection process for Round 1 of the NQDCN. It was clear that the majority of applicants did not conceptualise knowledge translation in the same way that the CDRN had, and this was further reinforced in the feedback AA received from a number of unsuccessful applicants. Workshop participants included a mix of researchers, service providers and policy makers involved in knowledge translation in dementia care. The day was structured in a way that clarified the role of the NHMRC in knowledge translation, highlighted the focus of practice-based translation of research that was of central concern to the CDRN, and provided the opportunity for participants to workshop draft project descriptions for Round 2 of the NQDCN. The involvement of consumers was central to the day, including members of the CDRN delivering presentations and leading discussion groups. The national evaluation team was in attendance in a participant/observer capacity. The data collected on the day provided valuable insights into the understanding of various stakeholder groups around knowledge translation, as well as elevating the profile of the role consumers can play in determining and shaping research agendas and projects. It should be noted that the data in Table 7 are based only on attendees who provided this information.

**Table 7** *NHMRC/AA knowledge translation workshop attendees by principal expertise*

Attendees principal area of expertise	Number of participants
Research	20
Service provision	17
Consumer	10
Policy	4
Consultancy group	4
Other	1
<b>Total respondents</b>	<b>56</b>

The workshop included one presentation relating to research administration, two presentations relating to aspects of knowledge translation and a further two presentations that addressed consumer engagement issues. Three group sessions were held that included:

- An introductory session, review of draft project briefs and discussion regarding consumer engagement;
- Key areas of evidence-practice gaps per priority area, enablers and barriers; and
- Development of possible strategies/projects to address issues raised in the previous session.

Workshop feedback was obtained through evaluation surveys and additional feedback provided directly to representatives of AA and members of the national evaluation team.

## 4 Findings

Each level of the evaluation framework includes a series of questions to ascertain the process, impacts and outcomes of network activities according to that target group/level; i.e. Level 1 (consumers); Level 2 (providers) and Level 3 (system). This section integrates the findings from the multiple data sources (described in Section 3.2), in relation to the questions posed in the CDRN evaluation framework. A large component of the data collected has come from qualitative sources and where possible we have used the words of members of the CDRN to illustrate views that were consistently reflected in several data sources. Those unfamiliar with qualitative methods can sometimes perceive these quotes as anecdotes that reflect the view of one respondent, this is not the case.

### 4.1 *Process, impacts and outcomes for consumers*

The primary aim of the CDRN is 'to provide individuals with dementia, their family carers and friends the opportunity to be actively involved in dementia research and knowledge translation'.<sup>4</sup>

The two key activities of the CDRN to date have been:

- establishing the overall direction and selection of projects and ongoing monitoring of the National Quality Dementia Care Network knowledge translation projects which seek to bridge the research – practice gap; and
- working with research organisations and funding agencies to ensure that the needs of people with dementia and their carers are better incorporated into research funding and implementation.

This section addresses the extent to which this aim has been achieved and provides the findings relevant to consumers.

#### 4.1.1 **Improvements in involvement of consumers in setting research priorities**

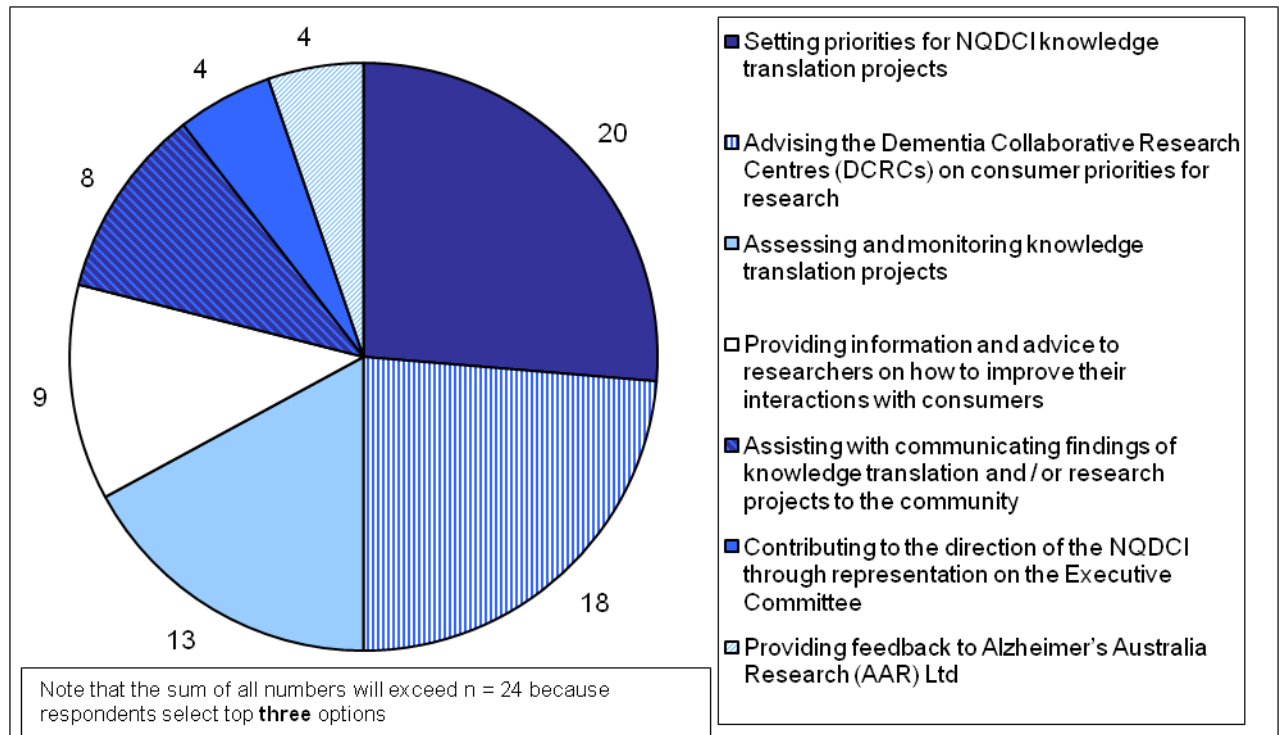
Role clarity has been important for the CDRN members. It has contributed to their sense of common purpose and focus. For several members it took some months for them to feel they properly understood their role and were 'on track'.

From a list of seven options (that came from the CDRN Terms of Reference), members were surveyed and asked to select what they considered to be the three most important roles of CDRN members. Figure 2 below displays the results to this question. Setting priorities for NQDCI knowledge translation projects was most frequently selected as an important role. This was closely followed by the role of advising the DCRCs on consumer priorities for research. The assessment and monitoring of knowledge translation projects was also ranked highly. The remaining four options were selected less often, indicating a perception of lower importance for these roles among respondents generally.

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<sup>4</sup> Available at: <http://www.fightdementia.org.au/quality-dementia-care-initiative.aspx> accessed 15 December 2011.



**Figure 2** Roles of CDRN members

The priority areas for the NQDCN projects were determined through group processes conducted during the inaugural CDRN summit. Members were asked to identify those areas where there appeared to be a need for research and or practice to improve outcomes for people with dementia and their carers. The topics identified by members were:

- Accreditation;
- Advance care planning;
- Consumer-directed care;
- Disclosure of diagnosis by GPs;
- Non-pharmacological approaches to behavioural symptoms of dementia;
- Palliative care;
- Person-centred care;
- Post diagnosis assistance;
- Respite;
- Restraints;
- Services for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse carers;
- Support services for carers;
- Symbol project – dementia; and
- Timely diagnosis and referral.

The DCRC representatives at this meeting were then asked to nominate whether there was strong research evidence for each of the suggested areas, and also to identify reasons why the research outcomes may not have been adopted in practice. Members were then asked to vote for their priority areas, and the top six priorities were:

1. Person centred care;
2. Advance care planning;
3. Support for carers;
4. Timely diagnosis of dementia;
5. Non-pharmacological approaches to managing behavioural symptoms of dementia; and
6. Palliative care for people with dementia.

The evaluation of the inaugural summit included a question which asked members if they agreed with the statement *'I was involved in the decision on priorities for projects'* which referred to the priorities for knowledge translation projects. In the workshop evaluation; all CDRN members who responded (21) indicated that they 'strongly agreed'. One member, however, did comment that they felt the process for determining priorities:

*'...was unclear and not fully reflective of issues'.*

The AA National Office subsequently commenced activities associated with Round 1 of the NQDCN for projects based on these six priority areas. The assessment of proposals was undertaken by the CDRN, who were assisted with summaries from key stakeholder groups (the SPN, and research, evaluation and knowledge translation experts). The final decision regarding the selection of the two projects funded was made by a sub-group of the CDRN. Most members perceived this as a difficult decision and one that was likely to raise the ire of researchers. It was fully supported by the CEO and team from AA. The following quotes from network members illustrate this view:

*"We didn't put forward more as we felt they were not addressing the priorities from a consumer perspective – we need to focus on research that will make a difference to the lives of people with dementia and the carers as well – we felt these projects could make a distinct difference."*

*"We were very tough in the first round of funding as we really wanted to only support projects we genuinely thought would have an impact on the care of people with dementia."*

The assessment and selection of the knowledge translation projects has been satisfying as well as challenging for CDRN members as per the following comments:

*"The most satisfying role to date has been the development of the priority areas and knowledge translation project proposal process – this is a key focus for the CDRN."*

*"I think when you know the amount of work that has gone into a submission and you are saying no to it and you understand the hours of getting it to this stage – you feel it and the fact that we can't do more, we are limited by money."*

Members of the CDRN recognise that it takes time to have an impact on research priorities and whilst members are generally positive about the network's progress in this area there remains a healthy scepticism about the degree to which the network has influenced change in its first year of operation.

*"The CDRN has been able to impact research priorities through the six priority areas it has selected for funding. Sometimes I feel it is existing research that is merely being reshaped into the priorities. We are not yet getting at the essence of what the CDRN is trying to do, for example, some project proposals are very tangential and want either a continuation of funding or to add on to existing work. There is a very big proportion that does not address knowledge translation or the priority areas."*

*"As for research priorities – gradually, I hope that some researchers are more aware of areas that consumers think there should be research in – this is also a slow process."*

Members have been successful in influencing the research funding priorities of Alzheimer's Australia Research Ltd (AAR), the body charged with allocating funding for dementia research within Alzheimer's Australia. A working group of four CDRN members developed protocols for working with AAR, which have resulted in the following outcomes:

- Inclusion of two questions within grant applications regarding consumer engagement/participation;
- Agreement that the CDRN will assess 'lay' summaries of proposals and provide feedback to the selection committee; and
- Agreement that funding will be allocated to a specific priority area identified by the CDRN.

These are significant achievements, particularly given that the CDRN had only been in operation for some months prior to the acceptance of their proposals. It also indicates the preparedness of AAR to accept consumer involvement in research decision-making.

### Consumer perceptions of achievements and impact

The personal opinions of members were sought in relation to what they believed the CDRN had achieved to date, through a number of questions in the CDRN membership survey.

It was stated that the CDRN represented a vehicle for consumer input in dementia research, and was a formal avenue for researchers to engage with consumers. Also, with skills and expertise being rapidly developed, respondents perceived that the group is beginning to be recognised as a resource for researchers, as indicated in several free text responses. Referring to the NQDCI projects, one respondent noted that these were ‘the first dementia projects in Australia directly driven by the needs of consumers’.

Other perceived achievements included:

- giving members insight into the problems and challenges faced by researchers;
- changing attitudes towards the inclusion of consumer perspectives in research;
- raising the profile of what consumers may be able to offer to the whole process of research in dementia (among researchers and consumers themselves);
- increasing researchers’ awareness of the importance of consumer input;
- providing an impetus for researchers to include consumer input in research proposals;
- guiding the direction of research;
- setting priorities for knowledge transfer and research projects which are important to consumers;
- allocating funding for knowledge transfer research projects; and
- establishing strong and supportive relationships within the CDRN, and strong networks in the dementia health sector and with the NHMRC.

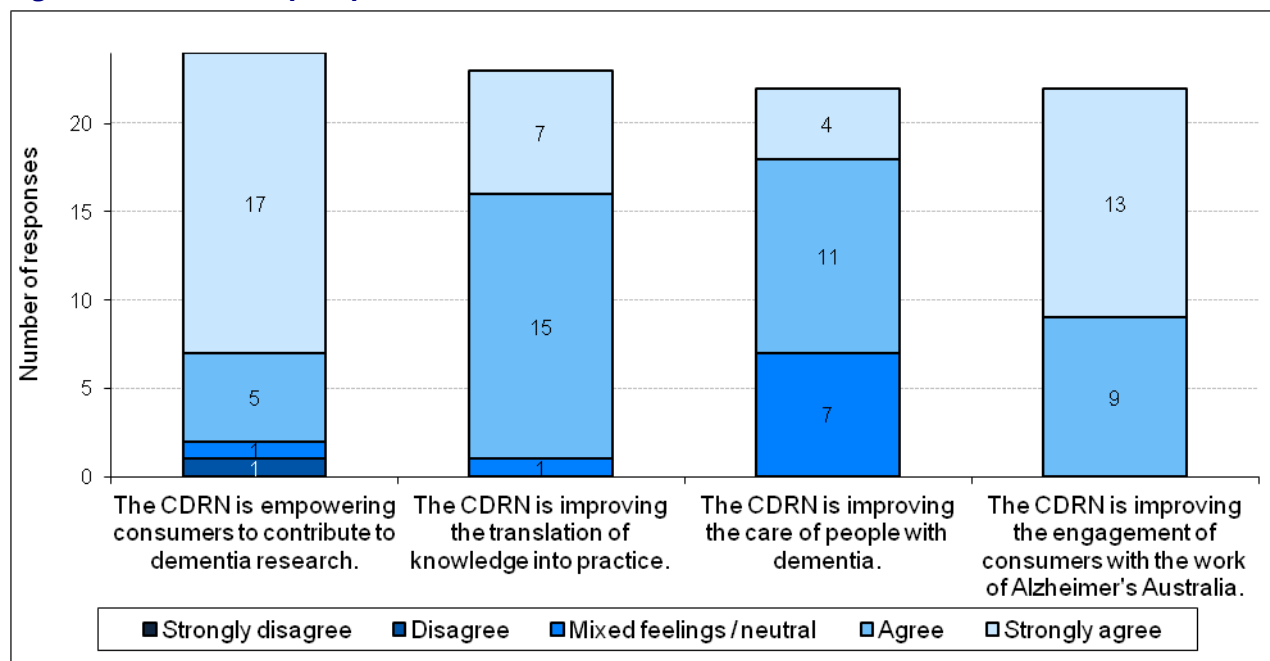
Two respondents stated that achievements in translating research into practice were minimal so far.

Survey respondents were also questioned about their perspectives of the CDRN’s achievement of its aims. Figure 3 shows very positive responses with the majority of responses being either agree or strongly agree. This reveals that respondents have a positive perception of the CDRN, and believe meaningful achievements are being realised. In particular, the strongest agreement was towards the statement that: ‘*The CDRN is empowering consumers to contribute to dementia research*’ with 17 of 24 respondents strongly agreeing. The statement that: ‘*The CDRN is improving the engagement of consumers with the work of Alzheimer’s Australia*’ also received strong agreement (13 of 22 respondents).

One respondent disagreed that the CDRN is empowering consumers to contribute to dementia research. However, this was the only negative response to all four statements.

Although not depicted in Figure 3, a small number of respondents stated in free text fields that they did not know whether the CDRN was contributing to certain achievements and impacts. This response is understandable as some members had only joined the CDRN relatively recently. Also, attributing achievements in relation to complex issues such as “improving the care of people with dementia” to one body such as the CDRN is difficult when many stakeholders contribute to this in practice.

**Figure 3 CDRN perspective of achievement of aims**



In terms of the CDRN's achievements, the critical nature of AA's support thus far and into the future is evident, as illustrated by the statement:

*“Without the support of AA, through Ellen, I don't think it would have achieved what it has to date and that level of support will be necessary to keep the group moving forward once the NQDCI projects are all initiated and underway”.*

In summary CDRN members have contributed to the work of the network in several ways including through:

- Setting priorities for and assessing and evaluating knowledge translation projects;
- Attending workshops, conferences and face-to-face meetings;
- Participating in teleconferences, discussion groups and network sub-group meetings;
- Reviewing research proposals from a consumer perspective;
- Providing comment through emails and surveys; and
- Representing the CDRN at various meetings and forums.

#### 4.1.2 Documentation of consumer experiences

It is clear from the data collected that the majority of members of the CDRN have had positive experiences as a result of their involvement.

For example CDRN member survey respondents were asked *‘From your perspective what are positive aspects about being a member of the CDRN?’* There were two responses consistently reported by the majority of respondents. Firstly, the opportunity to provide input which promotes consumers' needs and contributes positively and meaningfully to research that will hopefully lead to improved lives and care of people with dementia, their families and carers. This need to 'make a difference' was extremely important to most members of the CDRN. Secondly, being part of a group that is passionate and committed to improving lives and the care of people with dementia, families and carers was also frequently reported. Respondents perceived membership in a group of people that have and/or are facing the same challenges of dementia to be positive, as they felt understood, and could share similar experiences. For the majority of members, the network has provided a belonging and camaraderie that has united the group. This was a consistent message relayed throughout the member interviews:

*“I think a big thing about the CDRN is that it is made up of 25 consumers – we have a commonality of experience that gives us a broader understanding, acceptance and focus compared to other networks I have been involved with.”*

*“The CDRN is different because all members are like me; all have a loved one or have lost a loved one with dementia.”*

A consistent theme has been the sense of personal benefits and empowerment that members feel as a result of their involvement, particularly arising out of their active engagement in the assessment and selection of the NQDCN knowledge translation projects. An important galvanising factor appears to be the previously referred to decision to select only two projects in Round 1 and the subsequent unquestioned support of the AA National Office, particularly in the face of potential negative responses from key stakeholders such as researchers and AA State and Territory Associations. The personal benefits were consistently relayed in the free text fields of the member survey responses and in the member interviews. Examples that illustrate this majority view follow:

*“As for whether the CDRN has been a good investment of my time – I already feel that it has been so worthwhile as we have had our stories acknowledged and are seen as equals. We have been treated as professionals and we have a voice and you can’t discredit any of that, it has been one of the best experiences for me personally.”*

*“I feel with the CDRN we are making more of a difference as we are making decisions about the research grants.”*

When asked to identify the unintended consequences of their participation in the network during an evaluation activity at the May 2011 meeting, the responses confirmed the mix of personal and professional benefits that had arisen over time.

Members cited personal benefits such as meeting others (6 out of 17 respondents), emotional support (4) and enhanced respect (2) as positive and unanticipated benefits of their engagement in the network. Similarly, around two thirds mentioned the satisfaction that arose due to their enhanced ‘sphere of influence’, such as having involvement with and influencing researchers (6), and ‘making a contribution’ and ‘making a difference’ (5). In addition, a member identified improved skills development in terms of presentation skills and a further five indicated their improved knowledge of dementia, assessing research proposals and participating in advisory committees on research projects as a result of their membership of the network.

### **Challenges of membership**

Members of the CDRN were asked through interview to reflect on *‘the most challenging thing about being a member of the CDRN’*. Several themes emerged including the:

- importance of clear aims and a common understanding of the role of the CDRN;
- need for balance within the network between the needs of carers and the needs of people with dementia (noting that carers outnumber people with dementia by the ratio 5:1);
- geographical distance between network members;
- limited representation from some States and Territories, particularly the NT;
- pressures generated by competing time priorities;
- amount of work and material requiring review;
- difficulties with the terminology and language of research, particularly the widespread use of acronyms; and
- complexity of the field and multiple stakeholders involved in dementia care and research.

The following quote captures the views of several members relating to the challenge of membership:

*“...a bit of a steep learning curve...I actually found it quite challenging when we were asked to make comments from the consumer perspective and what was actually meant and what I should be looking for – what could I suggest in terms of ways of increasing consumer involvement.”*

In summary, despite what may appear to some as a slow start, in terms of having only two projects funded in the first NQDCN round, there continues to be a strong conviction by the majority of members that their work will result in positive outcomes for people with dementia and their carers more generally. These expectations have been evident in the engagement of members at the national meetings, their participation in working groups and the assessment and selection of knowledge translation projects, as well as their responses to requests for input to research projects by DCRCs and the AA National Office in its policy and related program activities.

### 4.1.3 Consumer capacity development

It is clear from the feedback received to date that consumers feel that they have developed capacity as a result of their involvement in the network. Capacity development was particularly evident to the national evaluation team when observing the increased confidence and competence of the group at the May 2011 workshop compared to the inaugural September 2010 meeting.

By the end of the inaugural meeting, members indicated their improved clarity regarding the skills they could bring to the work of the network, and their ability to contribute to its outcomes. The skills included a mix of personal experience, gained through personal experience of having dementia, caring for someone with dementia and involvement in other carer support groups (21 respondents out of 21). In addition, around half the members brought professional experience to the group, through their professional, clinical, research, knowledge translation, business and policy roles (12 respondents). Two members brought specific cultural and linguistic diversity perspectives, and one member brought a rural perspective. Perceptions of members' contributions are illustrated by the following comments generated from member interviews:

*"I think I have provided a perspective from a person with dementia which wasn't being said."*

*"I hope to contribute through my insights and ideas experienced through some of the difficulties I encountered in seeking care for my spouse – the more help one needs, the less is available."*

Whilst some members had exhibited signs of caution and hesitancy at the commencement of the meeting, the feedback indicated that by the meeting end all members had a better understanding of how they could contribute to the work of the network. In response to the statement: *'I can see opportunities to participate in this network in the future'*, 15 strongly agreed with this statement and 6 agreed. Despite this, however, members also indicated that they felt they needed improved skills and capacity to enable all members to contribute as well as more opportunity to interact with one-another (16 comments). The training needs identified have consistently been around the following four themes:

- Research: working with researchers, assessing proposals from a consumer perspective, updates of latest research findings;
- Technology: use of the online forum;
- Knowledge translation: clarity around definition, evidence and practices; and
- Advocacy skills: consumer engagement, advocacy and influencing skills appropriate to the role.

This capacity development came through strongly in the member interviews and is typified by the following quote:

*"I have been learning as I have gone along about the research methodologies and being able to see how the researchers have constructed their projects and what their attitudes seem to be relating to those projects."*

The May 2011 workshop included a number of presentations and activities to address the issues raised, including sessions on research issues, consumer advocacy and evaluation issues. These sessions were well regarded by the majority of participants; however several members expressed views which suggest some of the presenters had underestimated the level of skills and knowledge within the group, and consequently felt somewhat patronised as a result. This degree of frankness

was indicative of the increased confidence within the group about their ability to contribute to the research process, as well as their perspective of the validation of their role in that process.

The face-to-face meetings are perceived as critical to the development of the network. The following quotes from CDRN members illustrate views consistently expressed:

*“The first meeting was really an orientation and introduction – the second meeting we had a mission, something to do and this was satisfying.”*

*“May was excellent as they brought in the academics from the DCRCs to explain what was going on in their units and the teleconferences are good.”*

*“Face-to-face meetings are absolutely critical – what these meetings do is give people the chance to share experiences and knowledge, develop respect and relationships – to me it is the most amazing group to come together.”*

The confidence displayed within the group context, however, was not as apparent amongst the seven members involved in facilitating group activities at the joint AA/NHMRC Knowledge Translation workshop held in July 2011. While there had been a pre-event teleconference and members had been provided with some briefing materials and were actively engaged throughout the workshop, some of the informal comments made throughout the day suggested that they still felt under-prepared for the occasion, and had not expected such a large number of researchers to be attending. Others, however, felt that the meeting provided an important opportunity for them to highlight the importance of considering issues from a consumer perspective. This outcome was clearly achieved according to the workshop evaluation responses, with one participant noting that it was:

*“...a watershed meeting with the room full of illuminati of the dementia world, in serious discussion with the consumer network.”*

Several potential areas for skills development were identified by external stakeholders through their experience of the NQDCN funding round and the AA/NHMRC workshop. This included improved understanding by CDRN members of research processes, proposal assessment and facilitation skills. In particular, a number expressed concern that members did not have an appreciation of the amount of work involved in putting together a research proposal, the funding environment within which researchers work or the personal experience and commitment that many researchers have regarding improving care of people with dementia. Training in these areas would reduce the ‘scepticism’ that some in the research community have expressed regarding consumer involvement in research, as well as improve the CDRN’s ‘capacity to respect and appreciate the role of science’. A participant at the AA/NHMRC workshop observed that some CDRN members appeared ‘overwhelmed by the task’ and suggested that either an independent or impartial facilitator would have been more appropriate to ensure the discussions kept ‘on topic’. The participant went on to say that the consumer representative was ‘too busy keeping a hold of the discussion’, resulting in the group not having a chance to hear their perspective; the consequence was that it ‘served to reinforce the negative stereotypes that consumers may hold about researchers and researchers hold about consumers.’

That said, however, the need for consumers to have research skills was not ranked highly by respondents in the CDRN membership survey. The survey included a question regarding the capacities required for a CDRN member to participate effectively. The attributes were derived from feedback by CDRN members at their May 2011 workshop, and included the following (in order of importance according to the CDRN):

1. Experience and/ or empathy with dementia;
2. Passion to make a difference/ commitment;
3. Open-mindedness; and
4. Specialist skills such as research.

A fifth attribute was included in the survey question, Information Technology (IT) skills, given its importance in facilitating communication between members.

With regard to the importance of different capacities required for a member of the CDRN to participate effectively, a general pattern in the rankings emerged in the results (see Figure 4). Experience/empathy with dementia was overwhelmingly ranked as the most important capacity for network members.

**Figure 4** Ranked importance of capacities

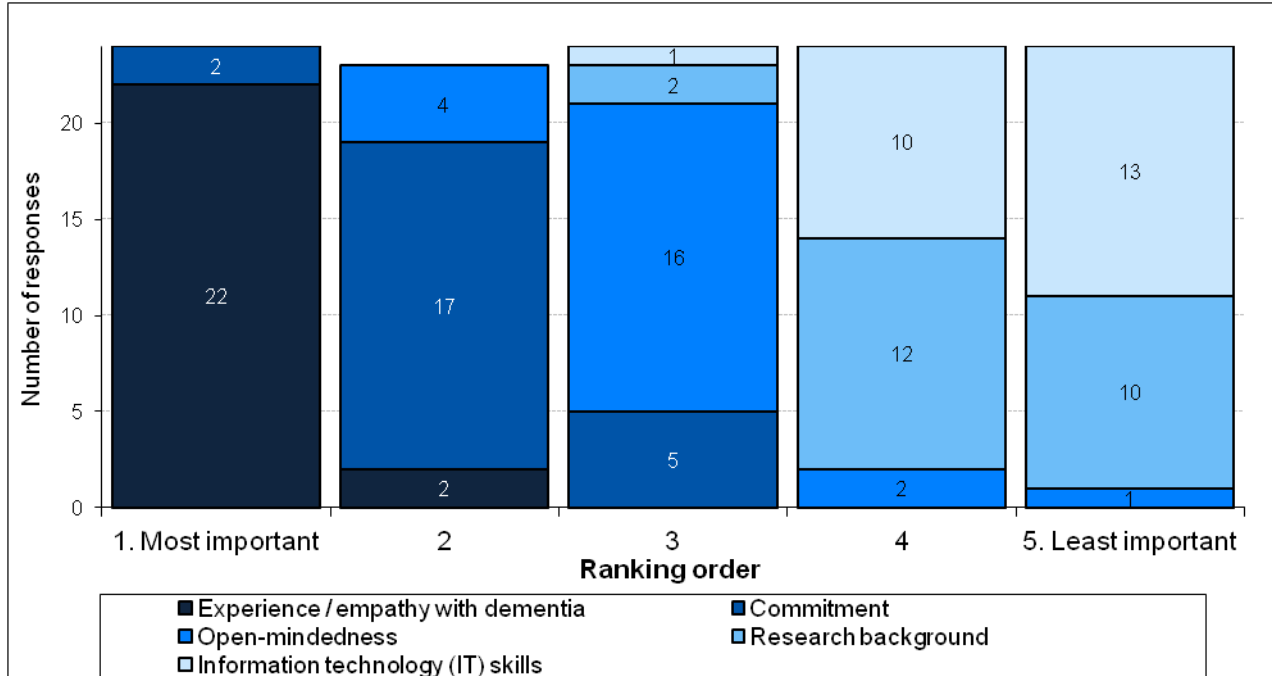


Figure 5 depicts the ranking of importance of resources and/or supports required for a member of the CDRN to participate effectively. This figure reveals a less distinguishable ranking pattern to that shown in Figure 4, which means there is less agreement among respondents in these rankings.

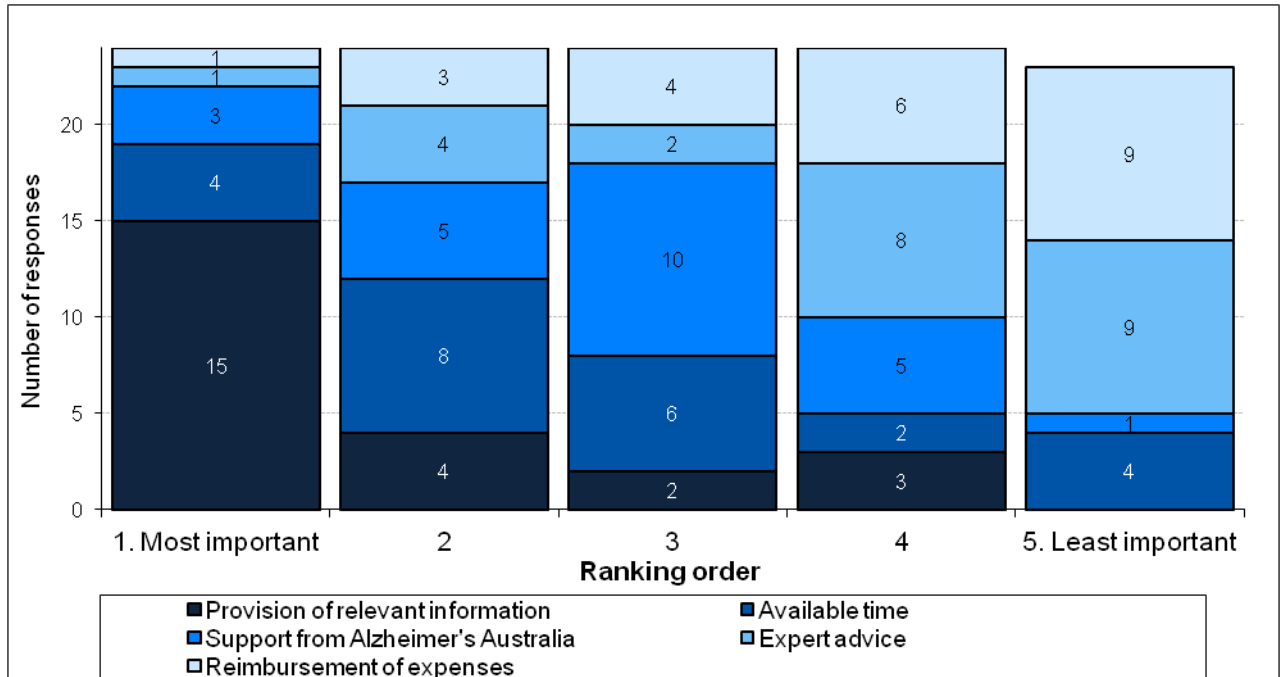
The majority of respondents consider the most important resource and/or support to be the provision of relevant information. Available time was generally ranked as second in importance, support from Alzheimer’s Australia ranked third, expert advice ranked fourth, and reimbursement of expenses ranked least important.

The majority of respondents rated research skills as being of lesser importance than empathy, commitment and open-mindedness. This supports the views expressed by a number of stakeholders, that the perceived deficits in understanding of research processes by network members is not insurmountable, and understanding should increase over time and with more opportunities for the two groups to interact and work together.

The fact reimbursement of expenses was perceived by many respondents as least important highlights that members are not motivated by reimbursement. This finding may also be related to other factors e.g. socio-demographic characteristics of members. However several comments were provided that indicated that for some members this financial support was a contributing factor in enabling them to participate.

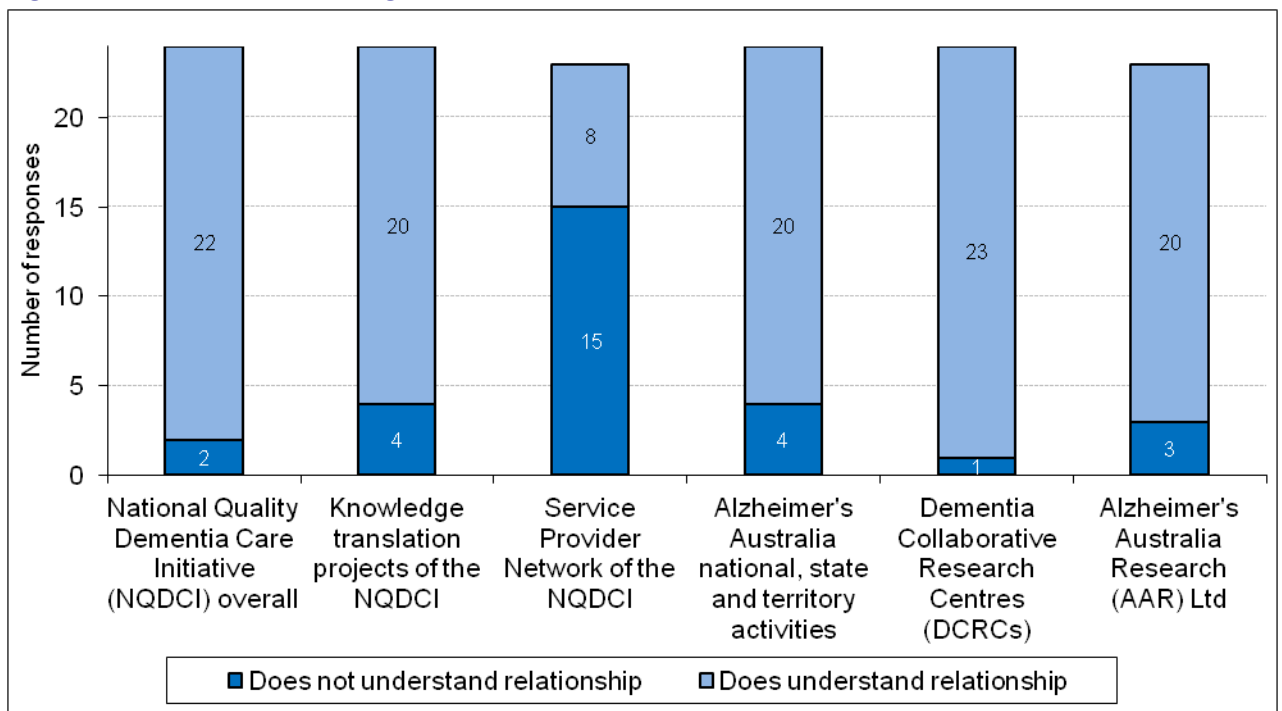


**Figure 5** Ranked importance of resources and/or supports



CDRN members were surveyed about their understanding of the relationship between the CDRN and other bodies/initiatives. As is evident in Figure 6, a high level of understanding of the relationship between the CDRN and other bodies/initiatives was indicated by survey respondents. It is worth noting, however, that 15 of 23 respondents indicated they did not understand the relationship between the CDRN and the Service Provider Network (SPN) of the NQDCI. This may be explained by the fact that the SPN had been relatively recently established, and the Terms of Reference of both networks do not explicitly include engagement with each other. For each of the other five bodies/initiatives, over 80% of respondents nominated that they understood the relationship with the CDRN.

**Figure 6** Understanding of the relationship between the CDRN and other initiatives



#### 4.1.4 Unintended consequences

The CDRN has started to be used as a general resource for organisations looking to contact or draw upon consumers with experience and expertise relating to dementia. For example, CDRN members have reported several unintended consequences arising from their membership of the network. One member was invited to represent carers (via the CDRN), at a number of different health related steering committees. Another member was invited to present to a large regional meeting of over 100 NSW Aged Care Assessment Team (ACAT) workers in metropolitan Sydney. The presentation was about a carer's perspective on living with a person with dementia. This member reported:

*“It was reassuring when they were interested in what I had to say and what we were able to share was helpful to the workers – there were lots of questions.”*

The feedback from the service providers was overwhelmingly positive as illustrated by the comment from an ACAT team leader:

*“...the presentation has challenged many of us to think about our practise, and the impact our involvement has on clients and families...this consumer is an amazing advocate for families, carers and Alzheimer's Australia.”*

Another member has been asked to speak about the role of the network at meetings within a residential care facility where their relative resides. Several members are involved in research project committees (frequently related to DCRC projects) but also others, for example, a committee reviewing the educational needs of tertiary students in relation to dementia care. One network member attended the Round Table discussion about NHMRC Partnership Centres with the federal Minister for Mental Health and Ageing. Several members have also been involved in setting up a spin off group through AA Qld to look at the support needs of people with younger onset dementia. There are also three members of the CDRN who are also members of the AA National Consumer Advisory Committee. Most recently one of the CDRN members has been invited by Palliative Care Australia to be the consumer representative on the National Standards Assessment Program Steering Committee.

For some network members, it has been apparent that participation has been part of a personal journey as they deal with the grief and personal impact of dementia. An observation of one key stakeholder was that there were different levels of 'readiness' to be involved amongst members, citing an example of where their clinical skills needed to be utilised in their working with one member on a research project. As the stakeholder did not elaborate on the issue or nature of the intervention, it is not clear if this was directly related to the member's role on the CDRN, or if it may have arisen anyway amongst the broad scope of activities within which the stakeholder is usually involved. That said, however, the episode does serve as a reminder that the nature of the caring journey and dementia trajectory means that there will be variables which can affect health and levels of participation over time, and these need to be taken into account in managing and supporting a group such as the CDRN.

While there is a general sense of positivity and achievement amongst the CDRN membership, there are also some examples of unanticipated challenges that have been identified by members. Even though the rationale for the establishment of the network has always been clear, a number of members have expressed concern at the ongoing difficulty they are experiencing in getting researchers to appropriately engage and incorporate their perspectives. This feedback was provided both during and following the May 2011 meeting, leading one member to question the value of the network if these difficulties could not be overcome.

Others have commented on the time and resource constraints associated with their participation in the network, and the need to manage their level of activity according to what is happening in primarily their personal lives, as well as professional lives.

*“The challenge is not to do with the network it is to do with the other competing priorities outside.”*

Another consistent message emerging from the network members is the importance of understanding the heterogeneity of dementia and the individual impact of the disease on people and families. This is also supported by the view that members of the network are not there to 'push their own barrows' but rather to advocate for diverse people and communities. This view is typified by the following comment from a CDRN member:

*"I think having the capacity to see past your own experiences – we of course bring our own experiences and our view of the world is influenced by our own experience of dementia – but we need to understand that every family's journey is different."*

## **4.2 Process, impacts and outcomes for providers**

This section addresses the findings relevant to the CDRN and their relationship and experiences with providers. These areas of inquiry are outlined in the evaluation framework - Level 2. Responses regarding enablers and inhibitors, and unintended consequences, relating to providers are integrated throughout this section of the report.

### **4.2.1 Impact on NQDCN activity and priorities**

As noted above, the CDRN chose fewer than expected projects for funding under Round 1 of the NQDCN, with two projects funded compared to the earlier expectations of five or six. There were a number of reasons behind the low number selected. A main reason appears to be the lack of clarity in the project documentation regarding the definition of knowledge translation. Another key factor identified was a lack of capacity within the sector to undertake knowledge translation projects (especially given the ambitious scope that the network was looking for). This was one of the key reasons for convening the joint workshop with the NHMRC. Consequently, many of the researchers who submitted applications appeared to have had a perception of research projects which had a practical application to improving care for people with dementia, as opposed to the practical application of research findings into practice which was the intent of the CDRN.

The competitive environment in which the process was conducted was also considered a factor in achieving a lower than expected success rate. Feedback from a number of stakeholders indicated that this resulted in some projects which seemed to have merit were not able to be optimised due to other groups submitting similar proposals and consequently they were regarded as being in competition with one another; the comment was made that if the two had collaborated it could have resulted in a strong national project resulting.

Another factor appears to be the timeframe within which the application process was conducted, and the requirement for AA State and Territory Associations to be involved in potential applications. While there was general agreement that there was merit in this latter requirement, a number noted that the result was a significant burden on State and Territory Association staff; there was a view that additional funding allocated to State and Territory Associations to build capacity and address the relationships with researchers may have optimised the opportunity for collaborative partnership development that the Initiative intended.

The AA National Office at the time received some highly negative feedback on the outcomes of the selection process from a number of key stakeholders and unsuccessful applicants. These views were echoed in some of the stakeholder interviews, although of lesser intensity partly as a result of the efforts of the AA National Office to clarify its position in terms of knowledge translation – and the NHMRC workshop appears to have been a significant vehicle for that – as well as feedback provided to unsuccessful applicants. However, there still appears to be some misapprehension amongst some stakeholders regarding the final decision-making processes for project selection, and the merits or otherwise of having consumers in a key decision-making role. It appears there would be benefit in more explicit information around the selection criteria and process, in particular the rationale for the CDRN's involvement in the process, to be communicated amongst stakeholders. Despite this negative feedback, however a number of stakeholders and CDRN members have commented on the integrity of the AA National Office in terms of its support of the decisions made by, and the processes of, the CDRN.

On a positive note, each of the funded NQDCN projects have a CDRN member on the steering committee, and CDRN members actively participated in the NHMRC/AA workshop on knowledge translation, in particular facilitating group discussions about each of the priority areas and draft proposal outlines for Round 2 NQDCN funding. At the time of this report Round 2 proposals have been issued to network members for review. Project selection will be finalised at the next face-to-face meeting in February 2012.

#### 4.2.2 Increased use of consumer involvement in research priority setting

The DCRCs have demonstrated clear leadership in terms of their support for consumer engagement in research, and the CDRN. While already having consumer engagement processes in place, the DCRCs invested funding to establish the Manager of the CDRN position. The three DCRC leads are members of the NQDCI Executive Committee and have been actively involved in CDRN national meetings. They have also incorporated CDRN members as members of their respective advisory committees as well as team members/advisers for specific research projects. The DCRC leads have been particularly helpful in contributing to the network at both the September 2010 and May 2011 face-to-face meetings through supporting the network's capacity development and providing an understanding of the role of the DCRCs. One DCRC lead has also facilitated the inclusion of a CDRN member on the steering committee of an aged care organisation.

*“Researchers do get nervous about involving lay people if they are unsure of their contribution and I think they have come to see that consumers are an ally and not a threat.”*

A working group comprising five members of the CDRN was established immediately following the inaugural meeting, and subsequently developed a protocol for engagement with the DCRCs. This included a request that the CDRN be invited to provide a consumer perspective on research proposals being developed by DCRCs. The protocol was agreed to by the DCRC leads in April 2011.

There has been a steady increase in requests for involvement of CDRN members in DCRC and related research projects. On at least three occasions research proposals for DCRC funding have been circulated to members for comment and feedback. Members have also been asked to participate on the planning committees for DCRC forums, as well as workshops on social participation and communication with people with dementia. Feedback and/or participation have been sought from members on the following DCRC research projects:

- carers;
- assessment;
- communication with people with dementia;
- respite;
- prevention;
- nutrition;
- sexuality and residential care;
- clinical trials; and
- assessment of early onset dementia.

In addition, related research groups have requested input from the Network:

- University of Wollongong – stigma;
- University of New South Wales – community care;
- University of Sydney – aged care funding instrument (ACFI);
- National Ageing Research Institute;
- Griffith University – social participation and carers; suicide risk and resilience;
- Australian National University – physical activity; and
- Dementia Training and Studies Centre – care pathways.

The CDRN members have been very appreciative of the contribution of the DCRC leads:

*“The DCRCs have been very supportive at involving us...input at the face-to-face sessions has been most helpful.”*

There is a genuine recognition amongst CDRN members of the challenges that researchers face and a high level of respect for the expertise and knowledge that they contribute. This is captured in the following CDRN member comment:

*“The very real constraints are the parameters the researchers have to work within – there is a keyhole view for researchers’ results.”*

There is some evidence to indicate that representatives from service provision, research and policy domains are increasingly recognising the importance of consumer input to research. In the stakeholder interviews conducted during November 2011, seven out of eight respondents were positive about the statement ‘*the CDRN is empowering consumers to contribute to dementia research*’ (six ‘strongly agreed’ and one ‘agreed’); the eighth respondent was not sufficiently familiar with the CDRN to provide an informed comment.

While the feedback on the NQDCN Round 1 funding process showed concerns by some researchers regarding the capacity of CDRN members to participate in determining research priorities and/or processes, in general there appears to have been an improvement over time in terms of the level of understanding between the two groups of what each group has to offer, and the constraints under which they operate.

Similarly, feedback from the AA/NHMRC knowledge translation workshop indicated that the profile of consumers in research had been raised. For example, in responding to the survey question regarding the three key messages participants took from the day, ten out of twenty respondents listed consumer participation in research as either the number one or number two message. There was a general sense that the workshop had proved successful in making researchers more aware of the role consumers can play in research.

That said, however, a related NHMRC meeting in October 2011 to shape the research agenda for ageing, proved that consumer engagement is not yet top-of-mind for researchers. Anecdotal feedback from one participant noted that after a full day workshoping research priorities the issue of consumer engagement in research, despite being discussed, was not chosen as a top priority. The NHMRC representative in his closing address brought this to the attention of participants.

The fact that consumer engagement and knowledge translation is firmly part of the thinking of those responsible for allocating research funding (the NHMRC), however, can only serve to enhance the continuing advancement of both these constructs and processes into the future. This view is expressed by the CDRN members through the following quote:

*“...I would like to see us be retained as a resource for other researchers or relevant groups such as policy groups etc., to provide guidance on consumer views...”*

#### **4.2.3 Training and resourcing of researchers to respond to increased consumer participation**

The need for researchers to be better equipped to increase consumer participation is inherent to the CDRN’s charter. The establishment of the network as a resource, as noted previously, is starting to contribute to this goal. The need for researchers to be trained to do this, however, is the subject of some contention.

A consistent theme arising from the research sector has been the need for greater respect of consumers for the work they do; this was a very strong message after only two projects were funded in Round 1 of the NQDCN. One stakeholder has seriously questioned the logic underpinning this agenda of the CDRN, noting that many researchers are also clinicians, and

therefore are constantly engaging with consumers and have a sound understanding of, and commitment to, consumer issues. Consequently, the CDRN is:

*“...merely formalising a lot of things that were already going on.”*

While it is clear that there are some within the dementia research field who already have a strong understanding of and commitment to ensuring consumer participation, it appears there is still uncertainty regarding the processes and/or the benefits. Two very important initiatives have occurred to address these uncertainties.

The first is the commitment by the DCRC leads to fund the Manager of the CDRN position to facilitate the CDRN. This sends a very strong signal to the rest of the sector that this is an issue worth investing in. It also is significant given that most of the DCRCs already have active consumer engagement processes in place and yet are willing to provide additional funding for this coordinated, national approach.

The second initiative is the AA/NHMRC workshop, which has proved critical in raising the profile of consumers, and the contribution that they can make to the research process. While not converting all dementia researchers to the value of consumer participation in research it did, however, firmly place it on the agenda of the NHMRC. This is evident in the outcomes of the subsequent high level round table, convened by the Minister for Mental Health and Ageing and the NHMRC in November, 2011 to discuss priorities for dementia research and the possible establishment of a new NHMRC Partnership Centre. This meeting included a number of consumers, including the Chairperson of the CDRN, Dr Ron Sinclair.

#### **4.2.4 Sustainability of the CDRN**

There is a general consensus that the CDRN is not sustainable without ongoing funding for the overall facilitation role and costs associated with travel, meetings, administration etc. The investment of the DCRCs in the facilitation function provided by the Manager of the CDRN has been extremely important, as has the additional funding sourced for the NQDCI overall from the Wicking Trust and through BUPA which has primarily focussed on supporting the NQDCN initiatives.

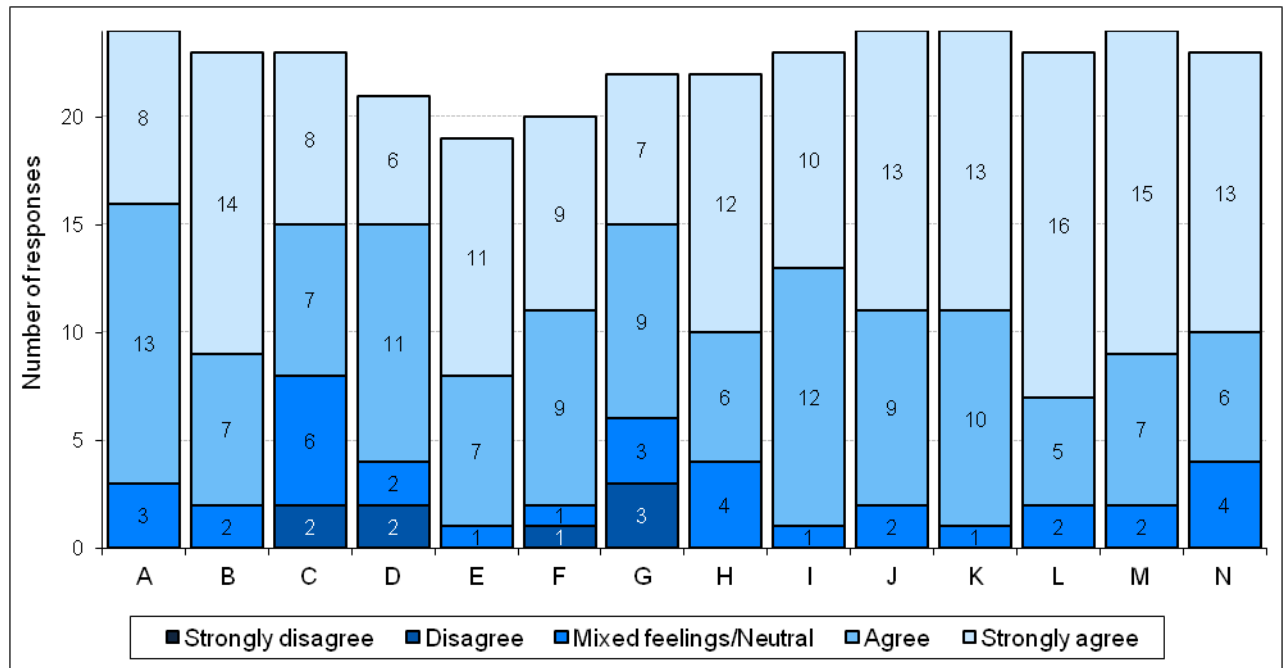
Similarly, there is a general consensus amongst key stakeholders that the goodwill which has resulted in the funding will only continue if the outcomes of the network are successful and have demonstrable benefits, particularly for the research sector.

There is a general sense that the first year of the network has been evolving in terms of clarifying purpose and the way it relates to the broader research community. There is recognition amongst stakeholders that culture change takes time, and the network has not been operating sufficiently long enough for either its outcomes to be clear, or processes integrated into the ‘system at all levels’. As one stakeholder noted:

*“...success will guarantee sustainability but the results are not in at this point in time”.*

The issue of the sustainability of the CDRN was explored through the CDRN membership survey with responses to two statements, illustrated in Figure 7 below. In response to statement B ‘*My investment (of time and effort) in the CDRN has been worth it*’, 14 of 23 respondents strongly agreed, 7 agreed, and 2 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement. This statement aimed to find out whether respondents were positive about the investment they had already made in the network as this is a potential indicator of their likelihood of continuing with the CDRN.

In response to the statement ‘*I intend to continue as a member of the CDRN for the foreseeable future*’, 13 of 24 respondents strongly agreed, 10 agreed, and 1 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 7, statement K).

**Figure 7** Level of agreement of CDRN members with key aspects of network operation

- A I have shared the knowledge gained from my participation in the CDRN
- B My investment (of time and effort) in the CDRN has been worth it
- C I have developed valuable skills through my participation in the CDRN
- D All members contribute to the work of the CDRN
- E My opinions are valued by other members of the CDRN
- F The CDRN is treated as an equal partner by Alzheimer's Australia
- G The direction of the CDRN is determined by members
- H The leadership of the CDRN comes from Alzheimer's Australia
- I The CDRN has influenced the selection of NQDCI knowledge translation projects
- J Members of the CDRN are representative of a range of dementia consumers
- K I intend to continue as a member of the CDRN for the foreseeable future
- L I have been provided with adequate resources (e.g. financial reimbursement, information) to participate in the CDRN
- M I have been provided with adequate support (e.g. guidance from Alzheimer's Australia) to participate in the CDRN
- N Communication between Alzheimer's Australia and the CDRN has been effective

Further perspectives about the sustainability of the CDRN were drawn from responses to the survey question: 'What do you feel is the single biggest issue facing the CDRN in the next 12 months?' The majority of responses were related to securing ongoing funding and financial support for the network. Thus, the biggest issue for the CDRN in the next 12 months was perceived by most respondents to be ensuring continuing and stable funding, which was seen as critical to the ongoing sustainability of the CDRN itself as well as the knowledge translation projects.

A number of other issues facing the CDRN in the coming year were listed by respondents. These included:

- the recruitment and utilisation of people with dementia as members;

- retaining members and continuing to enable their participation and engagement through facilitation and training;
- ensuring that expertise built up among current members is not lost;
- ensuring selected knowledge translation projects achieve good results (visible improvements in quality of life etc); and
- continuing to develop relationships with the DCRCs.

Illustrative of respondents' general positive attitude towards the CDRN, and a desire to see the network sustained and extended, are the following statements:

*“It would be very satisfying to see a CDRN role continue, strengthen, become broader in application to a fuller range of dementia issues – and to be even more representative of the spectrum of experiences of life with dementia in the community”.*

*“How sustainable is the CDRN – well AA has created a robust process and group regardless of whether people change, the process and systems and the way they have structured the network will make it work.”*

CDRN members are realistic in recognising the role of the NHMRC in shaping the future of dementia research:

*“To be frank the whole question of the research and role of the NHMRC will shape change and make it externally driven as dementia care will become a more significant issue for the health care system – the burden of disease with baby boomers will be extreme across delivery and treatment and this will push external action by governments.”*

*“I don't think one structure can be all things to all people – given the CDRN is a work in progress (still new) it has been doing well in how it can potentially be used – it should not try to be all things to all people.”*

#### **4.2.5 Unintended consequences**

The CDRN builds on the existing consumer mechanisms already employed by AA, such as the National Consumer Advisory Committee, Cross-cultural and Indigenous Advisory Committees funded by the Department of Health and Ageing under the Dementia Initiative, and those convened by AA State and Territory Associations.

Members were recruited through the established AA networks, as well as through publicity amongst broader consumer groups; applicants were then selected on the basis of ensuring as representative a mix as possible. While recommendations were sought from State and Territory AA Associations, the expectation was that the primary purpose was to inform the research priorities and projects associated with the NQDCI, with engagement with State and Territory Associations being a secondary objective. One member has participated in a related national committee: representing cultural and linguistically diverse communities and several members of the CDRN are also members of the National Consumer Advisory Committee.

Although members are drawn from each State and Territory, they are not identified as representatives as such, apart from providing the network with a reasonable geographic spread of members. Where there is a critical mass of members within states, these generally network amongst themselves between national meetings, although the focus is on national issues rather than issues pertaining to their state of origin.

While this has the advantage of ensuring that members are not distracted from the focus of the national network, it has led to some uncertainty amongst State and Territory Associations. Feedback through the stakeholder interviews and other observational sources suggest that there appears to be some disenfranchisement of State and Territory Associations, which also convene consumer advisory groups. The apparent parallel operation of national and local consumer groups led one stakeholder to comment that:



*“...you have different consumers working on different projects and never the twain shall meet.”*

Yet others have indicated that they are unsure what the difference is between the different groups. This suggests that there is room for improved communication between and engagement of the AA National Office and those of the State and Territory Associations.

Amidst the commentary on the success or otherwise of the CDRN there has been consistent recognition that consumer engagement, in terms of identifying research and project priorities, is a relatively new process within the Australian dementia research field. Consequently, it is an iterative experience, where all parties are ‘learning by doing’, often without the time for reflection or consolidation.

### **4.3 Process, impacts and outcomes for the system**

This section addresses the questions outlined in the evaluation framework related to the processes, impacts and outcomes of the CDRN on the system (Level 3).

#### **4.3.1 Opportunities which have arisen from the CDRN**

The evaluation framework asks two questions regarding the promotion of outcomes associated with the CDRN: one in terms of disseminating lessons learned, and the other regarding the opportunity to influence policy, research or service delivery.

In terms of the lessons learned, there has been relatively little direct focus of effort to disseminate formative findings and short term impacts to date. This interim evaluation report provides an opportunity to disseminate the lessons learned through the formative evaluation phase and to highlight that meaningful consumer engagement in research is a ‘two-way street’. It can only be successful if researchers and entities such as the NHMRC build upon the foundation established through the CDRN.

That said, however, AA has sought to increase the presence and profile of the CDRN through their participation in the national conference in Brisbane in May 2011, which included the announcement by the Minister for Mental Health and Ageing of the successful NQDCN projects. This had the very real potential to highlight the role consumers can play in determining research priorities and affecting practice change within the primarily service provider, research and policy sector representatives who attend AA conferences. To date, however, the national evaluation team has received no data on the impact of their presence as the conference was run by the Queensland association and not the AA National Office.

The AA National Office has had significant focus on enhancing its overall profile in the past year, in turn improving its ability to impact the policy, research and service delivery sectors. A key activity has been the AA rebranding exercise and the refreshing of the AA website which promotes a contemporary and coherent sense within the national federation. In addition, there has been much public and political campaign activity to increase awareness of the needs of people with dementia and their carers and highlight the need for ongoing funding for advocacy, research and service provision. These outcomes have in part been facilitated by the employment of the National Project Manager for the NQDCI and the Manager of the CDRN, both of whom have increasingly been called to undertake policy and publicity activities such as the Fight Dementia Campaign, BrainyApp development, submission writing, and undertaking national consultations on the Productivity Commission’s recommendations into aged care. As a consequence, the profile of AA appears to have increased amongst peak bodies and service providers within the aged care sector, with the national evaluation team noting that AA seems to have taken the lead in aspects of national policy around dementia and aged care. The downside, however, is that this increased activity is being undertaken from a relatively small team in the AA National Office, and may impact on its ability to consolidate findings and maximise the opportunities presented to them.

The outcomes of the NHMRC/AA knowledge translation workshop in July 2011, discussed previously, also highlight the enhanced profile of the AA National Office within the research, policy and service provider sectors.

The recent website audit reveals that the CDRN has relatively low online visibility amongst organisations that Alzheimer's Australia is seeking to develop relationships with over time.

From the search of each website listed, as might be expected, it is apparent that the Alzheimer's Australia website provides the most comprehensive information on the network. The implication of this finding is that Alzheimer's Australia is not maximising opportunities to leverage off its existing partnerships. Greater public awareness could be gained by having partner organisations provide information about the NQDCI and CDRN on their websites. Consideration could be given to requesting partner organisations to provide a link to the Alzheimer's Australia NQDCI webpage, as a minimum. This issue should be considered for the next 12 month period of the network.

#### **4.3.2 Relationship between the CDRN and national, state and territory AA Associations**

Since its inception, it is clear that the CDRN was to be a separate mechanism for consumer engagement within AA nationally, with a specific focus on knowledge translation and research. There has been cross-over of memberships between the consumer mechanisms within AA National Office, including co-opting of one member of the CDRN onto the Culturally and Linguistically Diverse Advisory Committee, and a joint dinner was held with all National Consumer Advisory Committee members prior to the AA national conference in Brisbane in May 2011. Feedback from CDRN members, however, suggests that there was limited engagement between the different groups, primarily because it was a rare opportunity for them to meet together informally and talk amongst themselves. This suggests that in the future, joint meetings of consumer groups may be more productive if there is a common agenda and focus of effort to work towards.

The involvement of AA State and Territory Associations has been limited to the initial promotion of information regarding the application process and subsequently through their experience in submitting proposals for the NQDCN funding. From the stakeholder interviews, and our conversations with and observations of State and Territory members at the inaugural meeting and at subsequent industry related occasions, it is clear that there are mixed views regarding the role of the CDRN, where it fits within the overall consumer engagement processes of the Associations, and what additional value it adds compared to the current or pre-existing consumer engagement processes already underway at the national, state and territory levels.

As a consequence, while there is general positivity regarding the relationships with the AA National Office and its communication processes, there does not appear to be a sense of coherence within AA as a whole in terms of its agenda, priorities or processes regarding consumers.

The influence of the CDRN on research has been discussed previously, in particular the heightened engagement of the NHMRC in knowledge translation and dementia research, as well as the changes to AAR funding processes. What is not clear, however, is the extent to which consumer directions in research will permeate beyond these areas; the anecdotal feedback regarding the ageing research agenda workshop held in Melbourne in late 2011 suggests there remains some way to go before consumers are top of mind for many in the research sector.

On the policy front, as noted previously, there appears to be a significant elevation of the profile of AA within the overall policy and/or political arena. Representatives of DoHA sit on the NQDCI Executive Committee, and have attended the national meetings. The approach by DoHA to the AA National Office to conduct consultations around the Productivity Commission's recommendations, together with the Minister's participation in several of AA's initiatives during the year (e.g. Fight Dementia Campaign, NHMRC workshop, AA National conference) confirms the positive relationship between government and the AA National Office.

## 5 Discussion

The evaluation framework (previously issued), notes the absence of appropriate tools and instruments by which consumer engagement processes can be adequately measured, and the lack of established benchmarks to compare and evaluate the effectiveness of networks such as the CDRN. Researchers involved in consumer engagement have, however, identified a number of key factors or attributes, which need to be taken into consideration to optimise consumer involvement in direction setting and participation in research projects. These are the eight ‘key domains’ which have shaped our approach to this interim evaluation of the CDRN. The following discussion synthesises our analysis in relation to each domain. It also includes observations about barriers and enablers encountered where relevant to each domain.

### 5.1 Leadership and culture

The leadership and culture which drive and underpin consumer engagement processes are one of the most important aspects of ensuring positive and effective outcomes for both participants and stakeholders. Dr Judy Gregory, in her review of consumer engagement literature identified eight key factors that support positive collaboration processes, highlighting the need for an organisational wide approach.<sup>5</sup>

*“Consumer engagement requires both time and money, and to succeed it needs an organisational champion.”<sup>6</sup>*

In the case of the CDRN, that organisational champion has been apparent from inception; the AA CEO has been a driving force in seeking funding, facilitating processes, and ensuring the integrity of the network’s deliberations and decisions. It was his vision to develop the NQDCI and to seek funding which would not constrain the processes or outcomes of the consumer engagement, but rather allow it to develop organically and be truly consumer driven. In the words of the CEO, the approach to the CDRN’s decisions around the NQDCN projects was very much ‘laissez-faire’ – and any preconceived notions about what these might result in have quickly been dispelled in favour of supporting the six priority areas identified by the CDRN. From members’ perspectives, the most significant demonstration of this has been his support of their decision to only choose two projects for funding under Round 1 of the NQDCN, which has been unwavering. This is in spite of heightened expectations within AA State and Territory Associations, and the DCRCs at the outset, and the negative feedback from a number of stakeholders arising from the outcomes. For many members, this signified a confirmation of the ‘genuine collaboration’ and ‘partnership’ between the AA National Office and the network, and validation of their role in research priority and decision-making processes. CDRN members perceive that this commitment to their perspectives has been in force from the inception of the CDRN as illustrated by the following member comments from interviews:

*“...Glenn Rees, the CEO of AA, is totally committed to the network – this full support is critical as this doesn’t always happen in my experience with State based activities.”*

*“...right from the beginning there has been consumer choice so I was on the panel that selected Ellen so this provided evidence that our involvement was to be real.”*

In addition to strong leadership, there is also a need for strong cultural alliance with the consumer engagement process. Of the eight principles of consumer engagement identified in the literature by Gregory, the organisational culture and processes were critical. The first principle to underpin collaboration was the recognition that ‘participation means partnership’, and this ‘means accepting uncertainty.’<sup>7</sup> The subsequent principles emphasise the need for organisational change to occur, including aligning ‘consumer involvement plans with organisational capacity’, and the importance of involving staff in building that capacity. In the case of the CDRN, the two key staff members

<sup>5</sup> Gregory J (2007) *Conceptualising consumer engagement: a review of the literature*. Australian Institute of Health Policy Studies Research Project. AIHP p48

<sup>6</sup> Ibid p42

<sup>7</sup> Ibid p48

involved in the day to day management of the CDRN, the Manager of the CDRN, Dr Ellen Skladzien and the NQDCI Project Manager, Dr Chris Hatherly, are examples of the capacity that has been built within the organisation that facilitates a collaborative culture with consumers. The feedback from members and a number of key stakeholders has been very positive about the skills, but perhaps more importantly, the style of these two individuals. Comments received by the national evaluation team confirm their collaborative working style, in particular how they have worked with the CEO and each other, particularly given their increasing workload over time. While a small number of stakeholders noted the relative inexperience of the two staff members, others have noted how they have 'grown into their roles'. This latter aspect has also been the perspective of the national evaluation team: having worked with the AA National Office in both an evaluation as well as capacity building role, we have seen an emerging confidence and competence in terms of project management over time.

CDRN members have highlighted the personal style and qualities of the Manager of the CDRN as being 'pivotal' to their continued involvement, and the success of the network. This has predominantly been framed in terms of her openness and honesty, interpersonal style, perceptiveness, patience and empathy, particularly with members who have dementia and others struggling with personal issues. Her willingness to tailor communication and resource needs for individual members, rather than applying a 'one-size fits all approach' has been greatly valued by members. These attributes demonstrate her 'genuine commitment' to the success of the network.

As a group, it is still relatively early days for the CDRN however there are definite signs of its maturation in terms of leadership and culture. There is increasing evidence of members' development in terms of their capacity and confidence and their ability to contribute to the leadership of the network. However, the group remains heavily reliant on the coordination role that the Manager of the CDRN provides, and would not be able to function effectively or efficiently without that position. This is consistent with what the literature reveals about principles to underpin successful consumer engagement. The members perceive that they are a long time away from independent functioning.

*"I don't think the network would work without Ellen – we need a leader or manager of the network to facilitate the process."*

*"I think Chris and Ellen have done a fantastic job, out of everyone they are the ones who have galvanised consumers far more and they seem to really believe in consumer involvement, it is not tokenistic, they actually want consumers involved and having an active part."*

Within the CDRN there is a sense that they are starting to identify a culture of their own. Although not overt in any tangible sense, members have commented on the importance of their having a common experience with dementia, and how this has provided a glue and bond that they have not experienced in other consumer groups. It is likely that the focus of activity, where members have been required to work together to achieve common goals, is a key factor in the development of this culture which, together with the personal relationships that have developed through their common experience of dementia, has assisted the group to 'gel'.

*"We have developed quite strong friendships as we are all in the same boat and have a very deep understanding of where we are each coming from because of our common experiences – this has created a strong bond."*

Respondents were asked via survey, whether the direction of the CDRN was determined by members and the majority of respondents agreed or strongly agreed with this statement. Survey respondents were asked to rate their level of agreement with two statements. Firstly, in response to the statement 'The direction of the CDRN is determined by members', 7 of 22 respondents strongly agreed, 9 agreed, 3 had mixed feelings / neutral, and 3 disagreed. No respondents strongly disagreed with the statement (see Figure 7, statement G). Secondly, in response to the statement 'The leadership of the CDRN comes from Alzheimer's Australia', 12 of 22 respondents

strongly agreed, 6 agreed, and 4 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 7, statement H).

To better understand network members' views about the culture between the CDRN and AA, survey respondents were asked to rate their level of agreement with the statement *'The CDRN is treated as an equal partner by Alzheimer's Australia'*. Out of the 20 respondents to this question, nine strongly agreed, nine agreed, one had mixed feelings / neutral, and one disagreed. No respondents strongly disagreed with this statement (see Figure 7, statement F).

The leadership (and support) provided by AA, and in particular Glenn Rees, Ellen Skladzien and Chris Hatherly, is praised in a number of the free text comments included in survey responses. There is consistent reference to the contribution of the personnel of AA who are perceived as an excellent and strong project team. The following comment is illustrative of this perspective:

*"The staff ... it's their commitment, consultative approach, and their expertise in the field, and their very good understanding of the national, state and territory contexts".*

Using Kendall's tau correlation coefficient (a statistic used to measure associations between ordinal variables), correlations between each of the fourteen statements in Figure 7 were calculated and analysed. The most significant correlations arose around the statement M *'I have been provided with adequate support (e.g. guidance from Alzheimer's Australia) to participate in the CDRN'*. Statements B, C and L correlated very strongly with this statement. Free text comments provided by respondents indicate that the culture of AA is one of support and transparency.

The statement with the weakest correlations with other statements was statement G *'The direction of the CDRN is determined by members'*. This is not unexpected as the CDRN has been operating for just over 12 months and as previously noted the leadership currently rests with the AA National Office – it will be interesting to track this perspective over time to see if this changes as the network matures.

## **5.2 Role clarity / governance**

Having clear Terms of Reference (ToR) is fundamental to consumer engagement processes as it ensures all parties are aware of, and agree to, the roles, contributions and outcomes of consumer input.

The roles of the CDRN are articulated in its ToR (refer to Appendix 1), which highlight its purpose:

*"Consumers will use their experience and expertise in dementia care to inform the research process and contribute to better care practice and outcomes."*

The principle functions of the CDRN in relation to the NQDCN projects include setting priorities, commenting on proposals, participating in the projects, monitoring, communicating outcomes and participating on the Executive Committee. These functions have been a significant focus of effort for the CDRN to date, particularly in terms of its development of an identity and culture. There have been, however, two additional - and perhaps more critical - functions of the CDRN that have provided coherence and a sense of unity of purpose for members and elevated its profile amongst external stakeholders such as researchers: the decision-making role of the CDRN in regards to NQDCN project selection; and its role in clarifying and, for many, reconceptualising what is meant by knowledge translation.

The principle functions of the CDRN in relation to their involvement with the DCRCs includes provision of advice on consumer priorities for research, communication of research findings and supporting researchers to improve their engagement with consumers. The National Health Scheme (NHS) in the United Kingdom has identified a series of principles to underpin consumer engagement in research processes, the first of which is:

*“The roles of consumers are agreed between the researchers.”<sup>8</sup>*

While inherently supported by researchers’ organisations such as the DCRCs, through the provision of funding for the network, the scope and processes by which consumer engagement was to be achieved was not initially clear for members. A working group was established within the CDRN to clarify the protocols through which consumer engagement with the DCRCs would occur, which was subsequently agreed to by the DCRCs. In responding to the protocols, Professor Brodaty, Director, Primary Dementia Collaborative Research Centre, School of Psychiatry, University of New South Wales, indicated the DCRCs will endeavour to follow the protocol to ensure effective communication. In addition, they will ensure that new proposals include a plan for consumer involvement where appropriate, and incorporate feedback from CDRN representatives on the DCRC Coordinating Committee (DCRC-CC) before projects are approved by the Committee. He concluded,

*“The DCRCs greatly value the contribution of the CDRN and the DCRCs would like to make every effort to support CDRN representatives through this process.”<sup>9</sup>*

In addition to its relationship with the DCRCs, the ToR note that the CDRN may also provide a consumer perspective on dementia research to other research organisations such as the NHMRC and/or government committees. While engagement with DCRCs was more tangible initially, due to the financial commitment and presence of the DCRC leads at the inaugural summit and subsequent May face-to-face meeting, the relationship with other research groups was less clear at that time. As time has gone on, however, there have been a number of unanticipated opportunities for the CDRN to establish processes for interaction with broader research groups, and influence related committees.

The previously referred to NHMRC/AA knowledge translation workshop in July 2011, was an opportunity for the CDRN’s perspectives of what constitutes knowledge translation to be understood by diverse research and provider groups. Many of these groups had been unsuccessful applicants in the Round 1 funding of the NQDCN projects, precisely because of their research-focussed approach to knowledge translation as opposed to implementation of research into practice – which is what the CDRN was looking for. Extending their influence to broader stakeholder groups has also been achieved through the participation of members in various summits, workshops and conferences, including the AA national conference in Brisbane in May 2011, and through their provision of input and participation in research projects unconnected to the DCRCs. The adoption by AAR of the recommendations to improve consumer involvement in research proposals it funds is also a significant achievement.

The ToR have provided a firm foundation for members, in terms of identifying their focus of effort and priorities. However, a number of respondents have indicated their uncertainty about the ongoing role of the CDRN following the conclusion of the selection process for Round 2 of the NQDCN. This also has been noted by the AA National Office as a key strategic issue for consideration, in terms of how to ensure members are provided with meaningful engagement opportunities, an active work program and tangible outcomes associated with their efforts. The relationship of the CDRN to consumer groups already operating in AA State and Territory Associations and the DCRCs, similarly remains unclear; and this is expected to become even less clear once the major focus of the CDRN on the NQDCN project selection is complete. A review of the CDRN’s ToR on an annual basis would assist in clarifying these relationships, as well as ensuring the CDRN’s relevance, particularly given the anticipated changes within the health, aged care and research sectors that are under consideration at the national level.

In terms of the CDRN’s influence on the selection of the knowledge translation projects, survey responses from CDRN members showed they generally believed the network was exerting influence. In response to the statement ‘*The CDRN has influenced the selection of NQDCI knowledge translation projects*’, 10 of 23 respondents strongly agreed, 12 agreed, and 1 had

<sup>8</sup> Telford, R., J Boote, et al. (2004) “What does it mean to involve consumers successfully in NHS research? A consensus study.” *Health Expectations* 7 (3) p216

<sup>9</sup> Correspondence: Prof Henry Brodaty to Dr Ellen Skladzien, re CDRN protocol, 19 December 2010

mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 7, statement I).

### 5.3 Resources

The engagement of consumers in a meaningful and effective way requires resources: for the consumers to participate as well as for the researchers to engage. For both groups, the resources required predominantly include information, time, and financial reimbursement. At a systems level, the resources also include appropriate organisational capacity in terms of processes and staffing.

There is some variability within the CDRN regarding resource requirements, and it appears that these can also change over time, depending on the members' individual experience of consumer engagement processes, their knowledge of the subject matter, as well as their personal circumstances. This was a focus of some discussion at the May 2011 workshop, where members evaluated the proposal review process for Round 1 of the NQDCN; while some were satisfied with the amount and content of information received, others found this 'overwhelming'. Similarly, while some found the response times satisfactory, others with personal or work circumstances noted the difficulty to respond quickly to requests for input. And while a number were satisfied with the opportunities to participate in face-to-face meetings there were others, particularly those geographically isolated, who indicated their preferences for these to occur more regularly. There was, however, no disagreement regarding the appreciation of the resourcing and organisational aspects associated with national meetings, in particular travel and accommodation arrangements and ability for spouses/carers to accompany the members with dementia. The Manager of the CDRN consistently works to identify and maintain an understanding of individual circumstances; need for resources and preferences for the provision of those resources; and the subsequent tailoring of communication and information sharing processes to individual needs to optimise members' engagement.

A recurring theme in the discussions regarding resources has been the time constraints of members, particularly for those with caring, work or family commitments. This has resulted in at least one resignation from the CDRN (albeit reluctantly).

The research and organisational resources identified in the literature reflect the issues members have identified in their identification of enablers and barriers to participation. That is, researchers and relevant organisations need to factor in financial resources to facilitate engagement processes, build capacity amongst staff to engage with consumers, provide information in a format that is accessible for consumers to digest and respond to, and ensure sufficient time is built into research processes to facilitate meaningful engagement. As Gregory noted,

*"Adequate resources are needed to promote engagement programs and ensure that consumers are given an opportunity to contribute."<sup>10</sup>*

These include engagement techniques 'that involve deliberation and contribution to decisions', and which are 'more than information gathering or one-off consultations.' Such techniques have resource, time and skills implications for researchers and related organisations.

This is particularly important in the case of people with dementia, where it is clear that engagement processes need to be specifically tailored according to their individual circumstance, and which is likely to vary throughout the course of their participation. As one member noted in a workshop activity, 'my comprehension is failing', and hence smaller group discussions with less background noise enabled them to concentrate and contribute more effectively. Another has indicated that the teleconferences hosted by the AA National Office were proving difficult to participate in, as the conversations sometimes drift from the agenda, making it difficult for the member to follow the thread of the discussion. The volume and presentation of information, as

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<sup>10</sup> Gregory J (2007) op cit

well as technology constraints (e.g. capacity of home computer) were also cited as considerations to better enable participation of people with dementia.

One of the key enablers of the CDRN has been its ability to host face-to-face meetings, which members have identified as being fundamental to the building of trust and functional relationships between members. Members recognise the costs associated with convening these meetings, and are very appreciative of the contribution of AA in meeting these costs and organisational arrangements. Despite this, there is a general consensus that the benefits arising from additional meetings (e.g. twice per year) would far outweigh the additional associated costs if this is warranted by the workload of the CDRN.

## **5.4 Participation**

In her international study tour of consumer engagement processes involving people with dementia, Doyle found the personal commitment and satisfaction of participants to be one of the 'standout lessons':

*"People with dementia and their family carers find it satisfying to be involved in research evaluation; it gives them confidence and makes them feel they are valued members of society."<sup>11</sup>*

The personal commitment to improving outcomes for people with dementia is a core driver for members of the CDRN. Membership of the network is voluntary, and members are not reimbursed financially for their time or contribution; the only financial contribution that the AA National Office makes to them is through the accommodation and travel costs associated with meetings, and reimbursement of out-of-pocket expenses. The personal satisfaction that arises from participation in the network has been discussed previously in Section 4.1.2 where members cited personal benefits arising from the relational aspects within the network, as well as the enhanced respect and sphere of influence with those outside. Network members also identified personal attributes such as commitment, empathy and open-mindedness of members as being more important than technical and research skills.

The activities in which members have participated – such as assessment and selection of NQDCN projects, participation in committees and working groups, contribution to research projects, assessment of research proposals – has been documented elsewhere in this report. The investment of time and effort is significant, considering members also have professional and personal commitments such as caring and family responsibilities, and many are also dealing with the protracted stress and grief often associated with caring for a person with dementia or living with dementia. The short term impacts that have been demonstrated through this interim evaluation of the CDRN are indicative of the time, effort and expertise that members have provided.

A key factor in enabling members to maintain high levels of participation has been the personal and professional qualities of the Manager of the CDRN and other members of the AA National Office. This has been raised time and time again by members in the formal data collection processes of the evaluation as well as through informal comments made to members of the national evaluation team. The regular checking-in with members via phone or email, and the responsiveness to the issues raised in terms of information, communication processes and time members require to participate have enabled members to vary their contribution according to their personal needs and circumstances. This has been particularly critical for members who have dementia, whose feedback has consistently highlighted the additional efforts of the Manager of the CDRN to address their particular needs. Members have pointed to her 'tolerance' for people to vary the intensity of their participation over time according to circumstances, knowing their requests for this will be respected and supported. Similarly, members have commented on the vigilance in communicating opportunities for members to participate, and her systematic approach

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<sup>11</sup> Doyle, C (2008) *Consumer Involvement in Dementia Care Research, Policy and Program Evaluation – Report on Alzheimer's Australia Research Ltd Travelling Scholarship* p28.



in matching the requests and activities to the particular areas of interest expressed by members. There is a sense that members are given 'every opportunity to participate', with 'more opportunities than people can take up'. These include the recent inclusion of a CDRN member in a palliative care consumer advisory committee, in an effort to raise the profile of people with dementia within that sector.

Not unexpectedly, and in spite of the efforts of the Manager of the CDRN, a number of factors have been identified that continue to impact on the ability of members to participate effectively and efficiently. The most common issue is the limited opportunities for members to meet face-to-face and the problems of distance and geographic isolation that some members experience, which is a consequence of the Australia-wide membership of the CDRN. Strategies suggested to address these issues include more regular face-to-face national meetings e.g. twice per year; development of state-based or inter-state sub-groups of the network which could meet more regularly and engage with local research groups; and, improved relationships and engagement with AA State and Territory Association consumer group processes.

Another cluster of issues that impact on participation is around communication processes – both within meetings and in between meetings. While members readily acknowledge the responsive approaches of the Manager of the CDRN to tailoring communication and information to individual needs, members with dementia continue to find aspects challenging. These members have identified strategies which could improve their level of participation, and those of future members with dementia:

#### National meetings:

- Meeting rooms to be at the same venue as accommodation to enable members to rest or break from proceedings as needed;
- Size of rooms need to be smaller to enable members to hear the discussion;
- Activities and/or break-out groups should be undertaken in separate rooms to minimise noise and distraction;
- Usual meeting protocols may need to be dispensed with to prioritise the contribution of members in discussions, and voice their perspectives before the train of thought has been lost;
- Ensure a clear and consistent logic and style to the way documentary information is presented through use of a classification system that identifies the issue the information relates to in a header; and
- The support for carers to accompany members who have dementia is very much appreciated and regarded as critical in ensuring their continued participation.

#### Inter-meeting communications:

- Teleconferences do not work well when there are a lot of people involved as it is very distracting;
- Strong and clear facilitation skills to ensure all perspectives are included (this may include regular checking with members to ensure they have been able to follow the agenda item and conversation);
- Strict adherence to the agenda, to allow members to follow the flow of the meeting and be in a position to add their perspectives (which may be written down on their agenda to assist in their contribution);
- Clear signals when each agenda item has been closed off for discussion – through verbal confirmation by the facilitator; and also
- Use of a classification system for all emails and printed materials issued to network members that is linked to the key tasks of the network and includes visual cues. This will assist members to quickly identify what task the material relates to and its associated priority for them.

The confidence of members to identify the barriers and enablers to their participation and posit remedial strategies, as they have done throughout the evaluation, is indicative of their confidence that their views are valued, and will be acted on. This confidence in the integrity of the consumer engagement process is also reflective of the development of the group. In our May 2011 progress

report, we commented on our observations regarding the change in group dynamics that was apparent at the May 2011 workshop in Brisbane compared to the inaugural summit in September 2010. We noted the stages of small group development popularised by Tuckmann (1977) who identified four distinct phases groups go through in the course of their development: forming, storming, norming and performing. The key characteristics of each phase are:<sup>12</sup>

- Forming – the focus of effort is on the clarification of the task, its parameters and what the group expected to achieve;
- Storming – during this time there is conflict between members and resistance to the demands of the task and each other;
- Norming – members start to identify as a group, are comfortable with each other and feel as if they are starting to function as a group; and,
- Performing – solutions are developed and chosen, and attempts to resolve problems are handled constructively.

In our report we indicated that we would monitor the dynamics and outputs of the group in order to identify potential barriers and/or enablers to the healthy development of a consumer participation group such as the network. It is our view that the CDRN moved quite quickly from the 'forming' to the 'norming' phase, with little evidence of any 'storming'. The most likely explanation for this smooth transition is the focus of effort of members around key activities. It is also likely that the strong personal commitment and opportunity to make an impact on the lives of people with dementia have meant that this was irrelevant for members, who were focussed on achieving the tasks at hand. We anticipate that the clarification of future directions for the CDRN, following the completion of the selection process for Round 2 of the NQDCN, will be critical for enabling the group to bed down its focus, operations and processes and function in line with the 'performing' phase.

## 5.5 Capacity building

In its review of the literature regarding patient safety initiatives, the Monash Institute of Health Services Research (2008) concluded:

*“The capacity building process for consumer representatives’ optimal participation in committees and advisory groups ... should be viewed as a joint partnership with three partners – the health system and health services personnel, health consumer organisations, and the individual health consumer representative rather than the sole responsibility of the individual consumer representative.”<sup>13</sup>*

In its approach to improving consumer engagement in dementia research, the AA National Office has similarly used a tripartite approach, focusing on building capacity within the CDRN (consumers), the research system and personnel, and within its own organisation.

The capacity building activities and outcomes for consumers have previously been discussed in this report under Section 4.1.3. In summary, there is evidence that several members have built capacity in presentation and public speaking, project assessment and review, as well as technological (computer) skills. A number of members have also been able to utilise their research, service delivery and policy skills to benefit network activities and build capacity amongst members, e.g. development of a research proposal review template, and provision of information regarding the aged care funding and accreditation processes.

The AA National Office has consistently sought feedback from members regarding their information and skill requirements, and has put in place strategies to address these where possible. The May 2011 workshop, for example was structured to provide opportunities for skills development and networking, including facilitated information and group work sessions on

<sup>12</sup> Bruce W Tuckmann, Mary Ann C Jensen, 'Stages of small-group development revisited', *Group & Organisation Studies*, Dec 1977 p 419

<sup>13</sup> Monash Institute of Health Services Research (2008). *Literature review regarding patient engagement in patient safety initiatives*, Monash University p25

evaluation issues, consumer participation processes, and research processes. The regular email communications from the Manager of the CDRN also include notices regarding opportunities for members. Members are also included on the electronic mailing list for the DCRC and the AA National Office newsletters and bulletins, which provide information on latest research findings and developments in the dementia research, service provision and policy sectors. There is still scope for further training of consumers, particularly in relation to the critique of research proposals and through the provision of examples of 'best practice' consumer engagement.

The research community and funding bodies have also been targeted for capacity building activities, primarily through the AA/NHMRC workshop held in July 2011. This workshop arose due to the dissonance between perceptions of knowledge translation activities of researchers and CDRN members, as evidenced in the low success rate of NQDCN Round 1 project applications. The workshop and its outcomes have been discussed in previous sections of this report.

Capacity has also clearly been built within the AA National Office, through the employment of the Manager of the CDRN and the NQDCI Project Manager. Their active engagement in the work of the CDRN and related policy work has resulted in an increased profile of AA and its programs (including the CDRN) within the broader service provision, research and policy sectors. At this point, however, there appears to be little evidence of additional capacity being built within the AA State and Territory Associations, primarily because these Associations have had a long history of consumer participation to support their advocacy roles, and also possibly due to the limited contact between the Associations and the CDRN.

## 5.6 Support

In our May 2011 progress report we noted the types of supports provided to the network ranged from administrative and information, such as the establishment and operation of working groups, through to personal support for individuals. Most members indicated that this latter support has been most welcomed; alleviating concerns they may have felt about their ability to contribute to the network. This approach has provided a caring and supportive role for CDRN members during times of personal difficulties such as health issues, or the death of a loved one. This 'human touch' appears to be a significant aspect to the continued engagement by members.

The support provided by the AA National Office continues to be a key theme in the data associated with membership of the CDRN. The consistent and overwhelming feedback from members has been their significant appreciation particularly of the personal and professional qualities of the Manager of the CDRN. It is the most common issue raised in terms of enablers for participation and resources associated with the network. Members have also cited the support provided by the NQDCI Project Manager and the AA CEO. As Gregory (2007) notes in her summary of the principles of consumer participation

*"Its all about relationships, so use and build people skills"; and*

*"Consumer participation needs partnerships, partnerships need dialogue, dialogue needs trust. So build trust!"<sup>14</sup>*

There is strong evidence that there is a high level of trust between the AA National Office and the members of the CDRN.

The personal support provided to members by the AA National Office has been a strong enabler for members, and the personalised approach to managing members' participation in activities indicates that staff are utilising a reflective practice approach in their roles. Reflective practice is used by professionals who face problems that are "messy", that is, 'they are complex and there are no right or wrong answers, simply best and not so good.'<sup>15</sup> This has indeed been the

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<sup>14</sup> Gregory (2007) op cit p 40

<sup>15</sup> Clarke, B., James, C., and J. Kelly (1996) "Reflective practice: reviewing the issues and refocussing the debate" *International Journal of Nursing Studies* 33 (2), p 171

experience of the evolution and development of the CDRN, where the research structures, agendas, processes and personalities have been in operation for some time, and effecting change within this context is not straightforward. Consequently, strategies to improve consumer participation in research priorities and improving outcomes for people with dementia are likely to be multifaceted and varied.

Reflective practice therefore requires a degree of maturity to undertake, in order for staff to critically appraise the situation, their responses, and possible alternatives. Some stakeholders have commented on the relative inexperience of the staff within the AA National Office, referring to the project selection process undertaken in Round 1 of the NQDCN, and the dissonance between expectations of applicants and the decision-makers. It is our view, however, that the key personnel associated with the CDRN and the NQDCI have demonstrated considerable personal growth and maturity as the Initiative has progressed, and this is evidenced by their ability to reflect on their practices, amend processes, tailor approaches to individual needs, and negotiate often conflicting relationships, in order to optimise the outcomes of the consumer engagement process.

The support provided by fellow CDRN members has also been a significant outcome and enabler within the CDRN. Feedback has consistently focused on the mutual support of members and how this has helped the network develop a sense of unity of purpose and enabled members to value-add arising from their shared experiences. This is particularly evident for members who share a common geographic location; for example, members living in Adelaide have met several times over the course of their involvement in the network and have developed close friendships and working relationships. The role of face-to-face meetings in building trust and confidence amongst members was also considered to be a critical factor in the 'melding' of the network.

## **5.7 Communication**

The content, style and processes of communication are critical elements in facilitating consumer involvement in research.

Content considerations include the use of appropriate, inclusive and transparent language and avoidance of complex language, jargon and acronyms. This has been a recurring issue for the CDRN from the outset, and while the material developed by the AA National Office generally adheres to these requirements, this is rarely incorporated into the presentations and material provided at meetings and workshops by people who are not closely involved with the network. This is a work-in-progress, and there have been some successes. For example, all NQDCN proposals are required to include a 'plain English' summary; it is understood that in some cases CDRN members have rejected applications on the basis of the dense and inappropriate language. This is seen as indicative of the applicant's ability to work with, engage and communicate with consumers as equal partners in the research process.

There are some signs that communication between members and researchers is improving. Members have at different times noted that they have felt a sense being intimidated by some members of the research community, and have felt ill-prepared to engage in discussions with them. However, the involvement of DCRC leads at the national meetings has played an important role in breaking down these barriers and the ready adoption of the communication protocols developed by the CDRN has also built confidence and trust. The requirement for researchers seeking funding through AAR and DCRCs to include 'plain English' summaries has also been a significant step forward in improving understanding and communication between the two sectors. While it is still early days, these developments bode well for researchers to incorporate user-friendly language elements in their proposals in an ongoing way.

Style considerations include the presentation of information in a clear, accessible and professional manner. Clarity of content and consistency in structure of meeting papers is particularly important in assisting members with dementia navigate the documentation and follow the flow of meetings. This is also the case for teleconferences, where the visual cues are not present and a number of

people may be trying to speak at one time; strong facilitation skills are required to ensure meetings adhere to the agenda and provide distinct opportunities for members with dementia to contribute.

A variety of communication processes have been implemented by the AA National Office to facilitate engagement with, and encourage interaction between, members. The most significant of these has been the national meetings, which have enabled members to meet face-to-face with each other, the AA National Office team, as well as researchers. Members have indicated their strong preference for more opportunities, to enable the group to continue to evolve as a functioning unit, as well as a way to obtain a better understanding of the perspectives of researchers, the context in which they work, and therefore the best way in which to interact with them.

The communication processes within the CDRN have evolved over time, responding to the needs, interests and circumstances of members. For some, the amount of information and means by which this has been received has been welcomed; others have expressed feelings of being 'overwhelmed' by the volume, and still others struggled due to the limitations of their home computer. This demonstrates the fine balance between effective communications which keep members informed and engaged without burdening them. Consequently, the majority of the AA National Office's communication is through regular emails to the network, working groups and individuals, and group teleconferences as well as regular telephone contact with individual members. The process for members has been tailored to their preferences, for example, with some receiving bimonthly emails, others monthly and yet others receiving a mix of electronic and hard copy communications.

*"The amount of emails is about right – the monthly update is particularly effective as it brings all the issues together and keeps us informed and allows us to see where we can be involved."*

Members have clearly indicated their preference not to use other forms of electronic communication apart from email. A blog or on-line chat room was initially established but has failed to gain traction, and members have consistently declined to be part of social networking sites such as Twitter or Facebook. The reasons behind this are not clear, although it is possible that social media are mainly used by a demographic not currently prominent in the network, while others have indicated that for them the computer is associated with their working day, and they do not want to use it as a social medium as well.

*"...one of the problems with the chat room is that the discussion may not be specific to your interests and is general so you may have to wade through information before you find things that are relevant. For example you may have more to contribute to some topics than others."*

A number of members were critical of the frequency of email communication and the amount of information distributed. References were made to strategies that the Manager of the CDRN had taken to address this through trialling different communication strategies and adjusting processes to suit the individual needs of members if required. There was also a consistent message conveyed about the importance of ensuring communication and meeting processes addressed the particular needs of members with dementia.

*"I am not involved in teleconferences – I feel a bit apprehensive as there are lots of people talking and it is hard for me to follow and contribute."*

*"I decided I needed to be proactive and comment on the need for people to slow down and be simpler in what they were saying."*

## **5.8 Recruitment and selection**

The recruitment of members was undertaken through seeking nominations from AA State and Territory Associations as well as through advertising amongst the AA networks. The resulting make-up of the group includes representatives of each State and Territory, although these

individuals do not represent the State and Territory Associations. The process was designed to cast a broader net than the usual approaches, to provide a fresh mix and approach to consumer engagement in research. Consequently, there is a disconnect between the State and Territory based consumer groups and the CDRN. Effort has been made, however, to facilitate connections between the national consumer groups convened by the AA National Office.

The defining feature of the CDRN is that it brings together consumers, including people with dementia, who are actively engaged in decision making about research priorities. While consumer groups have existed previously, these have predominantly been in an advisory capacity, and have not included mechanisms to involve the voice of people with dementia in research agenda setting. The representativeness of the group as it operates is mostly consistent with that anticipated in the CDRN Terms of Reference, which required:

- At least one member from each state and territory;
- At least 5 people with dementia;
- 1 or more members who live in regional or remote areas;
- 1 or more members from a CALD background; and
- 1 or more members from an indigenous background.

There is a general sense amongst members that the current mix and number of members is about right. Feedback received has been that the network has good diversity and a depth of skills and appropriate expertise amongst membership; this has helped their effectiveness and efficiency, with members readily sharing their expertise. The number of members was also deemed to be just right, as fewer members would likely place too much burden on members in terms of their involvement, particularly given the additional caring, family and professional responsibilities most members experience; and any more could impact on the cohesion and unity of the network. The majority view of members is illustrated by the quote below:

*“My overall comment is that I am surprised at how well the network has gelled together and that we have got two good projects off the ground. It has been very successful and more successful than I anticipated. This is because we have members who were carefully selected with a lot of enthusiasm and knowledge and Ellen has been a terrific coordinator.”*

A key point of concern was the number of members who were isolated due to geography and/or community background. It is evident that where there is a critical mass within a given geographical area (e.g. South Australia and Queensland), there are greater opportunities to work together, leading to a heightened sense of engagement, unity and purpose. Similarly, the low numbers of Culturally and Linguistically Diverse and Indigenous representatives within the group (one of each) limits their opportunity to represent the diverse interests of their communities. The participation of one member in a related national consumer group convened by the AA National Office has provided a mechanism for cross-fertilisation of ideas and issues between the groups.

The recruitment of people with dementia has taken some time to reach the identified number (five), with only two members participating in the inaugural summit in September 2010, increasing to four members at the May 2011 meeting. Their involvement in the network is a significant statement on the part of AA. It is far more usual for carers to be involved in consumer groups than for people with dementia. This poses significant problems, particularly for research-focussed advocacy groups, as:

*“..research into the differences between proxy perceptions and the perception of the person with dementia is showing that both the carer and the person with dementia have valuable, and sometimes different, points of view on health care.”<sup>16</sup>*

There is an obvious respect within the network for those members who have dementia, and appreciation of the efforts of the AA National Office to include and support their participation. We have observed very sensitive interactions between members at the national meetings, including

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<sup>16</sup> Doyle, C. (2008) op cit p 25

particular efforts of some to ensure that the contribution of people with dementia are maximised. As one member noted, the inclusion of people with dementia added a 'realness to the whole process', and even though all members had direct experience of dementia, having a constant reminder of a person living with dementia amongst them has helped them keep focussed as to the purpose of the group. This is illustrated by the quotes below from CDRN members:

*"I would agree that the perspectives of carers are different from people with dementia."*

*"I think the observation that there may be more of a focus on issues related to carers is reasonably accurate as there are more of us and we are an articulate group – but you can't separate the two easily, so much of this focus on carers is also relevant to people with dementia."*

*"All of us would unanimously agree that having people involved in the network who are living with dementia is vital to the network..."*

That said, however, sometimes the sheer weight of numbers can make it difficult for those with dementia to have their voices heard. The introduction of a 'buddy' system has been identified by several CDRN members as a way to assist new members, particularly those who are in rural and remote locations and/or members living with dementia. Suggested mechanisms to ensure the voices of people with dementia are captured within this context have been previously discussed in Section 5.4. There does appear to be some scope to improve the representativeness of the CDRN membership both geographically and in terms of general representativeness.

## 6 Conclusion and Recommendations

The CDRN has generated an impressive list of achievements and short term impacts in its first year of operation. The evaluation of the CDRN has been framed using an evaluation framework that considers impacts and outcomes across three levels – consumers, providers and the system. These impacts are in evidence primarily through the activities of the members of the CDRN. They have successfully determined priorities for knowledge translation projects and through a rigorous assessment and review process identified two projects for funding. The network will allocate further funding of Round 2 projects in February/March 2012. The CDRN has established a relationship, which is crucial, with the leads of the three Dementia Collaborative Research Centres (DCRCs).

The network has several key achievements that demonstrate the increasing capacity of its members to work with researchers and service providers. This has included contributing a consumer perspective to research projects, providing presentations to service providers and presenting at major research and health forums. Several members have been invited to have ongoing roles with research teams through their membership of consultative committees.

At the broader health and aged care system level – the need for members to develop capacities and experience with their role in the network, has been the focus. For system change to occur this will require time and a two-way investment between the research community and the CDRN. To date the major opportunity to influence dementia research at a system level has come through preliminary work with the National Health and Medical Research Council (NHMRC). The NHMRC has a key role in supporting the major attitudinal shift that will be required on the part of researchers through demonstrating that the research community values consumer input through championing the contribution and providing tangible support for the work of the CDRN.

### 6.1 Overview

The CDRN is still evolving after little more than twelve months of operation. The year ahead will provide a new phase of activity for the network with the roll out of further knowledge translation projects. The CDRN will have an ongoing role in the monitoring and implementation of these projects.

The members of the CDRN have a high level of satisfaction with the operation and functioning of the network in its first year of operation. The members have formed into an energetic and committed group which is characterised by shared vision, co-contribution to the tasks of the network and a desire to effect positive change for people with dementia, their carers and families. Whilst the leadership of the network still rests with AA there is increasing confidence and capacity development occurring amongst members. However there is also an ongoing need for clarity about the role of the network and the expectations of members.

The members recognise the considerable support provided by research experts from the DCRCs and the very significant contribution provided by the team from AA. The effective coordination role demonstrated by the Manager of the CDRN is perceived as pivotal to the success and ongoing viability of the network. There is currently recognition that the resources and support that members require to effectively participate are provided. However there is a need to acknowledge that a 'one size fits all' approach is not appropriate given the diversity of network members. Communication processes require continual refinement as the need for open and transparent sharing of information is balanced with the pressures of information overload. The importance of ensuring that people with dementia are adequately represented on the CDRN is critical as is the need to address barriers to the ongoing sustainability of the network.

The recruitment and selection of CDRN members has been effective if judged by the bond that has emerged amongst many members and the capacity for the network to work co-operatively on shared tasks, such as the identification of priority areas for knowledge translation projects and the selection of project proposals. There are two competing views as to whether the network has got



the right balance between the needs of carers and the needs of people with dementia. This is a challenge for the CDRN as it moves forward. The funding of a project in timely diagnosis is seen as particularly important for members with dementia and they feel the Round 2 process for generating project proposals has addressed this through the intention to fund at least one project in each priority area.

All network members bring diverse personal and professional experiences to their role, with their experience and empathy with dementia the critical common denominator. In some cases several members feel the need to advocate particularly for the needs of people with dementia and for the needs of carers in Aboriginal and Torres Strait Islander, Culturally and Linguistically Diverse and rural and remote communities.

## 6.2 Key strategic issues

The CDRN faces several strategic issues in the ensuing period. The landscape of the dementia research will continue to evolve with new initiatives such as the proposed development of NHMRC Partnership Centres. AA's involvement in advocating for dementia research to be at the forefront of partnership centre funding will impact significantly on the future of the CDRN particularly and consumer engagement in dementia research generally.

These key strategic issues are discussed below:

### Ensuring ongoing funding

The network is not sustainable without a coordinator and funding to support member participation. The importance of maintaining the support and engagement of the DCRCs has been recognised as critical, given their relationship with the network and support of the Manager of the CDRN. Currently the funds available provide a purpose and direction for the CDRN with the focus on selection and monitoring of knowledge translation projects. Without project funding, the main vehicle for the engagement of the DCRCs and CDRN members disappears. Efforts to secure ongoing funding for the CDRN are best spear-headed by the national office of AA in collaboration with the DCRC leads. Several stakeholders have identified the NHMRC as a potential future funding source.

The NHMRC has a key role in driving consumer engagement in research.

*“The NHMRC is Australia’s leading expert body promoting the development and maintenance of public and individual health standards. It brings together within a single national organisation the functions of research funding and development of advice. One of its strengths is that it draws upon the resources of all components of the health system, including governments, medical practitioners, nurses and allied health professionals, researchers, teaching and research institutions, public and private program managers, service administrators, community health organisations, social health researchers and consumers”.*<sup>17</sup>

As the leading national research agency the NHMRC has produced a framework in 2005 to guide consumer and community participation in research.<sup>18</sup> It remains, uniquely positioned to institute planned, supported and sustained commitment to consumer engagement in research through championing the contribution of consumer networks like the CDRN.

### Engaging researchers

As the primary aim of the CDRN is to support consumers in having an active role in research and knowledge translation, the ongoing engagement of researchers is fundamental to the survival of the network. This responsibility is a ‘two-way street’ with greater receptiveness required from

<sup>17</sup> Available at <http://www.nhmrc.gov.au/about/organisation-overview/nhmrcs-role> accessed 9 January 2012.

<sup>18</sup> NHMRC (2005) **A Model Framework for Consumer and Community Participation in Health and Medical Research**. Available at [http://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/r33.pdf](http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/r33.pdf) accessed 9 January 2012.

researchers if meaningful consumer engagement is to become a mainstay of the research process. The CDRN is providing a mechanism to showcase the commitment of consumers and provides a real time example of what can be done to involve consumers in research.

Whilst the principal focus should continue to be with the DCRCs the knowledge translation projects will provide opportunities for engagement with a wider group of dementia researchers. The CDRN will need to ensure that it identifies opportunities for interaction with the DCRCs and that if increasing demands occur, these are balanced for members with appropriate priority afforded to requests from the DCRCs. Opportunities to engage researchers more widely than this could be pursued by the NHMRC through small changes to their existing systems and processes. The CDRN provides a model that could be developed and made available more widely to the research community. Developments like this will require the influence of government.

### **Clarifying future roles**

The CDRN needs a clear role to be sustainable in the foreseeable future this role will coalesce around the knowledge translation projects and responding to requests from the DCRCs and other dementia researchers for consumer involvement. A review of the Terms of Reference on an annual basis will assist the network to clarify its role at the start of each year to ensure all members have a common understanding of the network's priorities.

The CDRN may in the future be invited to take up new roles and be used for other purposes, for example through providing guidance on consumer views for researchers working in other areas of the health and aged care sectors. A key strength of the network is the strong commitment generated by the common bond and experiences of dementia of the current members. While dementia will always be the unifying theme that brings the network members together there may be opportunities in the future for the CDRN to provide a model for other fields of research and ways in which they might advocate for consumer involvement more broadly.

The primary target group for the CDRN to date has been the research community. The experiences learnt through Round 1 of the NQDCN project selection process raised questions in the minds of several members as to the capacity of the network to influence the focus of research projects. Consideration may need to be given to broadening the network's agenda to include practitioners of care.

### **Cooperating with the Service Provider Network**

In this first twelve months of operation there has been very little, if any, interaction between the CDRN and Service Provider Network of the NQDCI. This has been identified as a 'gap' by several members. The potential synergies and spin-offs that might arise from a closer connection between these two networks provide a strategic opportunity for the future. As an initial step these organisations could be asked to promote the concept of consumer engagement in dementia research and/or the CDRN through direct links to the relevant AA web pages. This would contribute to greater public awareness about the contribution that consumers can make to the research process.

### **Relating to State and Territory AA associations**

There is currently a 'disconnect' between the work of the CDRN and State and Territory AA associations. The Round 2 knowledge translation projects will potentially provide the opportunity for closer cooperation with some State and Territory associations. Currently the consumer engagement processes of the CDRN and State and Territory associations are occurring in parallel. Whilst this might be appropriate in the short term, effort is needed to explore how improved interaction can occur between the network and other established AA National, State and Territory consultative committees. A useful starting point could be improved communication between the CDRN and AA State and Territory associations, for example, the quarterly issue of an update on the CDRN to all associations for inclusion in relevant newsletters.

### **Contributing appropriately to the policy process**

The CDRN has not yet established what its appropriate role is in the policy process as it relates to the care of people with dementia, or whether it sees itself as having a role in this process. Alzheimer's Australia does have a National Consumer Advisory Committee (NCAC) that has the primary function of providing advice and direction on policy, however to date; this group has not had significant involvement in developing priorities for research-related policy. With the new AA brand emphasising research as one of three key focus areas of activity (along with advocacy and service delivery), there may be scope for the CDRN to develop closer ties with the NCAC in contributing their specific research-related interest and expertise of members to the formulation of research-related policy.

### **Managing a national network**

The 'tyranny of distance' was consistently identified as an issue for many network members. This will become a strategic problem if the dispersed membership of the CDRN cannot be brought together at regular intervals and/or remain connected through appropriate communication mechanisms. If the workload of the network demands it, consideration might be given to the potential for two face-to-face meetings per year. This should be determined on the basis of the tasks the network faces, as the expense of bringing all members together has to be balanced against the likely outputs achieved.

The challenges of managing a national network are not new to AA or this sector and continued efforts will be needed to ensure that a national focus is maintained with appropriate and diverse representation. Currently the CDRN does not fulfil its aim (as per the CDRN Terms of Reference) to ensure that the committee should comprise at least 5 people with dementia), this should be addressed.

### **Maintaining member engagement**

Whilst maintaining member engagement is currently not a problem, in the future a lack of member continuity is perceived as a risk to the effectiveness of the network. The nature of the caring journey and dementia trajectory means that there will be variables which can affect health and levels of participation over time, and this should be taken into account in managing and supporting a group such as the CDRN. Early identification of emerging issues for members and appropriate corrective action may reduce this problem. On occasion it may be appropriate to institute leave of absence arrangements as an alternative to a member withdrawing entirely.

Supporting new members through a formal orientation to the CDRN and induction process may also maintain member engagement. Opportunities for appropriate training and development as required by network members may also be a useful tool in maintaining engagement. In addition the introduction of a 'buddy' system has been identified by several CDRN members as a way to assist new and current members. Several members have expressed interest in receiving feedback on their performance with the aim of continuously improving their contribution to the network, this may also contribute to their ongoing engagement.

### **Planning for succession**

The CDRN is currently reliant on the leadership provided by officers of AA and the significant commitment provided by the current Chairperson. Without the dynamism of these people the network would not have progressed as it has to date. Inevitably other demands arise for individuals, so it would be prudent for the network to look at how it might plan for these succession issues when they inevitably arise.

### **Evaluating success**

The difficulties of the CDRN demonstrating more than a contribution to improved health outcomes for people with dementia has previously been highlighted in this report. Over time network members may become disenchanted if they feel they are not seeing tangible results for their investment of time and effort. The majority of members were realistic as to what the CDRN can

achieve and recognised the structural barriers to changing service delivery and professional attitudes to people with dementia. There was also recognition of the stigma associated with dementia that also generates barriers to change. Members universally agreed that interim measures of success would be the most useful indicators of progress e.g. a direct reference to the CDRN priority areas by researchers would be seen as a positive sign of impact as would increased recognition of the contribution of consumers to the research process through leading national agencies such as the NHMRC.

### **6.3 Conclusion**

The CDRN is a new initiative that has genuinely applied the key principles of consumer engagement through its structure and operations to date. It is however still evolving and requires ongoing stewardship and investment if it is to achieve its potential. The CDRN has a clear path forward for the year ahead; decisions about the network's ongoing sustainability beyond that period will be the subject of further discussions.

The purpose of the network is to support consumers in having an active role in research and knowledge translation and to use their experience and expertise in dementia care to inform the research process and contribute to better care practice and outcomes. These efforts will hopefully improve outcomes for consumers, providers and the broader health and aged care system in the future, leading to new stories of person-centred care, timely diagnosis and best practice treatment and support for the many families that will face dementia in the future.

*“You hear your own story all over again and it is desperate and it is lonely and isolated in the midst of service providers. I wonder why? Can't we support people to cope with this and keep their loved one at home with the support that is needed? It seems that the world of cancer does this way, way better – far in excess of what we have in place for dementia.”*

### **6.4 Recommendations**

The following recommendations are based on an underlying premise that there is a need to build on what has been learnt so that there is ongoing improvement of the CDRN. They have been clustered into strategic recommendations (those fundamental to the ongoing viability of the network) and operational recommendations (those identifying process improvements for the network).

#### **Strategic Recommendations**

It is recommended that:

1. The NHMRC builds upon the infrastructure established by AA through providing ongoing funding for the CDRN beyond June 2013 as demonstration of the government's commitment to sustained, planned and supported consumer engagement in research.
2. The relationships with the DCRCs and researchers continue to be developed with opportunities identified for joint planning and action that will stimulate consumer engagement in all stages of the research process.
3. The leadership for the CDRN provided by the AA National Office and Board is maintained as further investment is needed to ensure the sustainability of the network.
4. The report of the interim evaluation of the CDRN is disseminated widely both within government, research, aged and health care sectors to foster greater debate and awareness about consumer involvement in research.

## **Operational Recommendations**

It is recommended that:

5. The CDRN reviews its Terms of Reference and membership with priority given to recruiting an additional member with dementia. To maintain continuity the current Chairperson of the network is invited to continue in the role for another 12 months.
6. The ongoing role of the CDRN following the conclusion of the selection process for Round 2 of the NQDCN is clarified and documented through a work program for the ensuing 12 month period. The impacts of strategic developments in the sector are considered by the CDRN in discussions about the network's role.
7. The AA National Office clarifies its expectations and the desired relationship between the CDRN and the Service Provider Network.
8. The CDRN identifies mechanisms through which it might improve communication between and engagement of the AA State and Territory Associations.
9. The CDRN reviews the support needs of all members on an annual basis with consideration given to holding face-to-face meetings twice per year when the work of the network requires this and pending the identification of additional funding.

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## Appendix 1 CDRN Terms of Reference



# Consumer Dementia Research Network (CDRN) Terms of Reference

## 1. Purpose

Alzheimer's Australia is committed to a consumer approach to research. The purpose of Alzheimer's Australia's Consumer Dementia Research Network (CDRN) is to support consumers in having an active role in research and knowledge translation. Consumers will use their experience and expertise in dementia care to inform the research process and contribute to better care practice and outcomes. Creation of the network is possible through financial support from the Dementia Collaborative Research Centres.

## 2. Principle Functions

The initial functions of the CDRN will include involvement with the National Quality Dementia Care Network (NQDCN) and the Dementia Collaborative Research Centres (DCRC's). It is likely that involvement with the network and the DCRCs will evolve over time.

Involvement in the NQDCN may include:

- Setting priorities for NQDCN knowledge translation projects;
- Commenting on knowledge translation project proposals;
- Participating in knowledge translation projects;
- Monitoring knowledge translation projects;
- Assisting with communicating findings of knowledge translation projects to the community; and
- Advising the management of the NQDCN through representation on the Executive Committee.

Involvement with the DCRC's may include:

- Advising the DCRC's on consumer priorities for research;
- Assisting with communicating findings of research projects to the community; and
- Providing information and advice to researchers on how to improve their interactions with consumers.

The CDRN may also provide a consumer perspective on dementia research to other research organisations such as the NHMRC and/or government committees.

### 3. Membership

Membership is open to people with dementia, family carers and friends. This includes individuals who are currently or have previously provided support to a person with dementia, as well as family carers with professional experience in dementia care. The CDRN will comprise between 20-30 people at any time.

Membership of the Committee should comprise:

- At least one member from each state and territory;
- At least 5 people with dementia;
- 1 or more members who live in regional or remote areas;
- 1 or more members from a CALD background; and
- 1 or more members from an Indigenous background

It is expected that initially some members involved in other Alzheimer's Australia consumer representative groups (ie. National Consumer Advisory Committee) will be included on the committee. New members of the committee will initially be appointed for a term of up to three years. The network will be chaired by a chairperson who will be nominated by members of the CDRN. The chairperson will be appointed for a 12 month term. Membership of the CDRN will be reviewed at the beginning of each calendar year to identify whether there is a need to recruit new members.

### 4. Reporting

- The CDRN will report to the Department of Health and Ageing (DoHA) through the Dementia Collaborative Research Centre-Carers and Consumers.
- The CDRN will report to the board of Alzheimer's Australia.

### 5. Meetings

The CDRN will meet face to face a minimum of once each year. Alzheimer's Australia will provide support for travel and accommodation costs associated with the meeting. The CDRN will also meet via regular teleconferences when required.

### 6. Secretariat

Secretariat will be provided by the manager of the CDRN. The Secretariat's responsibilities include:

- Arranging meetings and teleconferences
- Arranging travel and accommodation for the face-to-face meeting
- Circulating meeting and other information to members
- Induction and training for new members
- Other CDRN support functions, including records of meetings

### 7. Evaluation

The effectiveness of the CDRN will be reviewed by members annually and more formally by an external reviewer as part of the evaluation of the NQDCN in 2011/2012.

### 8. Review

These Terms of Reference are to be reviewed annually or as required to ensure they reflect the current requirements and priorities of the CDRN.\*

*\* Terms of Reference last reviewed by CDRN members on 16 May 2011.*



## **Appendix 2 Questions and Comments from CDRN Members Relating to the Evaluation**

At the CDRN meeting on 16 May 2011, members wrote down a key question they would like answered in the evaluation. The national evaluation team collected the information, and grouped the questions thematically. Five themes emerged. The national evaluation team explained that not all issues raised were within the scope of the evaluation.

### **1. Impact on research**

#### *Questions:*

- Is there a consumer representative on all committees considering dementia research?
- Has the work of the CDRN had a positive, permanent impact on the way researchers think about involving consumers in their projects?
- What are the gaps in dementia research in Australia? Has there been an audit?
- How do you achieve a situation where researchers involve consumers at the research planning phase rather than as an add-on later?
- Did the network influence a consumer perspective in research projects it advised on?
- Did the network influence the adoption of person centred care as the starting point for research enquiry?

### **2. Impact on knowledge translation**

#### *Questions:*

- What influence has the network had on the translation research projects?
- Did the network influence allocation of grants to top priority research projects?
- What impact can I as a consumer have in ensuring knowledge is translated into practice and to influence future policy?
- Did the network influence the uptake of knowledge translation projects by funders?
- Did you understand how the term knowledge translation was used in this network?
- How could the person with dementia you care for benefit from knowledge translation?
- Ensuring research implementation!

### **3. Impact on people with dementia**

#### *Questions:*

- How will our contributions at this national level make a difference to the individual living with dementia?
- Has my participation in the network been of benefit to people with dementia and their carers?
- Is the network substantially contributing to improving the circumstances of people living with dementia?
- How will the CDRN know what impact it has had on the care of people with dementia?
- Does the CDRN contribute effectively to the actual implementation of improving lives of people with dementia and not only contribute to more research?
- Will all people in Australia who are involved either, by having to live with dementia or care for a person with dementia, be improved?
- Has the CDRN really improved care practices in home and residential care?
- How could the person with dementia you care for benefit from knowledge translation?

### **4. Support for members**

#### *Questions:*

- The provision of sharing information with strengths and shortfalls has helped. I have struggled with some areas as I have never been involved with pure research. My comprehension is also failing.
- Can proposals be sent/provided in normal English? This would make it easier to respond in a more timely manner.
- Has AA provided enough support and resources to members? How could this be improved?

## 5. Individual contributions and roles

### Questions:

- Would you participate in a consumer group, like the CDRN again, and/or recommend it to a friend?
- Am I making a genuine (learned) contribution?
- Did you understand your role in the network?

### ***Appendix 3 Consumer Dementia Research Network – Survey Analysis***

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## Introduction

This report presents an analysis of a survey that was conducted to evaluate the experiences and ascertain the views of members of the effectiveness of the Consumer Dementia Research Network (CDRN). The CDRN was launched in September 2010 and has now been in operation for just over one year. The questions in this survey were designed to explore progress against the objectives or aims of the CDRN as described in the CDRN Terms of Reference<sup>19</sup> and the domains of effective consumer engagement, as outlined in the evaluation framework.<sup>20</sup> The evaluation framework for the CDRN describes eight domains that provide integrating themes for analysis of the data and information generated through the evaluation of the CDRN. These domains are:

- Leadership and culture
- Role clarity / governance
- Resources
- Participation
- Capacity building
- Support
- Communication
- Recruitment and selection

## Survey implementation

This survey was administered using SurveyMonkey®, an online survey tool. All 25 CDRN members were emailed an introductory message including a participant information sheet and consent form on 21 October 2011. To improve the response rate, a reminder email was sent on 28 October 2011 to those members that had not yet responded. The survey collection was closed on 1 November 2011.

## Response rate

In total, all 25 CDRN members who received the survey attempted to complete it. The data were then assessed for quality, usability and consistency to ensure a robust analysis could be performed. Following this, it was found that one respondent consented but due to personal circumstances was unable to complete the survey. This left a total of 24 (96%) surveys which were used in the final analysis. Whilst some respondents did not answer every question, the majority of respondents did provide an answer for each question.

These findings are presented in relation to the eight domains of effective consumer engagement. As multiple sources of data are being used in the evaluation of the CDRN, not all domains were intended to be fully explored through this survey.

## Leadership and culture

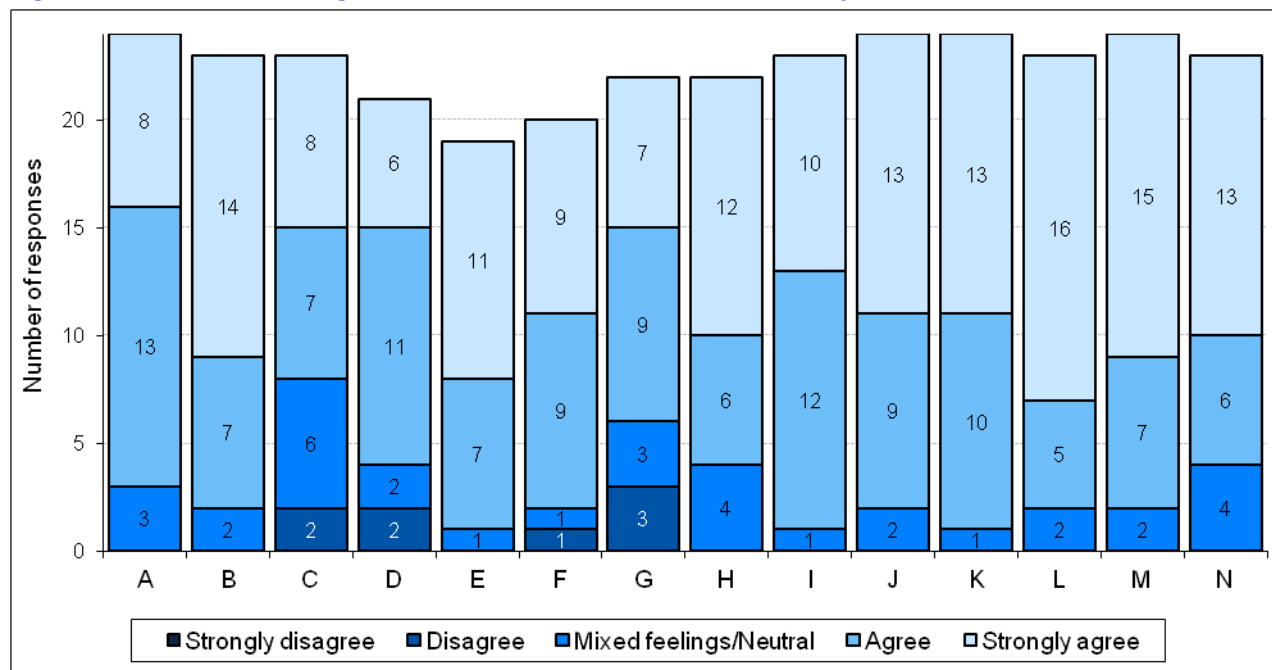
Whilst CDRN members do feel they are contributing to the direction of the CDRN, the leadership of the network is still seen to rest with the Alzheimer's Australia (AA) National Office. The coordination role provided by AA is perceived by members to be pivotal to the effective functioning of the network. Exploring the issue of leadership, survey respondents were asked to rate their level of agreement with two statements. Firstly, in response to the statement '*The direction of the CDRN is determined by members*', 7 of 22 of respondents strongly agreed, 9 of 22 agreed, 3 of 22 had mixed feelings / neutral, and 3 of 22 disagreed. No respondents strongly disagreed with the statement (see Figure 8, statement G).

<sup>19</sup> Alzheimer's Australia (September 2010) *Consumer Dementia Research Network Terms of Reference*.

<sup>20</sup> Centre for Health Service Development (2011) *National Quality Dementia Care Initiative Evaluation Framework – Version 2*.

Secondly, in response to the statement ‘The leadership of the CDRN comes from Alzheimer’s Australia’, 12 of 22 respondents strongly agreed, 6 of 22 agreed, and 4 of 22 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 8, statement H).

**Figure 8 Level of agreement of CDRN members with key aspects of network operation**



- A I have shared the knowledge gained from my participation in the CDRN
- B My investment (of time and effort) in the CDRN has been worth it
- C I have developed valuable skills through my participation in the CDRN
- D All members contribute to the work of the CDRN
- E My opinions are valued by other members of the CDRN
- F The CDRN is treated as an equal partner by Alzheimer's Australia
- G The direction of the CDRN is determined by members
- H The leadership of the CDRN comes from Alzheimer's Australia
- I The CDRN has influenced the selection of NQDCI knowledge translation projects
- J Members of the CDRN are representative of a range of dementia consumers
- K I intend to continue as a member of the CDRN for the foreseeable future
- L I have been provided with adequate resources (e.g. financial reimbursement, information) to participate in the CDRN
- M I have been provided with adequate support (e.g. guidance from Alzheimer's Australia) to participate in the CDRN
- N Communication between Alzheimer's Australia and the CDRN has been effective

To better understand network members views about the culture between the CDRN and AA, survey respondents were asked to rate their level of agreement with the statement ‘The CDRN is treated as an equal partner by Alzheimer’s Australia’. Out of the 20 respondents to this question, nine strongly agreed, nine agreed, one had mixed feelings / neutral, and one disagreed. No respondents strongly disagreed with this statement (see Figure 8, statement F).

The leadership (and support) provided by AA, and in particular Glenn Rees, Ellen Skladzien and Chris Hatherly, is praised in a number of the free text comments included in survey responses. There is consistent reference to the contribution of the personnel of AA who are perceived as an excellent and strong project team. The following comment is illustrative of this perspective:

*“The staff ... it’s their commitment, consultative approach, and their expertise in the field, and their very good understanding of the national, state and territory contexts”.*

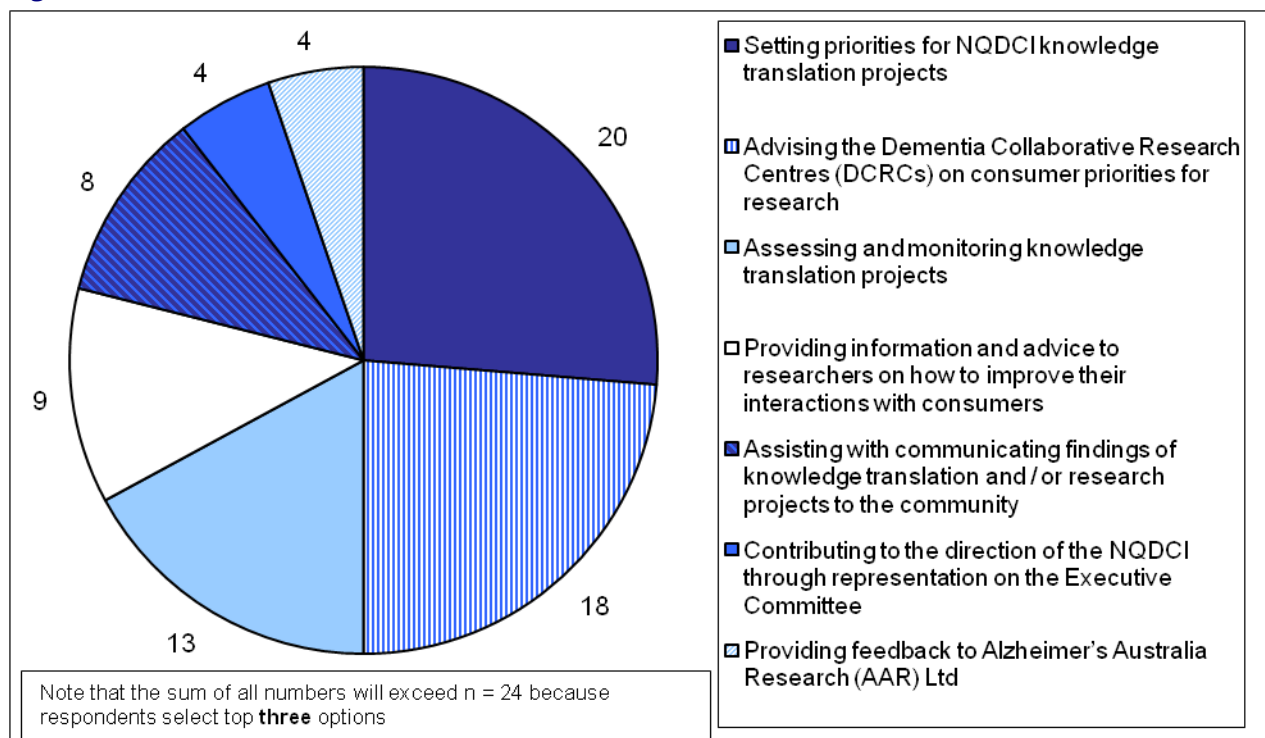
Using Kendall’s tau correlation coefficient (a statistic used to measure associations between ordinal variables), correlations between each of the fourteen statements were calculated and analysed. The most significant correlations arose around the statement M ‘I have been provided with adequate support (e.g. guidance from Alzheimer’s Australia) to participate in the CDRN’. Statements B, C and L correlated very strongly with this statement. Free text comments provided by respondents indicate that the culture of AA is one of support and transparency.

The statement with the weakest correlations with other statements was statement G ‘The direction of the CDRN is determined by members’. This is not unexpected as the CDRN has been operating for just over 12 months and leadership currently rests with AA – it will be interesting to track this perspective over time to see if this changes as the network matures.

### Role clarity / governance

From a list of seven options (that came from the CDRN Terms of Reference), survey respondents were asked to select what they considered to be the three most important roles of CDRN members. Figure 9 below displays the results to this question. Setting priorities for NQDCI knowledge translation projects was most frequently selected as an important role. This was closely followed by the role of advising the Dementia Collaborative Research Centres (DCRCs) on consumer priorities for research. The assessment and monitoring of knowledge translation projects was also ranked reasonably highly. The remaining four options were selected less often, indicating a perception of lower importance for these roles among respondents generally.

**Figure 9 Roles of CDRN members**



In terms of the CDRN’s influence on the selection of the National Quality Dementia Care Initiative (NQDCI) knowledge translation projects, survey respondents generally believed the network was

exerting influence. In response to the statement *'The CDRN has influenced the selection of NQDCI knowledge translation projects'*, 10 of 23 respondents strongly agreed, 12 agreed, and 1 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 8, statement I).

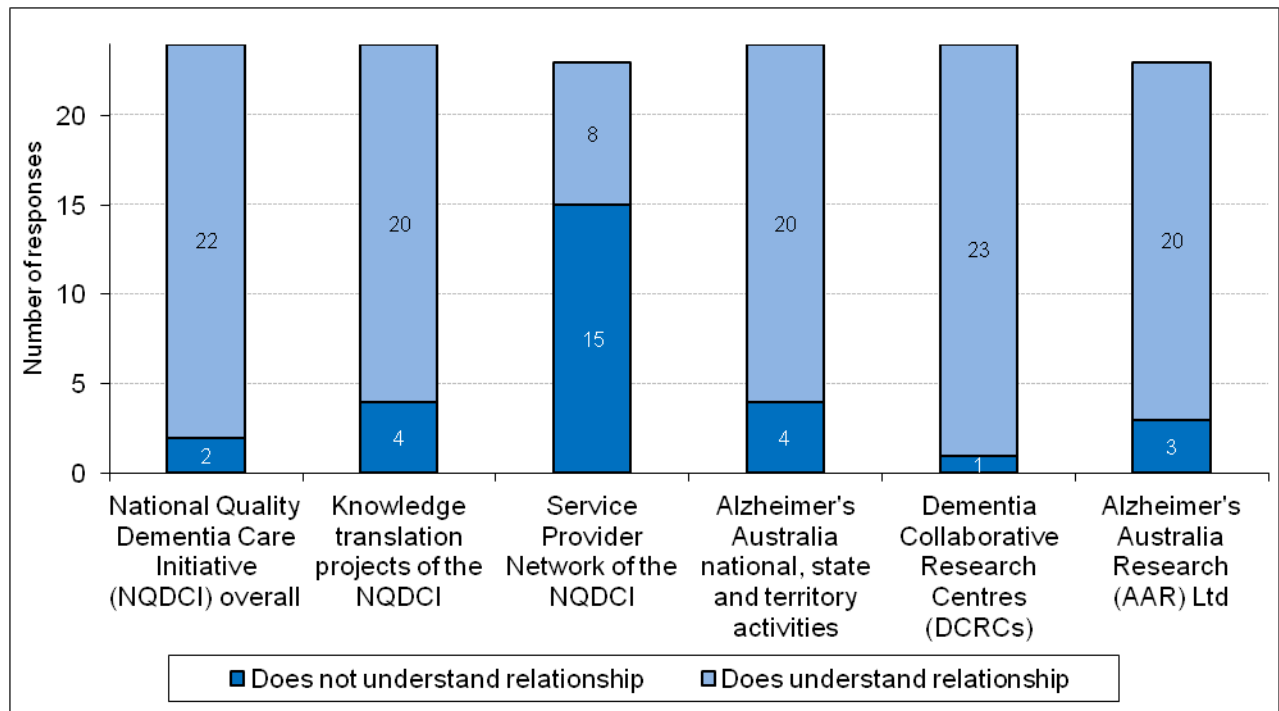
Survey respondents were also asked to provide comments on other ways they had participated as a member of the CDRN, in addition to those listed in Figure 9. Some respondents indicated that they have membership in various research groups as consumer representatives, for example bringing a consumer perspective to research project steering committees, reference groups, planning committees and focus groups (specific examples include participation in a DCRC Coordinating Committee, and a DCRC Postdoctoral Fellowship Review Panel).

Respondents have also participated at different summits, workshops and conferences, including the AA national conference in Brisbane in May 2011, and the National Health and Medical Research Council (NHMRC) workshop on consumer participation in dementia held in Canberra in July 2011. Some members have also presented at these and other related professional forums. Many members have evaluated and provided feedback on research proposals, for instance the NQDCI Expressions of Interest, with several members assisting the DCRCs and Alzheimer's Australia Research (AAR) with various aspects of research proposal reviews. Another form of participation for some respondents has been providing editorial feedback and commenting on topics for books and/or journal articles. One respondent was also invited to write a chapter for a dementia-related book targeted to consumers. Finally, supporting other members of the CDRN was also listed among the other ways that several members have participated.

Respondents were asked about their understanding of the relationship between the CDRN and other bodies/initiatives. As is evident in Figure 10, a high level of understanding of the relationship between the CDRN and other bodies/initiatives was indicated by survey respondents. It is worth noting, however, that 15 of 23 respondents indicated they did not understand the relationship between the CDRN and the Service Provider Network (SPN) of the NQDCI. This may be explained by the fact that the SPN had been relatively recently established, and the Terms of Reference of both networks do not explicitly include engagement with each other. For each of the other five bodies/initiatives, over 80% of respondents nominated that they understood the relationship with the CDRN.



**Figure 10** Understanding of the relationship between the CDRN and other initiatives



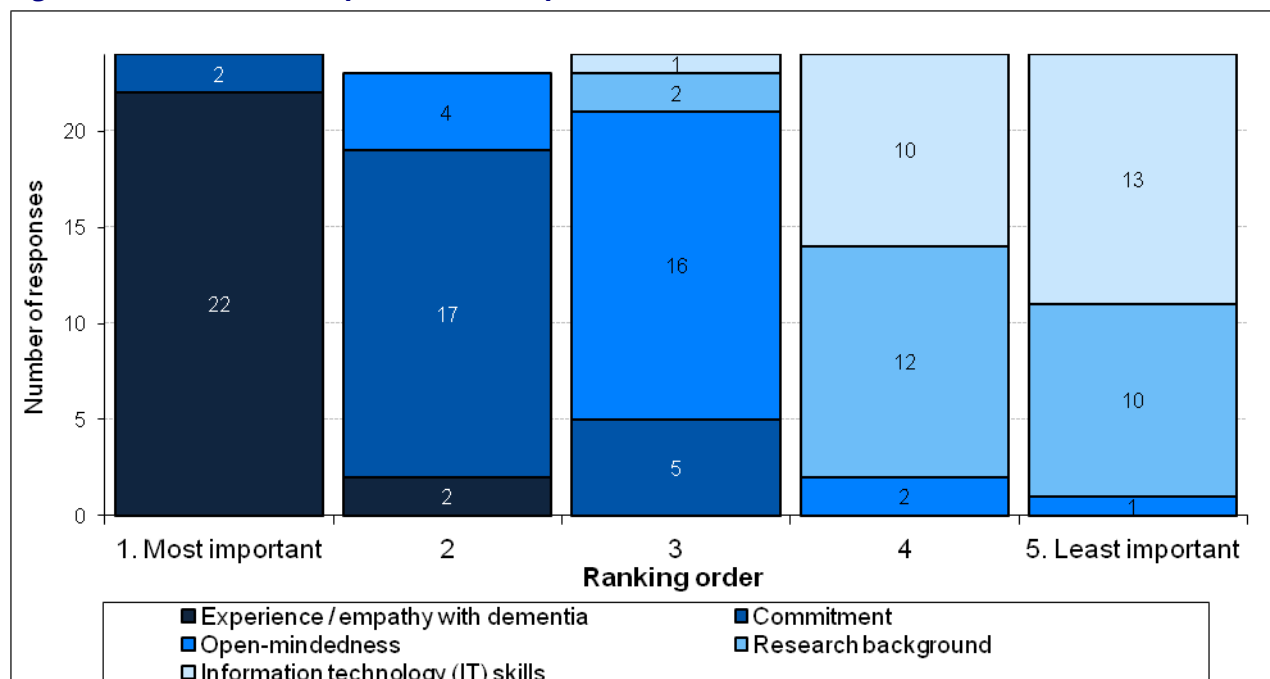
## Resources

With regard to the importance of different capacities required for a member of the CDRN to participate effectively, a general pattern in the rankings emerged in the results (see Figure 11). Experience/empathy with dementia was overwhelmingly ranked as the most important capacity for network members. The majority of respondents ranked commitment second, and open-mindedness third. Rankings for fourth and fifth were less distinct, however it can be seen that possessing information technology skills was perceived to be slightly less important than possessing a research background. Although some of these capacities may appear to relate to other domains such as culture, they were included in this section as they were seen as resources that equipped CDRN members to participate effectively.

Figure 12 depicts the ranking of importance of resources and/or supports required for a member of the CDRN to participate effectively. This figure reveals a less distinguishable ranking pattern to that shown in Figure 11, which means there is less agreement of respondents in these rankings.

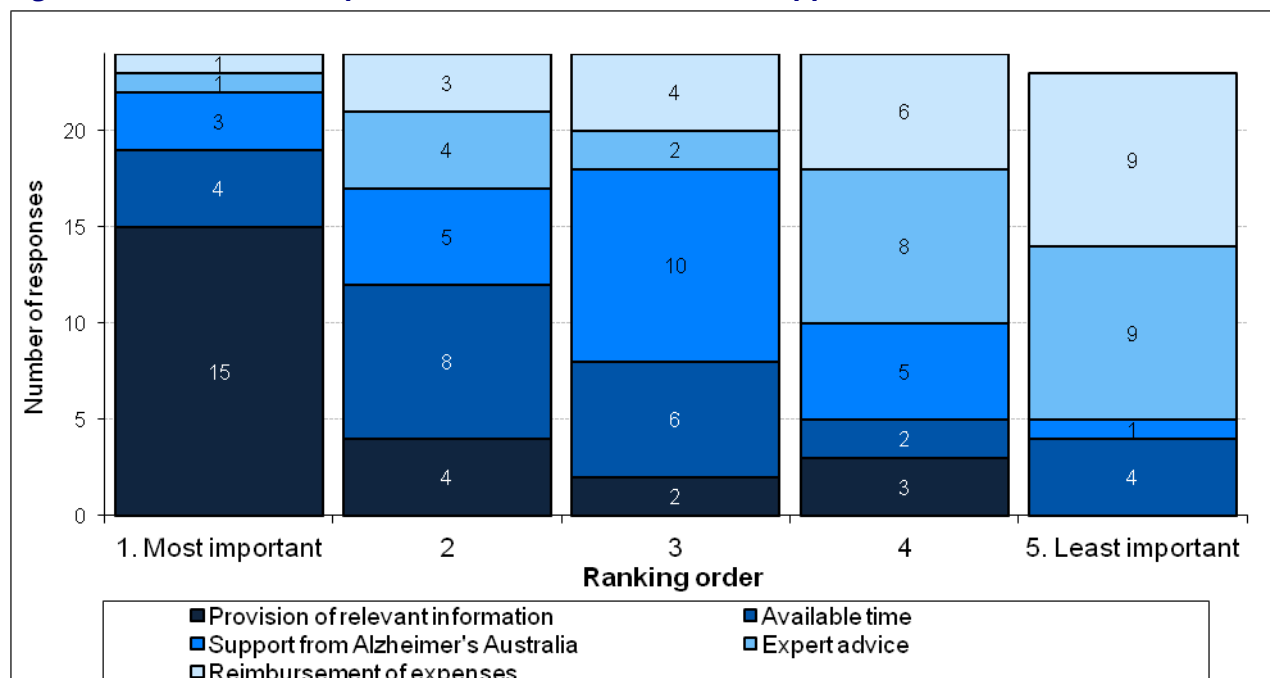
The majority of respondents consider the most important resource and/or support to be the provision of relevant information. Available time was generally ranked as second in importance, support from Alzheimer's Australia ranked third, expert advice ranked fourth, and reimbursement of expenses ranked least important.

**Figure 11** *Ranked importance of capacities*



The fact reimbursement of expenses was perceived by many respondents as least important highlights that members are not motivated by reimbursement. This finding may also be related to other factors e.g. socio-demographic characteristics of members. However several comments were provided that indicated that for some members this financial support was a contributing factor in enabling them to participate.

**Figure 12** *Ranked importance of resources and/or supports*



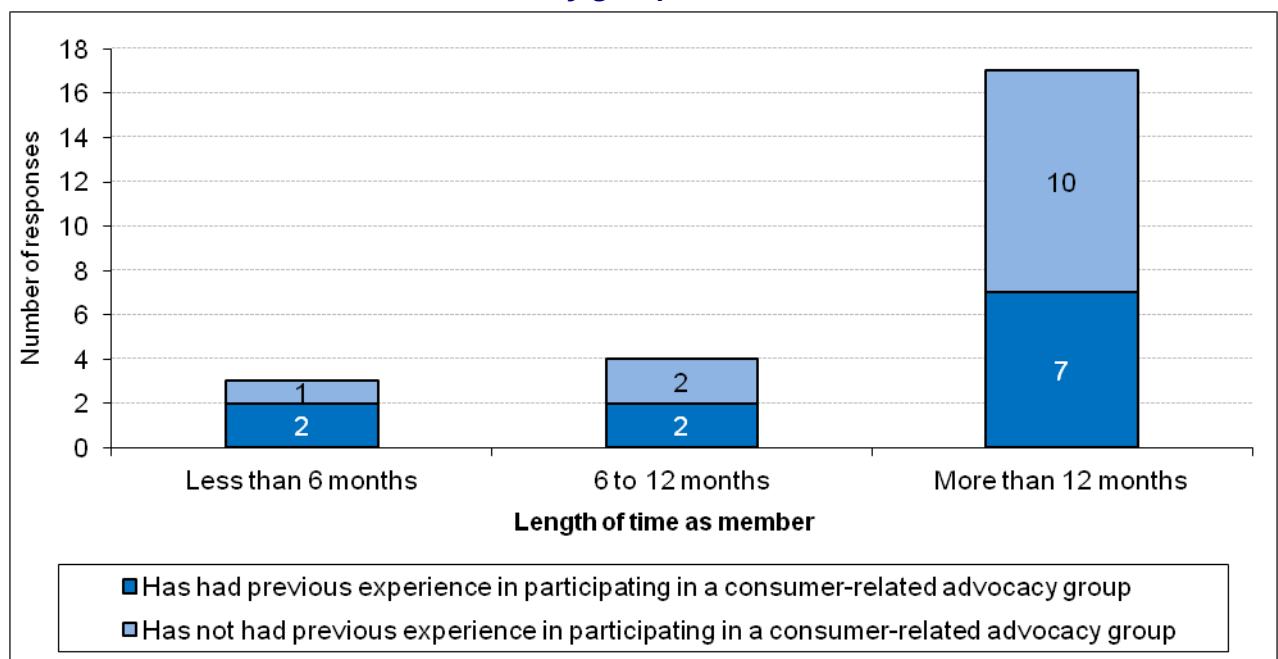
Exploring the issues of resources and support, survey respondents were asked to rate their level of agreement with two statements. In response to the statement 'I have been provided with adequate resources (e.g. financial reimbursement, information) to participate in the CDRN', 16 of 23 respondents strongly agreed, five agreed, and two had mixed feelings / neutral (see Figure 8, statement L). In response to the statement 'I have been provided with adequate support (e.g. guidance from Alzheimer's Australia) to participate in the CDRN', 15 of 24 respondents strongly agreed, seven agreed, and two had mixed feelings / neutral (see Figure 8, statement M). No

respondents disagreed or strongly disagreed to either statement L or M. Thus it is evident that survey respondents felt that they had been provided with adequate resources and support to participate in the CDRN.

## Participation

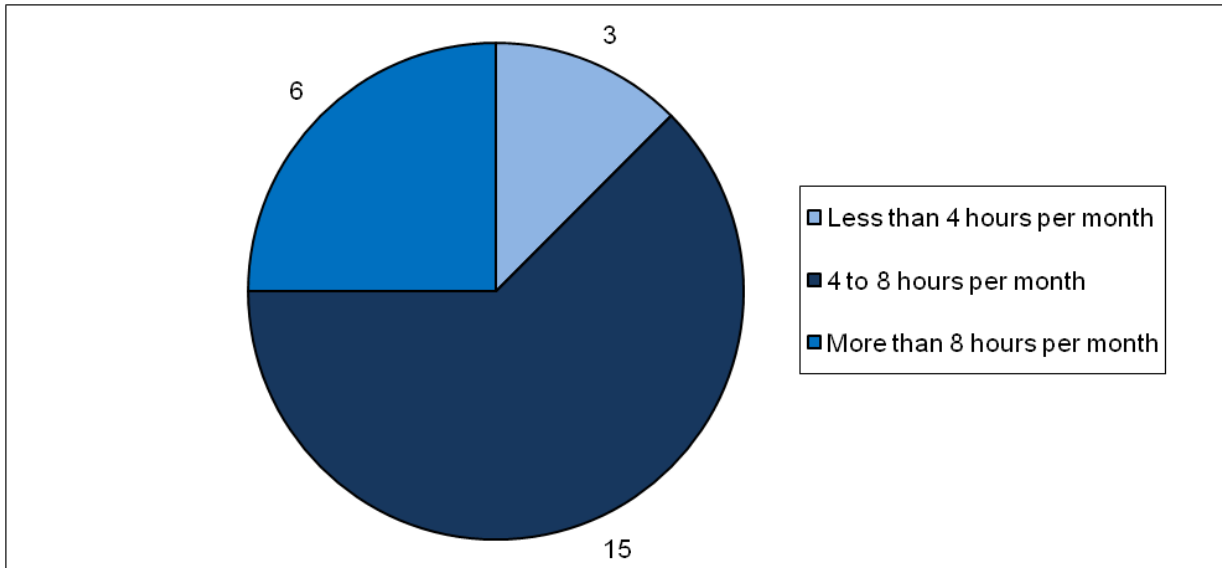
Figure 13 depicts the distribution of the length of time for which respondents had been members of the CDRN, and whether they had previous experience in participating in a consumer-related advocacy group. Most noticeably, the vast majority of respondents indicated that they had been members of the CDRN for more than 12 months. Previous experience in participating in a consumer-related advocacy group was evident in 11 of the 24 responses.

**Figure 13** *Length of time as a member of the CDRN and previous experience in consumer-related advocacy groups*



The time spent on CDRN activities by members is shown in Figure 14. It can be seen that the majority of respondents (15 out of 24) indicated that they spend between four to eight hours per month on CDRN activities, averaging to be one to two hours per week.

**Figure 14** Time spent on CDRN activities



## Capacity building

Several survey questions were designed to explore the issue of capacity building – did participants feel they developed their skills? Some of these responses also relate to aspects of participation. These findings are predominantly derived from data previously presented in Figure 8.

- In response to the statement *'I have shared the knowledge gained from my participation in the CDRN'*, 8 of 24 respondents strongly agreed, 13 agreed, and 3 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 8, statement A).
- In response to the statement *'I have developed valuable skills through my participation in the CDRN'*, 8 of 23 respondents strongly agreed, 7 agreed, 6 had mixed feelings / neutral, and 2 disagreed. No respondents strongly disagreed with the statement (see Figure 8, statement C).
- In response to the statement *'All members contribute to the work of the CDRN'*, 6 of 21 respondents strongly agreed, 11 agreed, 2 had mixed feelings / neutral, and 2 disagreed. No respondents strongly disagreed with the statement (see Figure 8, statement D).
- In response to the statement *'My opinions are valued by other members of the CDRN'*, 11 of 19 respondents strongly agreed, 7 agreed, and 1 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 8, statement E).

## Support

Survey responses relating to the supports provided to members of the CDRN to facilitate their active engagement have been included in the 'Resources' section. Additional responses relating to resources and support are discussed in the 'Enablers' section.

## Communication

Generally, survey respondents felt that communication between AA and the network has been effective. In response to the statement *'Communication between Alzheimer's Australia and the CDRN has been effective'*, 13 of 23 respondents strongly agreed, 6 agreed, and 4 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 8, statement N).

Communication assists the CDRN to function, in particular email communication, the distribution of information, regular feedback, and particularly face to face meetings. Communication between members also appears to be valued.

Conversely, a number of respondents were critical of the frequency of email communication and the amount of information distributed, conveying a sense of being overwhelmed by what they saw as excessive communication. References were made to strategies that the Manager of the CDRN had taken to address this through trialling different communication strategies and adjusting processes to suit the individual needs of members if required. This demonstrates the fine balance between effective communication which keeps members informed and engaged without burdening them.

## Recruitment and selection

Network members were primarily recruited through an invitation to apply, self-nomination in response to an advertisement or information, or through contact with an existing member of the CDRN. Sources of advertising included Australia Policy Online, DCRCs, AA groups, other professional groups, other aged and residential care groups and services and other consumer advocacy groups.

It would appear that the selection of members has been successful, as survey respondents commended the diversity of the group several times, and the commitment and dedication of the wide range of consumers involved in the network. This diversity of members was seen as a strength of the network, particularly the inclusion of members with dementia. The commitment of members was also supported by the high level of agreement that the majority of members are contributing to the work of the CDRN.

The general perception of respondents was that the CDRN membership has a high degree of representativeness, as shown in Figure 8 (see statement J). In response to the statement *'Members of the CDRN are representative of a range of dementia consumers'*, 13 of 24 respondents strongly agreed, 9 agreed, and 2 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement. A noticeable correlation was found in relation to statement J. The statement correlated strongly with statements A, K and L.

One comment indicated that there is scope to improve the representativeness of the CDRN membership both geographically and in terms of general representativeness.

## Achievements and impact

The personal opinions of respondents were sought in relation to what they believed the CDRN had achieved to date.

It was stated that the CDRN represented a vehicle for consumer input in dementia research, and was a formal avenue for researchers to engage with consumers. Also, with skills and expertise being rapidly developed, respondents perceived that the group is beginning to be recognised as a resource for dementia researchers, as indicated in several free text responses. Referring to the NQDCI projects, one respondent noted that these were *'the first dementia projects in Australia directly driven by the needs of consumers'*.

Other perceived achievements included:

- giving members insight into the problems and challenges faced by researchers;
- changing attitudes towards the inclusion of consumer perspectives in research;
- raising the profile of what consumers may be able to offer to the whole process of research in dementia (among researchers and consumers themselves);
- increasing researchers' awareness of the importance of consumer input;

- providing an impetus for researchers to include consumer input in research proposals;
- guiding the direction of research;
- setting priorities for knowledge transfer and research projects which are important to consumers;
- allocating funding for knowledge transfer research projects; and
- establishing strong and supportive relationships within the CDRN, and strong networks in the dementia health sector and with the NHMRC.

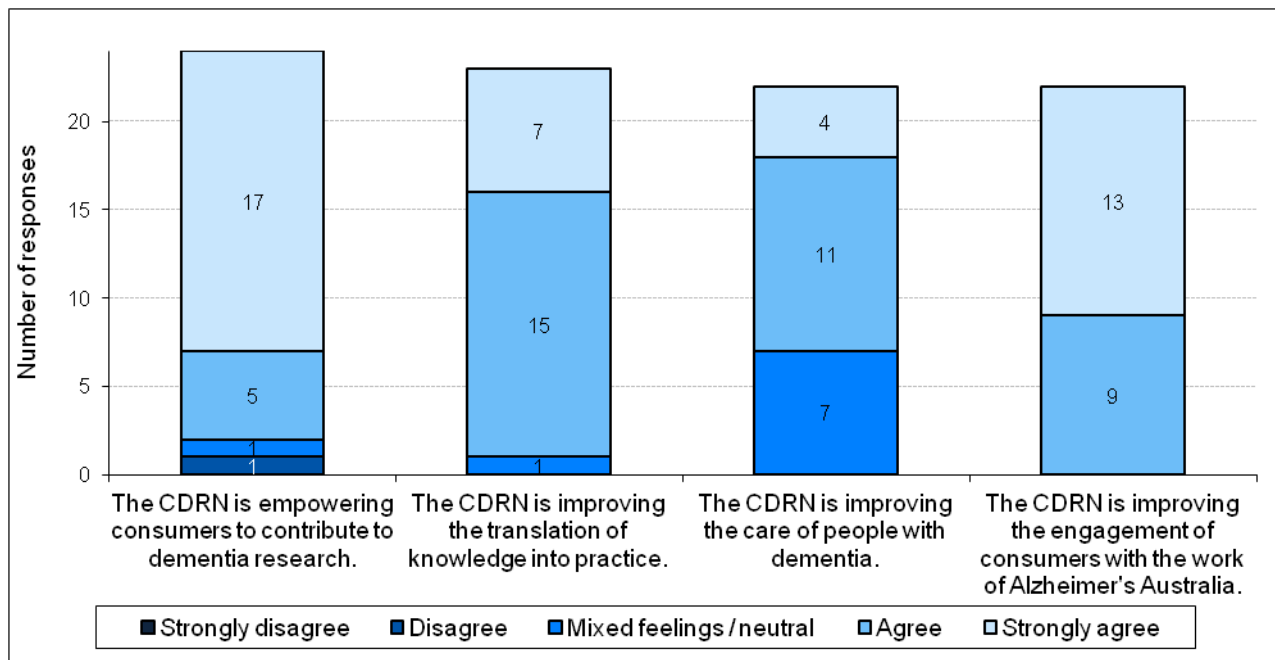
Two respondents stated that achievements in translating research into practice were minimal so far.

Survey respondents were also questioned about their perspectives of the CDRN’s achievement of its aims. Figure 15 shows very positive responses with the vast majority of responses being either agree or strongly agree. This reveals that respondents have a positive perception of the CDRN, and believe meaningful achievements are being realised. In particular, the strongest agreement was towards the statement that: ‘The CDRN is empowering consumers to contribute to dementia research’ with 17 of 24 respondents strongly agreeing. The statement that: ‘The CDRN is improving the engagement of consumers with the work of Alzheimer’s Australia’ also received strong agreement (13 of 22 respondents).

One respondent disagreed that the CDRN is empowering consumers to contribute to dementia research. However, this was the only negative response of all four statements.

Although not depicted in Figure 15, a small number of respondents stated in free text fields that they did not know whether the CDRN was contributing to certain achievements and impacts. This response is understandable as some members had only joined the CDRN relatively recently. Also, attributing achievements in relation to complex issues such as “improving the care of people with dementia” to one body such as the CDRN is difficult when many stakeholders contribute to this in practice.

**Figure 15 CDRN perspective of achievement of aims**



In terms of the CDRN’s achievements, the critical nature of AA’s support thus far and into the future is evident, as illustrated by the statement:

*“Without the support of AA, through Ellen, I don’t think it would have achieved what it has to date and that level of support will be necessary to keep the group moving forward once the NQDCI projects are all initiated and underway”.*

## Barriers

CDRN members were asked to nominate: *‘What are three things that have made it hard for the CDRN to function effectively?’* The limited number of face to face meetings was the hindering factor most often identified by respondents. This relates closely to another barrier reported by many respondents, which was based around problems of distance and geographic separation, which is a consequence of the Australia-wide membership of the CDRN. Limited resources/funding was another factor identified by numerous respondents as challenging the effective functioning of the CDRN and its ongoing sustainability. Members’ lack of available time for CDRN activities was also reported by respondents, a pressure generated by other commitments such as work and caring responsibilities.

Other barriers identified included:

- consumers’ lack of knowledge and experience engaging in research;
- the amount of work required to participate;
- lack of acceptance and recognition of the value of the CDRN contribution by researchers;
- complexities of communication;
- lack of a clear induction process; and
- lack of clarity regarding the role of members.

Survey respondents were also asked *‘From your perspective, what are negative aspects about being a member of the CDRN?’* The most commonly reported negative aspect about being a member of the CDRN was associated with perceptions that respondents lacked time to contribute effectively and complete all required tasks within allocated timeframes. A number of respondents also listed the lack of face to face meetings as a negative aspect, which seems to be a preferred forum for participation as opposed to teleconferences etc. Another negative aspect reported by several respondents related to receiving too much information via email at frequent intervals.

Other aspects about being a member of the CDRN reported by more than one member as being negative included:

- the tokenistic attitudes of some researchers towards the role of consumers in research;
- IT challenges; and
- feeling unable to contribute and participate meaningfully due to limited knowledge and understanding.

It should be noted that a number (n = 7) of responses indicated that there were no negative aspects about being a member of the CDRN.

## Enablers

When asked about things that have assisted the CDRN to function effectively, or enablers, a variety of responses were given. From the responses, the most important factor related to the AA staff. The commitment, efficiency, respect, consultative approach, expertise in the field, and enthusiasm of AA staff were commended, as was the provision of consistent, skilled and generous support and guidance.

Another factor that was frequently reported to have assisted the CDRN to function effectively was associated with the group itself. Having a diverse range of consumers (including male, female, multicultural, differing perspectives and experiences relating to dementia, and different age groups) was seen as an enabler of effective functioning. The network members’ professionalism, dedication, and their passion about the topic were reported by many respondents.

Face to face meetings were also reported as a key enabling factor of the CDRN by a number of respondents, referring to the relationship building that this contact can facilitate, not only between members but also with external people, such as DCRC representatives. The importance of building trust and confidence through this face to face contact was identified as a critical factor in the 'melding' of the network.

Other factors reported to have assisted/enabled the CDRN to function effectively included:

- the leadership of the National Office of AA;
- the positive response, acceptance, and mutual respect afforded members from the broader dementia research community in relation to the contribution of the CDRN;
- regular communication and provision of information;
- a good grasp of research language and methodology (although it was noted that a research background is not essential to participation);
- good communication skills; and
- a clear approach to linking stakeholders.

One respondent also noted the need for greater assistance for people with dementia to participate.

Survey respondents were also asked '*From your perspective what are positive aspects about being a member of the CDRN?*' There were two responses consistently reported by the majority of respondents. Firstly, the opportunity to provide input which promotes consumers' needs and contributes positively and meaningfully to research that will hopefully lead to improved lives and care of people with dementia, their families and carers. This need to 'make a difference' was extremely important to most members of the CDRN. Secondly, being part of a group that is passionate and committed to improving lives and care of people with dementia, families and carers was also frequently reported. Respondents perceived membership in a group of people that have and/or are facing the same challenges of dementia to be positive, as they felt understood, and could share similar experiences.

Some respondents also noted the support that they received from other members of the group, and the friendships that had formed within the group. Other respondents listed the opportunity to travel and attend the national dementia conference as a positive aspect of their membership.

Learning about, and increasing understanding of dementia, research and the sector were also seen as positive aspects of membership, allowing members to inform themselves and others.

Other positive aspects which were noted by at least one respondent included:

- receiving positive feedback about their contributions;
- seeing the CDRN's increased influence on the direction of dementia-related research;
- observing the gradual change in attitude of some researchers; and
- making links with leading Australian researchers.

## Sustainability

The issue of the sustainability of the CDRN was explored through responses to two statements, illustrated in Figure 8.

In response to statement B '*My investment (of time and effort) in the CDRN has been worth it*', 14 of 23 respondents strongly agreed, 7 agreed, and 2 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement. This statement aimed to find out whether respondents were positive about the investment they had already made in the network and their likelihood of continuing with the CDRN.



In response to the statement *'I intend to continue as a member of the CDRN for the foreseeable future'*, 13 of 24 respondents strongly agreed, 10 agreed, and 1 had mixed feelings / neutral. No respondents disagreed or strongly disagreed with the statement (see Figure 8, statement K).

Further perspectives about the sustainability of the CDRN were drawn from responses to the survey question: *'What do you feel is the single biggest issue facing the CDRN in the next 12 months?'* The majority of responses were related to securing ongoing funding and financial support for the network. Thus, the biggest issue for the CDRN in the next 12 months was perceived by most respondents to be ensuring continuing and stable funding, which was seen as critical to the ongoing sustainability of the CDRN itself as well as the knowledge translation projects.

A number of other issues facing the CDRN in the coming year were listed by respondents. These included:

- the recruitment and utilisation of people with dementia as members;
- retaining members and continuing to enable their participation and engagement through facilitation and training;
- ensuring that expertise built up among current members is not lost;
- ensuring selected NQDCI projects achieve good results (visible improvements in quality of life etc); and
- continuing to develop relationships with the DCRCs.

Illustrative of respondents' general positive attitude towards the CDRN, and a desire to see the network sustained and extended, is the following statement:

*"It would be very satisfying to see a CDRN role continue, strengthen, become broader in application to a fuller range of dementia issues – and to be even more representative of the spectrum of experiences of life with dementia in the community".*

## Conclusion

These survey results suggest that members of the CDRN have a high level of satisfaction with the operation and functioning of the network in its first year of operation. The members have formed into an energetic and committed group which is characterised by shared vision, co-contribution to the tasks of the network and a desire to effect positive change for people with dementia, their carers and families. Whilst the leadership of the network still rests with AA there is increasing confidence and capacity development occurring amongst members. There is an ongoing need for clarity about the role of the network and the expectations of members.

The members recognise the considerable support provided by research experts from the DCRCs and the very significant contribution provided by the team from AA. The effective coordination role demonstrated by the Manager of the CDRN is perceived as pivotal to the success and ongoing viability of the network. There is an ongoing need to ensure that the resources and support that members require to effectively participate are maintained with recognition that a 'one size fits all' approach is not appropriate given the diversity of network members. Communication processes require continual refinement as the need for open and transparent sharing of information is balanced with the pressures of information overload. The importance of ensuring that people with dementia are adequately represented on the CDRN is critical as is the need to address barriers to the ongoing sustainability of the network.

## Appendix 4 Consumer Dementia Research Network Survey for Alzheimer's Australia

### Introduction

You are invited to complete this online survey as you are currently a member of the Alzheimer's Australia Consumer Dementia Research Network (CDRN).

We would very much welcome your views and comments about the CDRN, and anticipate that the survey will take approximately 15 minutes to complete.

Your participation is entirely voluntary. Refusal to participate in this survey will not affect any relationship participants may have with Alzheimer's Australia or the University of Wollongong. This survey is being conducted by the University of Wollongong and confidentiality of this survey data will be maintained at all times. The aggregated survey results will be used to inform the evaluation of the National Quality Dementia Care Initiative (NQDCI).

If you would like further information, or have any questions about this survey, please contact Cristina Thompson from the national evaluation team, on (02) 4221 4411 or email [cthompso@uow.edu.au](mailto:cthompso@uow.edu.au)

#### \*1. Please confirm your consent to participate in this survey.

- Yes, I consent to participate.
- No, I do not wish to participate.

### General background

The following questions will help us understand your involvement with the CDRN.

#### 2. Have you had previous experience in participating in a consumer-related advocacy group?

- Yes
- No

#### 3. How long have you been a member of the CDRN?

- Less than 6 months
- 6 to 12 months
- More than 12 months

#### 4. How did you come to be a member of the CDRN?

**5. How much time do you spend on CDRN activities?**

- Less than 4 hours per month
- 4 to 8 hours per month
- More than 8 hours per month

**Roles and activities**

The following questions will help us understand the roles that CDRN members have, and the activities that they undertake.

**6. From the following list, please select what you consider to be the three most important roles of CDRN members:**

- Setting priorities for NQDCI knowledge translation projects
- Assessing and monitoring knowledge translation projects
- Assisting with communicating findings of knowledge translation and / or research projects to the community
- Contributing to the direction of the NQDCI through representation on the Executive Committee
- Advising the Dementia Collaborative Research Centres (DCRCs) on consumer priorities for research
- Providing information and advice to researchers on how to improve their interactions with consumers
- Providing feedback to Alzheimer's Australia Research (AAR) Ltd

Please provide comments on other ways you have participated as a member of the CDRN.

**7. Do you understand the relationship between the CDRN and the:**

	Yes	No
Alzheimer's Australia Research (AAR) Ltd	<input type="radio"/>	<input type="radio"/>
Dementia Collaborative Research Centres (DCRCs)	<input type="radio"/>	<input type="radio"/>
National Quality Dementia Care Initiative (NQDCI) overall	<input type="radio"/>	<input type="radio"/>
Knowledge translation projects of the NQDCI	<input type="radio"/>	<input type="radio"/>
Alzheimer's Australia national, state and territory activities	<input type="radio"/>	<input type="radio"/>
Service Provider Network of the NQDCI	<input type="radio"/>	<input type="radio"/>

**Skills and resources**

The following questions will help us understand the skills and resources that CDRN members require to participate.

**8. Please rank in order of importance (from least important to most important) which capacities are required for a member of the CDRN to participate effectively?**

**Please note: you can only select each ranking once.**

	Experience / empathy with dementia	Commitment	Open-mindedness	Research background	Information technology (IT) skills
1. Most important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Least important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any other comments?

**9. Please rank in order of importance (from least important to most important) which resources and/or supports are required for a member of the CDRN to participate effectively?**

**Please note: you can only select each ranking once.**

	Reimbursement of expenses	Expert advice	Provision of relevant information	Available time	Support from Alzheimer's Australia
1. Most important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Least important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any other comments?

## Achievements and impact

The following questions will help us understand how the CDRN is going.

### 10. In your opinion, what has the CDRN achieved to date?

### 11. Please indicate your level of agreement with the following statements.

	Strongly disagree	Disagree	Mixed feelings/neutral	Agree	Strongly agree	Don't know
The CDRN is empowering consumers to contribute to dementia research.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CDRN is improving the translation of knowledge into practice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CDRN is improving the care of people with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CDRN is improving the engagement of consumers with the work of Alzheimer's Australia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 12. What are three things that have assisted the CDRN to function effectively?

1

2

3

### 13. What are three things that have made it hard for the CDRN to function effectively?

1

2

3


## Personal reflection

The following questions will help us understand your experience as a member of the CDRN.

**14. From your perspective, what are positive aspects about being a member of the CDRN?**

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**15. From your perspective, what are negative aspects about being a member of the CDRN?**

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**16. Please indicate your level of agreement with the following statements:**

	Strongly disagree	Disagree	Mixed feelings/Neutral	Agree	Strongly agree	Don't know
I have been provided with adequate resources (e.g. financial reimbursement, information) to participate in the CDRN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I intend to continue as a member of the CDRN for the foreseeable future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My opinions are valued by other members of the CDRN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My investment (of time and effort) in the CDRN has been worth it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Members of the CDRN are representative of a range of dementia consumers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All members contribute to the work of the CDRN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CDRN is treated as an equal partner by Alzheimer's Australia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The leadership of the CDRN comes from Alzheimer's Australia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The direction of the CDRN is determined by members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CDRN has influenced the selection of NQDCI knowledge translation projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have developed valuable skills through my participation in the CDRN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been provided with adequate support (e.g. guidance from Alzheimer's Australia) to participate in the CDRN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication between Alzheimer's Australia and the CDRN has been effective	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have shared the knowledge gained from my participation in the CDRN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Conclusion**

The next questions give you a chance to comment on the future of the CDRN, and provide any other final thoughts.

**17. What do you feel is the single biggest issue facing the CDRN in the next 12 months?**

**18. Do you have any other comments?**

**Interviews**

The national evaluation team may decide to conduct further interviews with CDRN members to better understand some of the issues raised through the survey results.

**19. Are you willing to participate in a brief telephone conversation with Anita Westera or Cristina Thompson (from the national evaluation team)?**

- Yes
- No

**20. If you are agreeable to being interviewed please provide your details:**

Name

Telephone number (including your area code)

**21. Do you have any preferred days/times for an interview?**

**Thank you**

Thank you for your response and providing this feedback to the national evaluation team.

If you have any questions or concerns please contact Cristina Thompson on (02) 4221 4411 or email [cthompso@uow.edu.au](mailto:cthompso@uow.edu.au)