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Evaluation of the Consumer Dementia Research Network - final report

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The Centre for Health Service Development would like to gratefully acknowledge all members of the Alzheimer’s Australia Consumer Dementia Research Network (both past and present) who have so willingly contributed to the evaluation process throughout the three year period from September 2010 through to September 2013.

The Chairperson of the Consumer Dementia Research Network frequently compares the birth of the CDRN to the birth of a baby elephant calf...

Progress in moving dementia issues forward can be likened to that of a pregnant elephant, which has the longest gestation period of any land animal. Carrying this metaphor further, the birth of a new elephant calf results from a long and arduous labour by its mother cow. The calf is delivered gasping for air and struggling to get to its feet. The local Swahili tribe name for this calf is Seed-Aren.

The infancy life-cycle of an elephant is not a brief period. It is an important period of kinship and social contact for this allows the young elephant to successfully reach other stages.

Elephant herd structure is very complicated and consists of a number of social groups whose functions within the herd differ but sometimes overlap. Seed-Aren, as a new born calf will have to work out how close it needs to stay to the old cow and her social group or see whether it can move around the herd and assist by providing some cohesion between the functions of the various social groups within the herd. As a new calf Seed-Aren may see things differently from the other more experienced members of the herd and needs be given an opportunity to express its unique point of view.

In this brief analogy, the Swahili name Seed-Aren is a play-on-words for the CDRN. The Consumer Dementia Research Network is like a baby elephant and will continue to need to stay close to its parent, Alzheimer’s Australia. The network is growing and expanding its influence however this young calf will increase in independence as it continues to mature and develop.
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Abbreviations

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<tr>
<td>AA</td>
<td>Alzheimer’s Australia</td>
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<tr>
<td>AADRF</td>
<td>Alzheimer’s Australia Dementia Research Foundation</td>
</tr>
<tr>
<td>Bupa</td>
<td>Bupa Care Services Australia</td>
</tr>
<tr>
<td>CDRN</td>
<td>Consumer Dementia Research Network</td>
</tr>
<tr>
<td>CHSD</td>
<td>Centre for Health Service Development, University of Wollongong</td>
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<tr>
<td>DCRC</td>
<td>Dementia Collaborative Research Centres</td>
</tr>
<tr>
<td>DoH</td>
<td>Commonwealth Department of Health</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NQDCI</td>
<td>National Quality Dementia Care Initiative</td>
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<tr>
<td>PC</td>
<td>Partnership Centre for Cognitive and Related Functional Decline in Older People, also referred to as the Partnership Centre</td>
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Key messages

‘Research for us, with us’

The concept of consumer involvement in research is now firmly embedded within the Australian dementia research sector as a direct result of Alzheimer’s Australia’s Consumer Dementia Research Network.

In the three years since the CDRN was established, there have been a number of constants, and a number of changes. Constant has been the commitment of Alzheimer’s Australia (AA) and Dementia Collaborative Research Centre (DCRC) leaders in supporting the work of the Network, and that of the JO and JR Wicking Trust, and Bupa Care Services Australia. Likewise, the majority of members have remained involved, including the Chairperson.

The CDRN has assisted Alzheimer’s Australia strive to achieve the objectives of its National Quality Dementia Care Initiative (NQDCI), which is:

- To achieve changes in policy and practice that improve the quality of dementia care in Australia; and
- To enable people with dementia and their carers to set priorities for dementia research and research knowledge translation.1

The evidence is found in changes that have arisen as a result of the CDRN:

- More than fifty research projects are currently underway that have had input from consumers that may not have otherwise occurred;
- Approximately half that number again have been directly impacted on during the past three years by CDRN members;
- Eight major knowledge translation projects have been established implementing evidence across a range of care settings addressing priorities that were identified by consumers;
- Additional investments in dementia have been leveraged off the activities of members, including through Commonwealth aged care funding programs and in-kind support of service provider partners;
- The profile of dementia research has been raised within the broader political domain with the promise of additional investments in the future; and
- Awareness of the importance and value of consumer involvement in research (both dementia and health and medical research more broadly) has increased directly as a result of the activities and advocacy of the CDRN.

Conclusion

Throughout the deliberations of the CDRN, the Chairperson has provided ‘progress reports’ on the status of the analogous baby elephant, Seed-Aren. At the outset, the CDRN was likened to a baby elephant, which would continue to need to stay close to its parent, Alzheimer’s Australia. It is three years since that baby elephant took its first tentative steps; much has been achieved, with some issues still in need of attention. Perhaps it is now time for its namesake to stand on its own feet and engage with its ‘herd’ on an equal footing.

Executive summary

Background

The CDRN was established by Alzheimer’s Australia in September 2010 in response to international developments in the consumer participation environment which demonstrated the potential benefits which could arise from direct consumer involvement in research. In particular, the CDRN was regarded as a key mechanism for driving the translation of research findings into practice to result in better outcomes and improved quality of care for people with dementia.

Since its establishment, the CDRN has participated in over fifty research projects, identified six key priority areas for research implementation and selected a range of innovative projects to apply the research findings into practice. A core group of approximately twenty-five members, of which two-thirds have remained relatively stable over the course of the three years, has participated in face to face meetings (one to two per annum) and numerous teleconferences, email correspondence and research project advisory committees. The initial remit of the CDRN has expanded over time to include a greater focus on driving research priorities, particularly through its role in the newly established Partnership Centre for Cognitive and Related Functional Decline in Older People, and also through its advocacy in key policy and political contexts.

Purpose of the report

This report provides a snapshot of the key outcomes of the CDRN, the challenges it continues to face, and options for future operations. In particular, it positions this evaluation within the context of the international experience of consumer participation in research, of which there have been a number of important developments within the last few years.

In writing this report, we can in no way do justice to the amount of work that has been undertaken by members. Nor can we do justice to the passion and commitment that has enabled the CDRN to function so effectively within such a relatively short space of time and within the constraints of having geographically dispersed membership who contribute on a voluntary basis. Likewise, the facilitation of Alzheimer’s Australia and the embracing of consumer participation by leaders in the dementia research field that has enabled these achievements cannot be fully captured. That said the experience of the CDRN in the past three years provides valuable lessons for its future operations, and in particular its capacity to be sustainable.

Methods

This report utilises the key questions outlined in the evaluation framework developed in the early months of the CDRN’s operations to guide the presentation of findings. This includes consideration of impacts and outcomes of the CDRN across three levels: consumers, providers/researchers and the broader health and aged care system. A review of the international literature was undertaken to contextualise the evaluation, and identified a number of key facilitators for consumer engagement in research which we categorised as the following eight key domains: leadership and culture; role clarity and governance; resources; participation; capacity building; support; communication; and, recruitment and selection.

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A large component of the data collected throughout the evaluation has been from qualitative sources. Quantitative data has been generated from analysing patterns of meeting attendance, logging the activities of the CDRN over time and through an on-line survey administered annually to all CDRN members in 2011, 2012 and 2013.

**Findings**

The CDRN has achieved some important in-roads in consumer contribution to research and these have been summarised in the preceding ‘Key Messages’ section of this report. These are significant achievements, achieved through the foresight and commitment of an organisation to provide the framework which has been powered by the passion and commitment of a group of people who have an interest in improving quality of life for people with dementia.

A key objective of the CDRN is to improve the lives of those who have dementia and those involved in caring for them through facilitating relevant research and the translation of research findings into practice. The actual impact and outcomes of the CDRN activities on these groups of consumers has not been possible to ascertain within the context of this evaluation. That is because the CDRN has not directly engaged with the ‘end-users’ of their efforts, but rather their intent and efforts have been mediated through researchers and care providers; the logic being that these groups, in turn, will effect change in care practice at the local level. A small number of the knowledge translation projects have or will collect consumer level data, but the majority will be collecting data on processes and practices, rather than individual outcomes. Even in the projects that are collecting client level data, the difficulty in determining attribution versus contribution remains i.e., did the introduced processes or practices directly result in changed outcomes for consumers, or were there a range of factors involved? Consequently, this evaluation report focuses on the impacts and outcomes for members involved in the CDRN itself, addressing the questions raised in the evaluation framework.

**Impacts and outcomes for consumers**

The experience of members involved in the CDRN has, in the main, been extremely positive. They are a highly motivated and committed group of people, who come from a broad range of backgrounds, with differing skills and experiences, to form a cohesive and effective CDRN with a common agenda. The mutual respect shown by members is evident within its meetings and email communications, and is further reinforced by the opportunities that AA provides and facilitates for members to contribute. These experiences have helped reinforce the relevance and value of their efforts to be agents of change. The networking opportunities and friendships that have developed have also provided a sense of support and encouragement to those who, at times, have struggled with issues relating to their experience of dementia. Amongst these extremely positive outcomes, however, a number of issues have emerged that suggest there is room for improvement. These can generally be categorised as falling into three domains: operational (administrative support and meetings); strategic (aims and objectives, recruitment); and personal (support, induction and training).

**Impacts and outcomes for service providers and researchers**

The capacity of the CDRN to establish priorities for research and projects is directly correlated with the levers of influence they have had at their disposal. The Knowledge Translation priorities and projects are within the direct remit of the Network, which at the outset provided them with an advantage in achieving their objectives. As documented in our previous reports, members were actively involved in identifying priorities, developing project outlines, assessing applications
and selecting projects. The levers available to the CDRN to influence research priorities have been more subtle, requiring members to negotiate for changes within research processes and build relationships with researchers to take on board consumer perspectives. This has been a slow but ultimately successful process resulting in considerable cultural change for the majority of researchers who have direct experience of working with the CDRN. There continues to be debate between researchers and consumers regarding the point at which consumers can most effectively be involved across the research spectrum and within the research process.

Impacts and outcomes for the dementia specific sectors of the health and aged care system
The CDRN has made significant in-roads in regards to influencing the processes and impacts of research entities. Initial expectations regarding the Alzheimer’s Australia Dementia Research Foundation (AADRF) and DCRCs have been met, and expanded upon through its involvement with National Health and Medical Research Council (NHMRC) initiatives, in particular the recently established Partnership Centre.

The evaluation framework includes several questions that seek to identify the influence of the CDRN on the national, state and territory Alzheimer’s Australia organisations, and the broader research, service provider and policy contexts. The main system areas which the CDRN aims to influence are within the AA national network, research entities such as the DCRCs, AADRF and NHMRC; and, the broader policy context. The CDRN has significantly enhanced the processes, impacts and outcomes of Alzheimer’s Australian National Office, particularly in terms of its project and research income, credibility with stakeholders, and ability to influence research and policy objectives. The funding provided by the JO and JR Wicking Trust to develop the National Quality Dementia Care Initiative (NQDCI) provided a foundation upon which AA could build; this provided leverage to attract funding from Bupa Care Services Australia and subsequently the DCRCs to support the operations of the CDRN. The incentive for the latter was two-fold: to facilitate the inclusion of consumers in dementia research, as well as providing AA with the capacity to do so. The outcome has enabled AA to participate in a broad range of activities at the national level, including working with key research policy and funding bodies, and positioning itself as being a ‘consumer credible’ organisation. CDRN members are currently represented on a range of national dementia committees including the Minister’s Dementia Advisory Group and the Dementia Collaborative Research Centre’s Coordinating Committee, as well as a range of committees convened by AA.

The CDRN’s influence, however, has been negligible with State and Territory Alzheimer’s Associations. Apart from member involvement in knowledge translation projects that are being run by or in partnership with State and Territory Associations, and some crossover in membership between the CDRN and State or Territory consumer advisory committees, there appears to be little crossover in terms of focus of effort between jurisdictions. In part, this may reflect of the fact that most of the State and Territory Alzheimer’s Associations do not have a strong focus on research.

Conclusion and recommendations

Some important questions about consumer involvement in research have been raised throughout this report, in particular around the extent, mode and timing of the involvement, implications for research practice and measures of success. The answers to these questions can be derived from the answer to one overarching, fundamental question, Why have consumer
involvement in research? If consensus can be reached about this issue, then it is likely that the answers to the above questions will be more readily resolved.

Recommendations

1. The NHMRC be encouraged to develop options for resourcing of consumer involvement in dementia research, similar to international initiatives such as the Research Design Services of the National Institute of Health Research in the UK.

2. The CDRN is provided with dedicated resources to provide an effective secretariat function to enable its independence in decisions regarding systems, recruitment and processes, including funding for face to face meetings as required.

3. Alzheimer’s Australia review its consumer participation processes across national as well as State and Territory members to facilitate alignment of priorities, processes and improved communication for those involved in providing consumer input to research projects.

4. Strategic directions be developed by the CDRN with input from key stakeholders, including researchers, State and Territory Alzheimer’s Associations and service providers to ensure its relevance and opportunities to contribute are maximised. These strategic directions should inform the composition, accountabilities, core activities and structure of the Network.

5. A suite of CDRN resources should be developed that includes core documents such as strategic directions, induction program, training resources for consumers to enhance participation in research, guidelines for researchers in maximising contribution of consumers and a catalogue of research initiatives in which members have been involved. These resources should be publicly available, disseminated across different stakeholder groups and supported through the provision of training for researchers in engaging with consumers.

6. A formal recruitment process is established which clarifies the attributes, skills and representative nature of CDRN membership, to ensure a balance is maintained between different demographic constituencies and provides opportunities for membership renewal. This should be supported by a comprehensive skills development and training opportunities for members, ongoing communication and support from the point of induction through to the gradual disengagement of members who are no longer able to actively participate.
1 Introduction

The focus of this report is the final evaluation of the Consumer Dementia Research Network (CDRN) which has been operating since September 2010 as a key component of Alzheimer’s Australian National Quality Dementia Care Initiative (NQDCI). This is the fifth progress report from the evaluation of the Alzheimer’s Australia NQDCI and has been produced by the Centre for Health Service Development (CHSD), University of Wollongong.

The CDRN is an Australian first, providing:

**Individuals with dementia, their family carers and friends the opportunity to be actively involved in dementia research and knowledge translation.**

Initially focusing on establishing priorities and selecting the knowledge translation projects funded under the NQDCI, the CDRN (referred to also as the Network), has evolved significantly over the last three years. Its functions include advocacy with high level stakeholders for improved funding for dementia research and strengthening linkages with dementia researchers through its involvement in reviewing, advising and steering dementia research projects. The CDRN consists of approximately 25 members all with a lived experience of dementia either as a carer or as an individual with dementia. (The current Terms of Reference and membership is included in Appendix 1). The CDRN is supported by Alzheimer’s Australia (AA) with funding from the Dementia Collaborative Research Centres (DCRCs), the JO and JR Wicking Trust, and from Bupa Care Services Australia.

1.1 Aims of this report

This report builds on the earlier reports undertaken as part of the NQDCI evaluation, and in particular the Interim Evaluation of the CDRN report submitted in early 2012. These reports have been primarily formative in nature, documenting in detail the activities in which the CDRN has been involved and identifying key learnings to improve the design and delivery of CDRN activities. This final report of the evaluation of the CDRN is summative, and focuses on the extent to which the CDRN was implemented as intended, and whether the anticipated results were achieved. That is, it provides an overall judgement about its progress, to inform future planning, policy and resource allocation decisions.

The audience for this report includes a diverse range of stakeholders, such as the AA National Office, its Board and executive management team, as well as external groups such as policy makers and researchers. We have applied a variation of the ‘reader-friendly writing’ approach developed by the Canadian Foundation for Health Care Improvement. The 1:3:25 format, as it is known, is used to present research summaries for decision-makers, and tailors the information in a more accessible and less research-focused manner. Our aim in using this format is to enable AA to readily use the findings outlined in the report for a variety of purposes and audiences.

Throughout the report quotes are used to illustrate a particular theme that has consistently been identified from the synthesis of evaluation data and findings. We have endeavoured to

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4 Formerly the Canadian Health Services Research Foundation: [http://www.cfhi-fcass.ca/publicationsandresources/resourcesandtools/communicationnotes/10-06-01/d497a465-5398-4ec8-addf-d7cbf86b1e43.aspx](http://www.cfhi-fcass.ca/publicationsandresources/resourcesandtools/communicationnotes/10-06-01/d497a465-5398-4ec8-addf-d7cbf86b1e43.aspx)
ensure that views expressed and individual quotes used in this report cannot be directly attributed to any individual; however, given the nature of the dementia research context in which the CDRN has operated, some readers may assume they recognise the ‘voice’ behind the views expressed. The judgements made, conclusions drawn and recommendations that arise from this evaluation remain the sole responsibility of the evaluation team.
2 Evaluation Overview

2.1 Interim evaluation
The Interim Evaluation of the CDRN reported on developments that occurred within the first eighteen months of its operation. The report provided details of the range of activities of the CDRN and contained several strategic and operational recommendations, progress against which was documented in the subsequent evaluation report of September 2012. (A summary of CDRN activities is included in Appendix 2). In that report, we noted that progress had been slow on a number of recommendations, due to key staff within Alzheimer’s Australia National Office (AANO) being diverted to more pressing policy issues arising from the release of the Productivity Commission’s report into aged care, ‘Caring for Older Australians’.

2.1.1 Progress against recommendations
The recommendations arising from the Interim Evaluation were clustered into strategic recommendations (those fundamental to the ongoing viability of the Network) and operational recommendations (identifying process improvements for the Network). An indication of progress against recommendations of the Interim Evaluation Report of the CDRN is provided in Table 1 below. This is an evaluative judgement based on reviews of documentary sources and interview data from diverse stakeholders (more detailed information is provided throughout the body of this report).

2.1.2 Strategic Recommendations

Table 1 CDRN progress against recommendations in the Interim Evaluation Report

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Progress</th>
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<tbody>
<tr>
<td><strong>Strategic</strong></td>
<td></td>
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<tr>
<td>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.</td>
<td>Limited progress</td>
</tr>
<tr>
<td>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.</td>
<td>Significant progress</td>
</tr>
<tr>
<td>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.</td>
<td>Ongoing</td>
</tr>
<tr>
<td>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.</td>
<td>Completed</td>
</tr>
<tr>
<td><strong>Operational</strong></td>
<td></td>
</tr>
<tr>
<td>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 CDRN is invited to continue in the role for another 12 months.</td>
<td>Significant progress</td>
</tr>
<tr>
<td>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.</td>
<td>Significant progress</td>
</tr>
<tr>
<td>7 The AA National Office clarifies its expectations and the desired relationship between the CDRN and the Service Provider Network.</td>
<td>Completed</td>
</tr>
<tr>
<td>8 The CDRN identifies mechanisms through which it might improve communication between and engagement of the AA State and Territory Associations.</td>
<td>Limited progress</td>
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<tr>
<td>9 The CDRN reviews the support needs of all members on an annual basis with consideration given to holding</td>
<td>Limited progress</td>
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### Recommendations

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>face-to-face meetings twice per year when the work of the CDRN requires this and pending the identification of additional funding.</td>
<td>progress</td>
</tr>
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3 Methods

Understanding the impact of the CDRN relies on a combination of qualitative and quantitative data. We have used a mixed methods approach to inform data collection, analysis and synthesis. At the core of our evaluation strategy is the concept of triangulation. Use of triangulation in evaluation strengthens a study by combining methods to arrive at a better idea of what has been achieved.

3.1 Evaluation methodology

In developing our evaluation methodology for the CDRN, we noted there is no simple assessment process by which all aspects of consumer engagement and participation can be adequately measured, and therefore no optimal benchmarks for evaluating its effectiveness. The focus of discussion regarding evaluation within the academic and ‘grey’ or practice literature has relied on identifying the key attributes of consumer engagement and using these as a checklist against which performance and outcomes can be measured.

Drawing on the literature, the following eight domains were developed and used to assess the engagement experiences of the CDRN:

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

Our evaluation framework addresses the objectives of the CDRN, as outlined in its Terms of Reference (refer to Appendix 1), and identifies specific questions that align to the eight key domains (refer to Appendix 3). The evaluation has been structured to include processes, impacts and outcomes for the consumer participants, service providers and professionals interacting with the CDRN and broader health and ageing system.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Evaluation questions</th>
<th>Domains</th>
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<tbody>
<tr>
<td>Level 1: Processes, impacts and outcomes for consumers (carers, families, friends, communities)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improvements in involvement of consumers in setting research priorities</td>
<td>1a Were members engaged and utilised as intended?</td>
<td>Role clarity / governance</td>
</tr>
<tr>
<td></td>
<td>1b Does selection of dementia research priorities reflect consumer priorities?</td>
<td>Participation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recruitment &amp; selection</td>
</tr>
</tbody>
</table>
**Objectives** | **Evaluation questions** | **Domains**
--- | --- | ---
**Documentation of consumer experiences** | 1c What has been the experience of consumer involvement in the project? | Communication
| 1d Did consumers develop capacity? | Participation
| 1e What are the enablers or inhibitors to consumer engagement? | Leadership & culture

**Documentation of any unintended consequences** | 1f Are there any unintended consequences for consumers arising from their participation in the CDRN? | All

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**Level 2: Processes, impacts and outcomes for providers (professionals, volunteers, organisations)**

| Impact on NQDCN activity priorities | 2a Were NQDCN projects and DCRC initiatives funded in line with research priorities identified by the CDRN? | Role clarity / governance
| Increased use of consumer involvement in research priority setting | 2b Did DCRCs or other bodies utilise the services of the CDRN? | Leadership & culture
| | 2c What are the enablers or inhibitors to researchers using the CDRN? | Role clarity / governance
| | 2d Have researchers been trained and resourced to respond to increased consumer participation? | Capacity building
| | 2e Is the CDRN sustainable? | Recruitment & selection
| | | Resources

**Documentation of any unintended consequences** | 2f Are there any unintended consequences for NQDCN projects and researchers arising from the CDRN? | All
| 2g How did the CDRN relate to the consumer engagement processes already underway within national, state and territory AA Associations? | Role clarity / governance

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**Level 3: Processes, impacts and outcomes for the system (structures and processes, networks, relationships)**

| Dissemination of research findings | 3a How has Alzheimer’s Australia disseminated the lessons learned from the CDRN? | Communication
| Influence of CDRN on broader policy, research and service delivery agenda | 3b Has there been any improvement in the opportunities for the Alzheimer’s Australia to influence policy, research or service delivery as a result of the CDRN? | Leadership & culture
| | 3c How did the CDRN relate to the consumer engagement processes already underway within national, state and territory AA Associations, research, service provider and policy contexts? | Role clarity / governance
| | | Communication
3.2 CDRN member input into evaluation priorities

We have used direct feedback from CDRN members to shape the structure and areas of focus for this final report. At the CDRN meeting in Brisbane in May 2011, CDRN members were asked to nominate a key evaluation question they wanted the evaluation of the CDRN and broader National Quality Dementia Care Initiative to address. 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. All questions were reviewed in conjunction with representatives of AA. The majority of issues raised by the CDRN resonated with those already being captured within the evaluation framework, however not all issues were within the scope of the evaluation.

At the CDRN meeting in Hobart in May 2013 CDRN members were given the list of evaluation questions they had previously identified as important, and were asked to nominate a maximum of three questions that they felt were most important to them as a member of the CDRN, for each theme. This evaluation activity aimed to determine whether the collective view of members has changed over time. Thirteen members completed this activity. However, as one respondent nominated more than the maximum of three questions for several categories, this response was not included. The evaluation questions perceived as relevant by most members in order of importance were:

- 1.2 Has the work of the CDRN had a positive, permanent impact on the way researchers think about involving consumers in their projects?
- 4.4 How have CDRN members been assisted to contribute if they have not previously had any involvement with research?
- 5.1 Would you participate in a consumer group, like the CDRN again?
- 5.3 How could CDRN members receive feedback about their contribution?
- 1.4: How do you achieve a situation where researchers involve consumers at the research planning phase rather than as an add-on later? (Refer to Appendix 4 for the full list of evaluation questions).

The issue of most interest was the impact of the CDRN on research; particularly whether the work of the CDRN has had a positive, permanent impact on the way researchers think about involving consumers in their project and how researchers can involve consumers at the research planning phase. There was also a high level of interest in the individual contributions and roles of CDRN members, including views on continuing participation in consumer groups like the CDRN and mechanisms for how members receive feedback on their contributions. Finally, support for members, particularly the things that have assisted CDRN members to contribute if they have not previously had any involvement with research, was of interest to most respondents.

At this stage of its evolution the CDRN is unlikely to be able to demonstrate a direct impact on the care of people with dementia. One of the major levers for this change is the series of knowledge translation projects selected by the CDRN and funded through the NQDCI. These projects work in a variety of ways and are at varying levels of completion. The CDRN remains engaged in monitoring their progress and outcomes.
3.3 Data sources

This final evaluation of the CDRN has been shaped using data from a range of sources. A large component of the data collected has been from qualitative sources. Quantitative data has been generated from analysing patterns of meeting attendance, logging the activities of the CDRN over time and through an on-line survey administered annually to all CDRN members in 2011, 2012 and 2013. The majority of the data collection tools were developed and/or adapted by the national evaluation team.

Data sources include:

- CDRN communications (regular email communications between AA staff and CDRN members such as regular CDRN updates, and records of monthly teleconferences);
- Semi-structured interviews of CDRN members and key stakeholders;
- Exit interviews of several resigning CDRN members;
- National Quality Dementia Care Network (NQDCN) documentation (including project proposals, selection material and project reports);
- NQDCN project site visits and observations conducted by members of the evaluation team;
- Website audits (a range of organisations were identified that AA believe are likely to be engaged in various aspects of the NQDCI and more particularly the CDRN, the websites of these organisations were reviewed in December 2011, February 2013 and August 2013 using various relevant search terms. Refer to Appendix 5 for full results);
- Surveys of CDRN members (a web-based survey was conducted with members of the CDRN in 2011, 2012 and 2013. The collated results of the 2013 survey and a comparative analysis of the three surveys are included in their entirety in Appendix 6);
- Communications and issues logs (providing a summary record of communications from the staff of the AANO to the members of the CDRN, as well as a separate issues log which assists AANO staff track issues that required attention and resolution over time);
- Evaluations and observations from the national summit, CDRN forums/meetings, and the joint AA/NHMRC knowledge translation in dementia workshop; and
- CDRN member telephone survey (de-identified information provided by the Manager of the CDRN following telephone conversations with each member of the CDRN during early 2011).

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
- The interview schedules used with stakeholders such as DCRC leads, AA State and Territory Associations, Service Provider Network (SPN) members, and Department of Health (DoH; formerly Department of Health and Ageing, or DoHA) representatives.
4 Results
This section integrates findings from multiple data sources to answer the questions posed in the evaluation framework.

4.1 Processes, impacts and outcomes for consumers
A key objective of the CDRN is to improve the lives of those who have dementia and those involved in caring for them through facilitating relevant research and the translation of research findings into practice. The actual impact and outcomes of the CDRN activities on these groups of consumers has not been possible to ascertain within the context of this evaluation. That is because the CDRN has not directly engaged with the ‘end-users’ of their efforts, but rather their intent and efforts have been mediated through researchers and care providers; the logic being that these groups, in turn, will effect change in care practice at the local level. A small number of the knowledge translation projects have or will collect consumer level data, but the majority will be collecting data on processes and practices, rather than individual outcomes. Even in the projects that are collecting client level data, the difficulty in determining attribution versus contribution remains i.e., did the introduced processes or practices directly result in changed outcomes for consumers, or were there a range of factors involved?

Consequently, this evaluation report focuses on the impacts and outcomes for members involved in the CDRN itself, addressing the questions raised in the evaluation framework.

4.1.1 CDRN activities
This section outlines some of the main impacts and outcomes for CDRN members generated through their participation in CDRN meetings, NQDCI knowledge translation projects, research initiatives, and activities aimed at instituting changes to the broader health and aged care system.

CDRN Forums/Meetings
Since its inception, the CDRN has met face to face through five major forums or meetings facilitated by AA. Whilst there has been a small turnover in members over the past three years, membership has been highly stable with 19 of the original 25 members still actively involved and additional members recruited to replace retiring members.

Table 3 CDRN Forum Attendance 2010 - 2013

<table>
<thead>
<tr>
<th>Meeting Number</th>
<th>Date</th>
<th>Attendees</th>
<th>People with dementia: Carers</th>
<th>Existing members</th>
<th>New members</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>September 2010</td>
<td>24</td>
<td>2:22</td>
<td>0</td>
<td>24</td>
</tr>
<tr>
<td>2</td>
<td>May 2011</td>
<td>27</td>
<td>4:23</td>
<td>24</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>February 2012</td>
<td>29</td>
<td>5:24</td>
<td>26</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>May/June 2012</td>
<td>26</td>
<td>4:22</td>
<td>25</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>May 2013</td>
<td>18</td>
<td>2:16</td>
<td>15</td>
<td>3</td>
</tr>
</tbody>
</table>
Knowledge translation projects

In line with the initial expectations for the CDRN, members have been actively involved in all eight knowledge translation projects funded under the NQDCI from the outset. This has included:

- identifying research-practice gaps that could be addressed – all members
- prioritising subjects for funding – all
- developing project outlines – most
- assessing proposals – all
- selecting projects for funding – all
- participating in steering/advisory committees – all
- reviewing materials and processes developed – all
- participation in dissemination activities – few

It is clear that these activities have been a galvanising force for the Network, providing members with a sense of purpose and unity around a common focus of effort. The process has not been without its challenges, particularly in terms of processes (priority setting, selection of projects, monitoring progress) and outcomes (feedback on member contributions).

In the case of the process issues, these have been accommodated through open dialogue in meetings and email communications and the establishment of small working groups, with positive effect. This has been facilitated by the consensus philosophy that has underpinned the Network’s activities, in recognition of the diversity of opinions, experiences and capacities of members, and which is clearly modelled by the Chairperson and AA staff. It has been identified as a significant achievement for AA:

...to bring together a disparate group, getting them to work together cohesively in a relatively short time

As a consequence, it has enabled members to have

...stamped their authority on all the projects, which (wasn’t) anticipated at the outset

Despite this, there continues to be difficulties for the CDRN as a whole in monitoring progress of the projects. This is in part due to communication processes across the CDRN being reliant on a central coordinating role within AA, which has been reduced over time due to personnel changes. It is not clear if the recent restructuring within AA will ensure a more coherent line of communication across the Network, and line of sight of the projects overall. Direct communication from projects through presentations at CDRN meetings has been a further attempt to provide members with information, with varying success. While some have presented their information in a succinct and accessible manner, the majority have not appropriately targeted their message for the audience. In the Interim Evaluation report we noted the importance of ‘the use of appropriate, inclusive and transparent language and avoidance of complex language, jargon and acronyms’ and noted that this ‘is rarely incorporated into the presentations and materials provided at meetings and workshops by people who are
not closely involved with the Network.\footnote{Westera A et al (2012) Report of the Interim Evaluation of the Consumer Dementia Research Network, Centre for Health Service Development, University of Wollongong, Page 42} While all project proposals were required to include a ‘plain English summary’, it is clear that further work needs to be undertaken to better clarify the communication and presentation styles which work best for members.

In a similar vein, communication from projects in terms of feedback of individual member contribution remains problematic. Members are highly motivated to ensure that their contribution is meaningful; without feedback they are unable to measure the value they provide, or identify ways to improve their contribution. A common theme expressed is that:

\textit{CDRN members (are) not remunerated and therefore the only means of gaining satisfaction comes from feedback \ldots about their contribution to the CDRN or from the project teams or researchers they support \ldots Very few members ever receive any feedback as to whether their contribution to projects and activities is useful.}

Research initiatives

The level and nature of engagement with researchers and research initiatives has likewise grown and evolved over the last three years. In contrast to the projects, where the CDRN was much more in the ‘driving seat’, its work with researchers has primarily been in terms of influencing and relationship building. This has required different skills and processes, and has also meant that members have needed to clarify their roles and expectations around the nature of their engagement. The key research entities with which the CDRN have worked include: the Dementia Collaborative Research Centres (DCRCs), the Alzheimer’s Australia Dementia Research Foundation (AADRF) and the National Health and Medical Research Council (NHMRC) Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People (Partnership Centre). Members have been involved in the following types of activities:

- provision of advice and assessment of research proposals (DCRCs, AADRF and Partnership Centre) – all members
- participation in steering/advisory committees (DCRCs and Partnership Centre) – most members – and AADRF – one member from early 2013
- priority setting (AADRF and Partnership Centre) – all members
- participating in research forums (DCRC, Partnership Centre, NHMRC Knowledge Translation Workshop) – most members

As documented in the Interim Evaluation report, the receptive context within the DCRCs that the consumers first experienced provided an important platform from which the CDRN commenced their engagement with researchers. The provision of resources for the position of Program Manager within AA; the time, expertise and willingness to engage with consumers at the inaugural Summit and subsequent meetings; and, increasing frequency of requests for advice regarding research proposals started to bridge the chasm between the research community and consumers. Members have since contributed to numerous research projects, much more than anticipated at the outset. At the time of writing this report, the Alzheimer’s Australia National Research Manager reports that the CDRN has been involved in over 50 research projects, with
most members being involved in more than two projects at any one time (in addition to the knowledge translation projects). This is a significant achievement and investment of volunteer members’ time.

The initial hesitancy experienced by the majority of members at the outset, due to their lack of familiarity with research processes, contexts and constraints, has been replaced with an increasing sense of confidence. The experience of participating ‘in all phases of the research and not just as subjects’ has enabled members to build their knowledge base of how research is conducted. Discussions at CDRN meetings and other events have provided opportunities to debrief about experiences and clarify expectations. Consequently, members appear to have a greater sense of legitimacy within the research process, and clarity about their role vis-à-vis researchers:

*Researchers are important in determining the quality of proposals, but equally important are consumers in determining the relevance.*

The extent to which this has been recognised or valued by researchers is, on the whole, unclear. The validating experience of the level of participation and engagement with DCRC and Partnership Centre leads has been contrasted with the virtual absence of feedback about members’ contributions from other researchers. As noted previously, the absence of feedback has a greater impact on those whose commitment is driven by altruistic motives. It also makes it difficult for members to judge their impact and effectiveness, or to identify areas for improvement. Consequently, there are mixed views expressed by members which appear to be very dependent on their level of engagement with researchers, as evidenced by these comments ranging from those confident that ‘we’ve earned the respect of researchers’ as seen by the fact that ‘researchers have taken up (consumer involvement) with gusto!’, to those who think their contribution ‘may be slightly tokenistic’.

The perspectives of researchers regarding consumer involvement are likewise mixed, with some concerned about the extent to which consumers are ‘objective’ and able to ‘assess research proposals on relative merit’ while others noted that input had ‘helped us shape the research so that maybe it was a little more relevant’. Communication between researchers and the CDRN clearly continues to be an area for improvement. This could be in the form of resources, developed in collaboration with AA, CDRN members and DCRC representatives, that provide practical tips to facilitate the inclusion of consumers in research (targeting researchers) and clarify the anticipated role of consumers and provide an orientation to the context in which research is conducted (targeting consumers).

**System activities**

The CDRN was initially conceived as primarily a vehicle to influence research through the funding of the knowledge translation projects and working with researchers such as the DCRCs. Once established, opportunities subsequently arose for members to participate in, and influence, broader sectors. These include representation on various committees and processes within the AA network, the policy and political arenas, and the broader consumer movement. A number of these engagements are of strategic significance, including memberships of the Minister’s Dementia Advisory Group, the Dementia Collaborative Research Centre co-ordinating committee, the Partnership Centre executive management group, and the Dementia Advisory Committee of Palliative Care Australia. These engagements have provided the CDRN with the
opportunity to influence policy makers and researchers at a high level, and access information that is current and relevant.

Members have also had the opportunity to influence the community more generally through their participation in the Fight Dementia Campaign, and working with Bupa Care Services Australia on the development of a resource to support members of the public in choosing a residential aged care service that practices person-centred care. Another member has contributed two chapters in a recent book on dementia care entitled, Living With Dementia.6

These have proved valuable experiences for members, with many indicating that they feel their ‘lived experience’ of dementia is being validated, and their perspectives valued. Members speak of having ‘a sense of purpose’ and ‘huge personal growth’ arising from these opportunities to influence others; at the same time, however, there is also a sense of ‘reality’ about the length of time it takes to influence change.

4.1.2 Consumer experiences
The experience of members involved in the CDRN has, in the main, been extremely positive (refer to Appendix 6). They are a highly motivated and committed group of people, who come from a broad range of backgrounds, with differing skills and experiences, to form a cohesive and effective CDRN with a common agenda. The mutual respect shown by members is evident within its meetings and email communications, and is further reinforced by the opportunities that AA provides and facilitates for members to contribute. These experiences have helped reinforce the relevance and value of their efforts to be agents of change. The networking opportunities and friendships that have developed have also provided a sense of support and encouragement to those who, at times, have struggled with issues relating to their experience of dementia.

Amongst these extremely positive outcomes, however, a number of issues have emerged that suggest there is room for improvement. These can generally be categorised as falling into three domains: operational (administrative support and meetings); strategic (aims and objectives, recruitment); and personal (support, induction and training).

Operational issues
The level of administrative support provided to the CDRN by AA has varied over time. While initially supported by a full-time position, resourcing has changed due to competing internal pressures within AA and staffing changes. The effects have in part been offset by the employment on a part-time basis of a CDRN member to progress some of the more strategic and operational issues that were raised in the Interim Evaluation. However, most members feel that the reduced communication and support that has occurred is not sustainable, given the voluntary nature of their involvement. Members have clearly indicated the need for adequate dedicated resources to support the Network, to ensure it remains a cohesive group and is able to operate efficiently and effectively.

A key mechanism for the CDRN to function effectively is the face to face meetings, which provide members with the opportunity to reflect on progress, share learnings, receive feedback (ideally) and updates from researchers and projects, as well as progress the priorities in the CDRN work

plan. The infrequency of meetings continues to be a concern for members, as is the continued inability of many presenters to target their information for the particular needs of the CDRN (described previously). Members recognise the resource and staffing constraints which have impacted on the ability to have regular meetings, however it is clear that they feel these are vital to the capacity of the diverse and disparate members to function as a group.

Strategic issues

From the beginning the CDRN has aimed to influence dementia research and practice within the context of a supportive and enabling environment in recognition of the emotional and physical impacts that are part of the experience of dementia. As it has evolved over time, its role has expanded and is likely to continue to do so. In recognition of the need for change, members are currently involved in reviewing and refining the objectives and structure of the CDRN to ensure its sustainability. These are outlined in the ‘Guiding Principles’ document being circulated amongst members at the time of reporting.

Clarifying the overall aims and objectives for the CDRN should also assist in clarifying the membership attributes. There are clear differences between expectations of members about their purpose as a member, with some finding it difficult at times to strike a balance between the personal support the CDRN provides and its strategic imperatives. This tension is not surprising, given that membership requires people to have a ‘lived experience of dementia’, either directly as a person with dementia or as a carer of a person with dementia, which inevitably includes experiencing a range of personal, emotional, physical and social impacts associated with the illness. The key factors that appear to optimise contribution within the meetings include members being able to have some ‘distance’ between or time from the emotion associated with the experience of dementia as well as inherent capacity to address issues strategically.

Personal needs

A corollary to the discussion regarding membership is a number of recurring issues around the personal needs of members. Some of these issues impact on particular groups more than others, such as the need for support, while others affect members across the board, for example, induction and ongoing education and training.

As noted above, the CDRN comprises a range of individuals who have all had a different ‘lived experience’ of dementia, and have different backgrounds, skills and levels of personal resources. At the outset, AA deliberately sought to provide a supportive environment that would enable all members to effectively contribute; this has continued to occur through the leadership provided by the Chair as well as AA staff. The down-side of an inclusive and collaborative operating model, however, is that progress can be slow and decision-making may need to be compromised to accommodate a variety of perspectives.

As identified in the Interim Evaluation, a number find it difficult to juggle competing ‘life pressures’ such as family, work and caring responsibilities. This is a particularly acute issue for an entity such as the CDRN, which is dependent on the passion and drive that motivates members

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to contribute in a voluntary capacity, where members continue to struggle with the ‘logistics’ of being involved:

   *Not being as free and available to participate as I would like to be effective... I need to be available and flexible but this is hard...*

Members’ constraints in terms of time and their capacity to contribute are also the reason some members feel a sense of frustration in meetings. While appreciative of the collaborative and inclusive ethos underpinning meeting processes, some feel that the CDRN is not optimising its capacity to impact and influence the external environment.

   *We are not a support group; we need to be more focused and strategic*

It is clear, however, that the support provided by fellow members continues to play a significant role in maintaining high levels of engagement and motivation. This is particularly evident in the face to face meetings, where members actively engage with each other and critically and constructively with those presenting, and in their application to tasks required. The CDRN has matured over the last three years in both style and content, with members now more confident and ambitious in what they want to achieve.

   *It’s inspiring to see the energy and enthusiasm of members (at meetings) ... seeing people come together with collective intent*

Within such a broad group of people, it is inevitable that the support needs will be different and influenced by their experience of dementia and the broader work and life skills they bring to the group. A large number of members nominate the importance of the friendships that have been formed and camaraderie resulting from their participation in the Network, and this is clearly a central factor in their ongoing engagement, motivation and confidence levels.

The confidence of members continues to be challenged as their roles take them into new territory and they meet with all sorts of different groups of people. While the divide between researchers and consumers appear to be lessening, for many it is an ongoing struggle to remain positive and engaged.

   *I still have varying degrees of confidence in putting issues on the table .... especially when it comes to researchers for those members without a research background ... I often wonder ‘will it be credible’?*

Even for those members with a research background, the experience of putting a consumer’s perspective across to researchers can be ‘daunting’ because of their expertise and perceived authority. It has been suggested that consumers should always ‘travel in pairs’ when attending meetings with researchers, to support and bolster each other’s confidence in speaking up.

The confidence to participate can also be assisted by having an initial induction program which clearly outlines the roles of members, identifies the challenges, and provides resources to assist members maximise their contribution. A number of members commented on their ‘coming in late’ to the CDRN and found it extremely difficult to understand its purpose, processes and how decisions were arrived at, particularly in relation to the priorities for the knowledge translation projects. The relationship of the CDRN to other consumer groups across the Alzheimer’s network continues to be a mystery for many. Establishing mechanisms for routine dissemination of information, orientation and ongoing skills development will be important to address as the CDRN moves into its next phase of evolution.
4.2 Processes, impacts and outcomes for researchers
The evaluation framework includes a number of questions to best capture the CDRN processes, impacts and outcomes for researchers and the facilitation of knowledge translation projects.

4.2.1 Consumer involvement research and project priority setting and processes
The capacity of the CDRN to establish priorities for research and projects is directly correlated with the levers of influence they have had at their disposal.

Knowledge translation projects
The Knowledge Translation priorities and projects are within the direct remit of the Network, which at the outset provided them with an advantage in achieving their objectives. As documented in our previous reports, members were actively involved in identifying priorities, developing project outlines, assessing applications and selecting projects. The experience of the first round of funding, where the CDRN only chose two projects out of the numerous proposals received, provided a firm platform from which it has continued to operate.\(^8\)

CDRN members have participated in all project steering/advisory committees, and have been regularly approached by the project leads to provide input to project processes and developments. The capacity for the CDRN as a whole to monitor progress of individual projects, however, has been limited, with updates tending to align with requests for input or summarily provided at the face to face meetings. While it is clear that the CDRN has achieved its objectives in this area, the value of their contribution remains uncertain given the limited feedback received to date from projects. We anticipate that the projects’ final reports will be able to provide a clearer picture of consumer impacts and outcomes, and this will be addressed more fully in our final NQDCI Evaluation Report in May 2014.

Research
The levers available to the CDRN to influence research priorities have been more subtle, requiring members to negotiate for changes within research processes and build relationships with researchers to take on board consumer perspectives. The success achieved has been remarkable, and has led to considerable cultural change for the majority of researchers who have direct experience of working with the Network.

The progress described in the Interim Evaluation has been consolidated and extended upon. Members continue to participate in assessment; steering and advisory committees associated with DCRC and AADRF research projects, and annually identify one priority area for funding through the AARF. With the establishment of the Partnership Centre, members have been actively involved in assisting Partnership Centre researchers to identify priority projects to form part of the work program. Partnership Centre Director A/Prof Sue Kurrle reports that feedback received from CDRN members in May/June, 2012 on the preliminary list of project concepts was instrumental in shaping the Centre’s final work plan. An advisory mechanism has been established within the CDRN to assist in the monitoring and support across all of the Partnership Centre projects over the coming five years.

There continues to be debate between researchers and consumers regarding the point at which consumers can most effectively be involved across the research spectrum and within the

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8 There were 44 Expressions of Interest lodged and 20 of these deemed appropriate for further review.
research process. Some researchers refer to research being conducted along a spectrum that runs from the ‘higher level’ lab-based research such as genetics or cellular activity which then moves along a ‘supply chain’ to more ‘practice-level’ clinical and social research. The NHMRC refers to this as a ‘virtuous cycle of research’ whereby developments within the research spectrum are inter-related. The extent to which the CDRN has been able to impact on researchers arises predominantly from where researchers view themselves as sitting within that spectrum/cycle. For example, researchers most responsive to CDRN input appear to be those who are involved in clinical, care and practice research areas of dementia, whereas there has been limited engagement by those more involved in lab-based research. The CDRN has had virtually no success impacting on the work of lab-based research, although equally it has not put much emphasis on trying to do so.

There is also a lack of clear consensus between researchers and consumers about the point at which consumers can legitimately and effectively be involved in the research process, and about the extent of control that consumers have within the process. For example, there appears to be general agreement regarding the inclusion of consumers in identifying and advising on research priorities at the clinical/care/practice end of the research spectrum. However, most research stakeholders have argued that consumer input should be a contributing rather than a deciding factor when it comes to assessing projects for funding; most were adamant that the researchers’ expertise in regard to ‘quality of research’ (the researchers’ judgement) should always take primacy over ‘relevance of the research’ (the consumers’ perspective). Similarly, while the CDRN is represented on the Dementia Collaborative Research Centre at the level of the Coordinating committee, and on numerous DCRC projects and activities (for example, the planning committee for the 2013 Dementia Research Forum), their ability to contribute at the DCRC Research forums has been limited to being offered poster presentations instead of speaking opportunities. This is a missed opportunity for the broader dementia research sector to hear of the contribution that consumers are making to research.

4.2.2 Project and researcher experiences

Knowledge translation projects’ experiences

Given that the majority of projects are still underway, our ability to comment in detail about their experiences of consumer involvement is limited; we anticipate the final project reports will be a key source of data to address this question of the evaluation framework. At the time of writing, one project is complete and another in its final stages; the remaining six projects are expected to be complete by early 2014. A final report template for all projects has recently been distributed to the remaining projects, and includes a number of questions relating to the involvement of consumers. As noted previously, we will report more fully on the experiences of projects in the final NQDCI Evaluation Report in May 2014.

Through our reviews of progress reports submitted to date, and discussions with project leads, it is clear that the contribution of consumers has been extremely valuable. Preliminary project related outcomes include:

9 NHMRC Discussion Paper - Health and medical research and the future in NHMRC’s 75th year. The virtuous cycle and the economic benefits of health and medical research
http://www.nhmrc.gov.au/_files_nhmrc/file/about/senior_staff/articles/economic_benefits_health_research_wa_110909.pdf accessed 15 September 2013
- Improved targeting of information within resources to better meet the needs of the relevant audiences;
- Access to broader networks for consultation regarding, and participation in, project activities; and
- Improved appreciation by audiences of project activities of the perspectives of consumers, as a result of member participation in training activities convened by projects, and inclusion of their stories as case studies in resources developed.

In addition, project leads have indicated the personal benefits they have received arising from their interactions with members, including having a better appreciation of:

- The real impacts of living with dementia and the associated gaps in quality of care available;
- The capacity of consumers to provide constructive input to their projects – the ‘value-add’ they provide;
- How to work with consumers as partners in the project development and implementation; and
- The barriers to consumer participation in projects, and lack of opportunities for consumers to currently provide meaningful input to project work and research.

These learnings have also extended to broader stakeholders involved in projects, through the participation of members on steering and advisory committees. At project events which members of the evaluation team have attended, we have received feedback from both stakeholders and project leads in terms of their ‘profound respect’ for the consumers involved, how consumer contribution had ‘opened their eyes’ to seeing things differently and for some, how they had been inspired to do further work in the field of dementia, something they had not previously considered.

The Interim Evaluation described some of the issues which arose from the selection process for Round 1 of the NQDCI knowledge translation projects. While most unsuccessful applicants have ‘moved on’, we are aware that amongst some there remains a degree of antipathy towards AA and the Network. In the stakeholder interviews we conducted in preparation for this report, one agency representative indicated they would remain ‘sceptical’ about applying for funding in the future, while another indicated that some of their colleagues ‘were still bruised’ by the experience. That these sentiments continue today is indeed regrettable as some of the individuals concerned are in positions of relative influence within the broader dementia network of services.

**Researcher experiences**

Researchers’ experiences of the CDRN have been derived from a number of sources, including feedback provided directly to CDRN members and AA, our observations and conversations with researchers at related CDRN events and Knowledge Translation project activities, as well as from stakeholder interviews conducted in preparation for this report.

The vast majority of researchers who have experienced working with the CDRN have been extremely positive about their contribution in terms of quality, timeliness and relevance.
They always come back to researchers in a timely manner, and for the most, with quite relevant and pertinent comments

Members have taken on various roles as part of their dealings with researchers, and particularly the DCRCs. These include membership of steering committees and/or project reference groups; assessing proposals, participating in projects and assisting in recruitment of participants. More recently, the CDRN has taken a proactive role working with the Partnership Centre both in a strategic capacity, as a member of the management committee, and operationally as part of project advisory groups. Prior to this, the inaugural planning workshop for the Partnership Centre had been deliberately scheduled to align with a CDRN face to face meeting to enable members to provide input at its outset, and for representatives to attend the all-day workshop which was to occur the following day. The evaluation team understands that the contribution of members was highly valued and informative for the researchers in the meeting, and resulted in a number of proposals being brought forward that would otherwise not have been included. One example was a proposal for a research project that would develop a risk assessment tool to facilitate the involvement of people with dementia in community activities:

Consumers thought this was really important; more so than others in the room

CDRN members who have a strong research background have been singled out by a number of stakeholders as being ‘an impressive group of people’. They are appreciated for their contribution to research projects, as well as the way they have worked with other members of the CDRN who are less familiar with research processes. This is particularly highlighted in members’ feedback on proposals for funding, where there have been rather divergent views about the relative merit of proposals.

Still some variation in the calibre of responses, which is to be expected given the diverse nature of the group

The issue that appears to cause most difficulty for researchers continues to be the differing expectations of some members regarding their role in the research process. As discussed previously, there are a number of different perspectives about research that continue to be a source of tension for researchers and consumers alike. These include:

- the stage of the research process at which consumers can best contribute;
- the nature of the contribution i.e., advisory role or decision making; and
- the priority of ‘relevance of research’ versus ‘quality of research’ in decision-making about funding.

Nearly all researchers that the evaluation team have spoken with over the course of the CDRN’s activities have struggled with one or more of the aforementioned issues at some time or other. Researchers outlined a number of examples where they felt the ‘relative merit’ of the research question, or the quality of the research methodology, precluded prioritisation for funding, but were strongly advocated for by the consumer representatives based on their personal experience. That said, however, there are also examples where the consumer perspective has been a deciding factor in funding, particularly when there are no pressing concerns about the ‘relative merit’ and ‘quality’ of proposals being considered.

Indeed, one researcher recounted their experience of being at a function and hearing a CDRN member’s presentation of a distressing experience whereby the partner had struggled with an undiagnosed illness in a particular care setting, which had been the very subject of a recent
project the researcher had directed but which had ceased due to uncertainty regarding ongoing funding. The researcher was significantly moved by this account, and subsequently ensured an internal reallocation of organisational funding to maintain the project until such time alternative sources of funding could be secured. In a similar vein, attending the NHMRC Knowledge Translation workshop in July 2011 was a ‘higher-level’ lab-based researcher who had no direct engagement with consumers in day to day work, but left the workshop ‘so effusive at how effective the consumer resource will be’ to the sector; it is understood that relations between that researcher and the local AA have been significantly strengthened in the intervening period.

The CDRN has recently refined its charter to better clarify its role in relation to dementia researchers. The new ‘Guiding Principles’ clearly articulates the anticipated roles and responsibilities of members in relation to the NQDCI Knowledge Translation projects, which was an initial source of tension within some elements of the research community; the upfront activities continue to include ‘setting priorities’ for the projects, but involve ‘commenting on’ proposals rather than selecting proposals for funding, as has been the case to date.

4.3 Processes, impacts and outcomes for the system
The evaluation framework included several questions that sought to identify the influence of the CDRN on the national, state and territory Alzheimer’s Australia organisations, and the broader research, service provider and policy contexts.

4.3.1 Systems influenced and their experiences
The main system areas which the CDRN sought to influence were within the AA national network, research entities such as the DCRCs, AADRF and NHMRC; and, the broader policy context.

Alzheimer’s Australia national network
The CDRN has significantly enhanced the processes, impacts and outcomes of Alzheimer’s Australian National Office, particularly in terms of its project and research income, credibility with stakeholders, and ability to influence research and policy objectives.

The funding provided by the JO and JR Wicking Trust to develop the Initiative provided a foundation upon which AA could build; this provided leverage to attract funding from Bupa Care Services Australia and subsequently the DCRCs to support the operations of the CDRN. The incentive for the latter was two-fold: to facilitate the inclusion of consumers in dementia research, as well as providing AA with the capacity to do so.

The outcome has enabled AA to participate in a broad range of activities at the national level, including working with key research policy and funding bodies, and further positioning itself as being a ‘consumer credible’ organisation.

CDRN members are currently represented on a range of national dementia committees including the Ministerial National Dementia Advisory Group and the Dementia Collaborative Research Centres, as well as those convened by AA including the:

- National Consumer Advisory Council
- National Cross-Cultural Dementia Network
- National Aboriginal and Torres Strait Islander Dementia Advisory Group
The CDRN’s influence, however, has been negligible with State and Territory Alzheimer’s Associations. Apart from member involvement in knowledge translation projects that are being run by or in partnership with State and Territory Associations, there appears to be little crossover in terms of focus of effort between jurisdictions.

This appears to be largely due to the differing roles of the national and state and territory Alzheimer’s organisations. The role of the national office:

... is to advocate on the basis of evidence based policy, promote awareness of dementia, administer national contracts with the Commonwealth Government and provide research grants to emerging researchers through the Alzheimer’s Australia Dementia Research Foundation.10

In contrast, the State and Territory Associations have a greater focus on service delivery, including counselling services, education and training and carer support services. Most state and territory Alzheimer’s Australia organisations also do not have much direct involvement in research; the primary remit of the CDRN. That said, however, there is a degree of overlap between the two levels, particularly in terms of emergent issues and the need for improved service models. For example, Alzheimer’s NSW has a contract research project with the University of NSW and a number of service providers to clarify the needs of people with younger onset dementia.11 These research projects, in turn, can inform the advocacy that is undertaken by both State and National bodies, as evidenced by the younger onset dementia program developments, such as the NSW Government’s Younger Onset Dementia Program12 and the Department of Health’s Literature Review and Needs and Feasibility Assessment of Services for People with Younger Onset Dementia project currently underway, the Request for Quotation of which sought to build on the recent Alzheimer’s NSW report.

The low level of engagement by State and Territory Associations with the CDRN appears also to be attributed to the limited communication processes available within the AA network. For example, it is understood that there are mechanisms in place for regular communication to occur between of the policy, service delivery and program activities of the network, however little in terms of the research activities. Furthermore, it is understood that a number of States remain ‘aggrieved’ over the project development process associated with the first and second rounds of NQDCI knowledge translation projects, where prospective applicants were required to partner with their local AA Association. As noted previously, it appears that the lack of compensation for State and Territory involvement in this process continues to be a source of contention within some elements of the national network.

The potential for improved engagement with State and Territory Associations should be pursued, particularly in the absence of more formal communication mechanisms across the network and to ensure that evidence informs decision making. For example, it is understood that

in one jurisdiction consumers had recommended funding for a research project into oral health which was subsequently rejected by local management due to its unlikeliness to generate publicity and general community interest (and consequently public donations); this is despite the clear evidence that poor oral health for people with dementia is a major contributor to poor general health, nutrition and quality of life. Through their exposure with contemporary national research projects, the CDRN is likely to provide more contextual information to States and Territories regarding their research priorities and opportunities.

**Research entities: AADRF, DCRCs and NHMRC**

The CDRN has made significant in-roads in regards to influencing the processes and impacts of research entities. Initial expectations regarding the AADRF and DCRCs have been met, and expanded upon through its involvement with NHMRC initiatives, in particular the recently established Partnership Centre. To assist researchers improve the involvement of consumers in research, an information sheet has been developed and made available on the Alzheimer’s Australia website.\(^{13}\)

AADRF has embraced the involvement of the CDRN, through including CDRN members in assessing proposals and identifying priority areas for funding. All proposals for funding submitted to AADRF must now include a one-page ‘lay summary’ which is designed to assist consumers understand the merit and/or make informed comment on the relevance of the proposal. The CDRN is also involved in providing commentary to assist with the selection of AADRF projects. Each year since 2012 AADRF has allocated a research grant or scholarship to a priority area nominated by the CDRN, which further extends the Network’s influence. The CDRN Chair has also recently been appointed to the Board of AADRF. The involvement of the CDRN in AADRF activities is formally acknowledged in AADRF annual reports, which are available on the Alzheimer’s Australia website.

As indicated in our Interim Evaluation report, the DCRCs have likewise embraced the involvement of the CDRN in terms of inclusion of a requirement that all research proposals clarify their proposed consumer engagement strategies, and through routinely seeking feedback from members regarding proposals received. This is in addition to the annual contribution of approximately $80,000 (indexed annually) provided to support the Network’s operations. The DCRCs that have had most involvement with the CDRN are those with the clinical and care focuses, DCRC Assessment and Better Care based at the University of New South Wales, and DCRC Carers and Consumers based at Queensland University of Technology. These Centres have built on their existing consumer mechanisms, which have generally had an advisory and recruitment function, and included consideration of the directions and feedback on project proposals provided by the CDRN. The effect of this has been to influence the broader dementia research community, with researchers now seeing it as:

*A win for us to include involvement of consumers, and it strengthens our argument for funding*

While consumer involvement now appears to be more embedded within the DCRC processes, the extent to which this permeates their culture remains unclear. Within the leadership of the

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\(^{13}\) *Involving people living with dementia and their families in your research*  
DCRCs there is a clear recognition of the importance of involving consumers, albeit with some differences in terms of the roles and contribution they can make. The introduction of mechanisms and processes that require researchers to involve consumers is regarded as the first step in acclimatising researchers to the concept of consumer involvement more generally; i.e., the rationale being that once researchers realise the contribution consumers can make, it will be a fait accompli. However, the value that consumers can provide to research beyond the ‘tick-box’ approach to securing funding remains a long way from reality.

As we indicated in the Interim Evaluation Report, the CDRN has also made significant in-roads with regard to influencing the NHMRC. The involvement of members at the Knowledge Translation workshop in July 2011 was seen as a turning point in terms of influencing senior administrators as well as the researchers who participated. It has been suggested that this influenced the fashioning of the Partnership Centre model, which has consumer representation embedded from the outset. Likewise, the CDRN input to the McKeon Review is understood to have been the only submission directly provided by consumers, and was influential in AA being invited to be a representative on the newly formed Consumer and Community Advisory Committee. That said, however, it is unclear why the decision was made by the NHMRC to select an AA representative (the national CEO) as opposed to one of the number of CDRN members who applied for membership.

Despite this, as one stakeholder summarised, the CDRN has made a significant impact, as:

*People are now on notice that their research can’t just be investigator driven*

**Policy initiatives**

An unanticipated role of the CDRN has been its involvement in broader policy initiatives where the voices of consumers have been presented. These include the Senate Standing Committee on Community Affairs: Palliative Care in Australia, at which members presented at one of the Hearings; and the House of Representatives Standing Committee on Health and Ageing: Inquiry into Dementia; Early Diagnosis and Intervention, where four members provided individual submissions. Members have also provided input into AA submissions such as the Pharmaceutical Benefits Advisory Committee Review of Dementia Medications, and its Fight Dementia Campaign document. Alliances with other consumer groups have also been strengthened through participation of members, including membership on the advisory committee for Palliative Care Australia and participation with National Aged Care Alliance and Consumer Health Forum activities. These ‘extra-curricular’ activities have greatly strengthened the resolve and confidence of individual members, as well as the group as a whole. As one stakeholder observed:

*The CDRN is a lot more sophisticated now than at the outset ... there’s been more focus on NHMRC and lobbying for research funding*

Consequently, a number of stakeholders have suggested their involvement has assisted the AA in its lobbying in the pre-election period, which saw both major political parties committing to increased funding for dementia research.
5  Discussion
Since the establishment of the CDRN in September 2010 there have been a number of developments in the broader arena of consumer involvement in research. At the time of developing the evaluation framework for the CDRN, we summarised the known facilitators or elements of consumer engagement in research as comprising the following eight key domains: leadership and culture; role clarity and governance; resources; participation; capacity building; support; communication; and, recruitment and selection.

The intervening three years has seen an expansion of resources to assist consumer involvement in health services research, as well as improved understanding of the barriers and enablers to consumer participation. Of particular relevance are two major literature reviews, one on Consumer and Community Engagement undertaken on behalf of the NSW Agency for Clinical Innovation and the other supporting the Dementia Engagement and Empowering Project (DEEP) on behalf of the UK Mental Health Foundation.\textsuperscript{14, 15} In addition, the Cochrane Collaboration has undertaken a strategic review of its consumer engagement mechanism, CCNet and refinement of its resources designed to assist consumers in research. The key findings of these developments align well with the key domains we have been using to evaluate the CDRN.

5.1  Leadership and culture
As we noted in the Interim Evaluation report, the leadership provided by the Chief Executive Officer of Alzheimer’s Australia has been a key facilitator and driving force for the CDRN. This continues to be the case, as evidenced by the inclusion of members within advocacy processes (previously described), focus of effort on securing ongoing funding for the Network, and personal involvement in CDRN activities and meetings. What is less clear, however, is the extent to which this permeates the culture of the AA network overall.

There is a demarcation between responsibilities of the National and State and Territory members of the AA federation, i.e., research, policy and advocacy undertaken at national level, and fund-raising and service provision undertaken at a more localised level. Furthermore, it is impacted by the federated nature of the network, whereby State and Territory members are autonomous and maintain a degree of territorialism in terms of their functions and priorities. Consequently, there are missed opportunities to maximise input of the CDRN across the national network, share learnings and provide greater coherence in terms of dementia research policy, priorities and processes. Refer to Appendix 6 for further information on CDRN members’ views about the leadership and direction of the CDRN.

5.2  Role clarity and governance
The role of the CDRN has expanded over time, moving from an initial focus on selection of priority areas for knowledge translation projects and improved engagement with researchers, to involvement within research policy and advocacy processes. These developments have occurred incrementally and opportunistically, and have had the effect of increasing the ‘consumer credibility’ of the national body. In recognition of the increasing sphere and number of activities,


the CDRN is currently undergoing a process of review of its structure and function through the consultations on the draft ‘Guiding Principles’ document. While this is timely, it would appear that the content and process may require further consideration; with the structure of the CDRN appearing to have greater clarity than its purpose i.e., ‘form’ is driving ‘function’.

A fundamental issue to be resolved is the role of the CDRN in relation to research and knowledge translation projects. Initially, the CDRN had a very real decision-making role in terms of identifying research priorities and selection of knowledge translation projects; the ‘Guiding Principles’ document has reframed this to be primarily an advisory role. Arising from this initial experience of CDRN members, there appears to have been a disjuncture between some members’ expectations in regard to their role in the research process, and that of researchers. The lack of clarity regarding the role of consumers was further compounded by the different views about the stage of research at which consumers can most effectively contribute. It is unclear whether researchers will be engaged in the consultations about the ‘Guiding Principles’ and whether there will be an opportunity to clarify expectations and roles prior to the new structure being implemented. The international literature provides a number of examples of models where consumers have interacted in the research process in various roles and at different stages, which could assist in framing consultations with the research community.

In addition to the need to clarify roles of the CDRN, there is also a need for improved clarity around governance arrangements. While AA continues to assume overall responsibility for maintaining and resourcing the CDRN, this relationship is not without its constraints; in particular is the ability of the CDRN to effectively negotiate with AA regarding its priorities. While there is obvious support provided by the current leadership within AA, the administrative support and funding restraints have impacted on the Network. For example, members have consistently identified the importance of having regular face to face meetings (two or three per year) yet to date have had limited capacity to influence this occurring, or the timing of such meetings. Likewise, while AA has expanded the opportunity for the CDRN to participate in more strategic research policy initiatives, it is conceivable that there may come a time when the CDRN may want to provide a different perspective to that of AA.

At the heart of the matter is the independence of the Network. Currently, members are dependent on AA to inform them of opportunities to contribute and to facilitate their input. An independent means of accessing information and opportunities for input will ensure the CDRN is not left vulnerable to changes in internal AA priorities and/or personnel.

5.3 Resources

An ongoing issue for the CDRN is the ability to secure recurrent funding for its continuation. The current resources allocated to facilitate its operations amount to approximately $140,000 per annum, comprising $80,000 from the DCRCs and the residual a combination of funding from the JO and JR Wicking Trust, Bupa Care Services Australia and Alzheimer’s Australia Dementia Research Foundation (which funds the salary of the Partnership Centre Consumer Investigator). In addition, the DCRCs have contributed funding for CDRN members to attend annual Dementia

17 Boote J et al (2010) Public Involvement at the design stage of primary health research: a narrative review of case examples, Health Policy (95); Williamson T, (2010) op cit
Forums, as well as providing contributions for costs associated with members’ participation in research advisory mechanisms. At the time of writing, funding from the DCRCs is only available to support the CDRN until June 2014 (the extent of the DCRCs’ current funding agreement with the NHMRC); beyond this, the national office of AA has indicated it will seek to fund the CDRN from internal and other external sources until a more secure revenue stream is confirmed.

This is a critical issue for the CDRN in terms of its sustainability, as well as its independence; furthermore, it is critical to maintain the momentum which has been established within the research community regarding consumer engagement. The ability to support consumer participation in research is currently severely limited for researchers, who are constrained by NHMRC funding rules which limit expenditure to direct research costs only. This is in contrast to the NHMRC’s equivalent in the United Kingdom, the National Institute for Health Research (NIHR), which includes provision within its Research Design Services (RDS) to facilitate consumer involvement in the development of research proposals, i.e., before an application for formal funding is made. The NIHR has recently distributed a user-friendly guide to assist researchers to budget to actively involve consumers in research in the publication ‘Budgeting for Involvement: Practical advice on budgeting for actively involving the public in research studies’. 18

The NHMRC has recently revived its consumer engagement approach, through the establishment of the Consumer and Communities Advisory Group, of which AA is a member. Whilst this is a positive step to facilitating greater consumer input into research, it does little to enable researchers to embrace the concept at the local level. This will only occur if resources are made available, either within the current funding sources through a more liberal interpretation of the legislation within funding guidelines, or through the establishment of a separate funding pool to support groups such as the CDRN and/or researchers to engage consumers such as that available through the NIHR Research Design Services.

5.4 Participation

The level of participation by members in CDRN activities remains, on the whole, relatively high. This is reflected in the number of projects in which members are involved (currently 50) and also the attendance levels at the face to face meetings. As we indicated in the Interim Evaluation report, the personal commitment of members to improving outcomes for people with dementia is a core driver for involvement; in addition, members constantly refer to the personal benefits that participation provides. These include a sense of purpose, acceptance, and the ability to influence others, developing meaningful friendships and networking. A key facilitator for high levels of participation has been the core staff involved in supporting the Network; however, there has been an apparent tapering off of a number of members’ involvement over the past year or so, at the same time that AA has experienced staffing changes and internal restructuring. It is quite possible that these issues may be unrelated and merely reflective of different personal contexts in which members find themselves. However a number of members raised this issue with the evaluation team, suggesting there may be a degree of apprehension within the broader membership regarding the support available to the Network, particularly for new members.

18 Mental Health Research Network and INVOLVE (2013) Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies, Mental Health Research Network, London and INVOLVE, Eastleigh
An important facilitator of participation has been the active engagement of the CDRN in research and knowledge translation projects. The newly established Partnership Centre, although relatively slow to get underway, promises to be an important focus of effort for the CDRN into the future. There remains some concern, however, that the expectations associated with this and future initiatives may be beyond the capacity of a volunteer network. The employment of a CDRN member part-time to participate in the management and co-ordination of CDRN activities associated with the Partnership Centre is an important asset, and systems have been introduced to support this person and other members’ involvement in oversight of the Centre’s research projects. There remains concern, however, about the capacity of a CDRN comprised of volunteer members to maintain the required level of engagement with these projects, and the anticipated increase in projects over the longer term.

The proposed two-tier structure outlined in the ‘Guiding Principles’ document is clearly designed to alleviate over-burdening of key members while at the same time facilitating involvement of members who have more limited capacity. Based on the UK model, this appears a sensible approach but it remains unclear whether this is appropriate for the federated nature of Alzheimer’s Australia. Given the issue of geographic isolation that continues to be an issue for many CDRN members, it is possible that a more localised approach to project oversight may enhance member participation, for example, building on the infrastructure and resources currently available within AA State and Territory members and within DCRCs.

Related to this is the capacity of members living with dementia to participate in CDRN activities. Our observations suggest that the level of engagement is directly related to the level of capacity, confidence and articulateness of members. It is clear that the larger group meetings can impact on the ability of members with dementia to participate optimally, and therefore the two-tier structure may provide for greater engagement, particularly with a smaller core. At this stage it is not clear how the needs of people with dementia will be specifically addressed across the different levels of the proposed new operating structure; the international literature indicates that to support greater involvement by people with dementia, organisations need to:

> ...utilise methods that are appropriate for people with a wide range of experiences and degrees of impairment, incorporating where appropriate audio-visual methods and the internet.\(^{19}\)

A recurring theme in both the literature and stakeholder feedback (including CDRN members) in factors that enhance participation of consumers is the need for feedback. This has been an increasing feature of commentary in recent CDRN meetings, particularly in regard to the input members have provided to research proposals and assessment processes. As noted previously, feedback is important to ensure members know their contribution is valued and appropriate, particularly when provided in the context of volunteer capacity. This is an international phenomenon, and not just specific to the Network’s experience, for example:

> Recognise the importance of reciprocity and ensure that individuals involved gain from their experience of participation as well as those who are benefitting from their input.\(^{20}\)

\(^{19}\) Williamson, T. op cit, p17 of 18

\(^{20}\) Ibid
5.5 Capacity building

The focus of effort over the last three years has been to build relationships with research entities and demonstrate the capacity of consumers to effectively contribute to research; this has been done with great effect. The knowledge and skills required to participate in these processes have been predominantly obtained through the more active engagement of those members with research backgrounds, and the participation of researchers at CDRN meetings. What is clear from international experience, and feedback from members, is the need for skills development in a more systematic and accessible manner, which commences at the outset in the form of an induction program for members. This is likely to become even more critical in the less centralised structure proposed in the ‘Guiding Principles’ document, as new members are recruited from a broader range of backgrounds.

The Cochrane Collaboration is a mechanism to promote evidence-based health care, and does this by facilitating a:

...combination of best research evidence, the expertise of the healthcare provider and patient values.  

It views consumers as ‘one link in the chain’ of the evidence review process, and has dedicated resources to facilitate their involvement. A series of training resources have been developed including guidance on providing comments on reviews and protocols, as well as an interactive learning resource ‘Making sense of research’. These could provide a useful foundation for CDRN specific resources.

Capacity also needs to be built amongst the research community to ensure they are able to effectively collaborate in partnership with consumers. This was a key objective of the AA/NHMRC Knowledge Translation workshop held in July 2011, with good effect. We understand that a number of key researchers left the workshop with a renewed impression of the capacity of consumers to effectively contribute to research. However, there continues to be a dissonance between the intent and its implementation; for example, very few presenters at CDRN meetings appear to have developed materials or tailored their presentations in a way that would optimise member contribution. The literature identifies a range of strategies that can facilitate participation that moves ‘beyond informed consent’, and how researchers need to be encouraged to ‘use flexible collaborative processes’. These include enhancing consumers’ ‘research literacy’; researchers valuing ‘lay knowledge’; and, addressing the ‘professionalising strategies’ that researchers often employ to ‘maintain their power/status.’

In the Interim Evaluation report we recommended that a set of ‘guidelines’ be developed to assist those wishing to engage with consumers in a meaningful way. We understand that AA is currently revising its ‘tip sheet’ for communicating with people with dementia, and is seeking

22 http://training.cochrane.org/consumers/making-sense-research, accessed 14 September 2013
input from CDRN members; this should be tailored, in terms of content, style and dissemination strategies, to appropriately target and influence the broader dementia research community.

5.6 Support
The nature of members who participate in the CDRN, with their direct experiences of living with dementia or caring for someone with dementia, means that there will always be a high level of support needed to maximise participation of members at any one time. The support provided to members at the outset of the CDRN was a key enabler, assisting people build confidence in their ability to contribute in an unfamiliar field of expertise (i.e., research and knowledge translation project selection), as well as overcome some personal challenges arising from that lived experience of dementia. As we have noted previously in this report, the degree and nature of support provided during the last year has shifted, resulting from a number of staffing changes and internal restructure within AA. For some members, the impact is less significant as their confidence levels over the last three years have increased and they have developed their own internal support mechanisms amongst fellow CDRN members. This is consistent with the international experience which highlights:

...the benefits experienced by members ... include friendship and camaraderie, increased confidence and self-esteem, the development of new skills, being part of an international “dementia family” and pride in seeing changes take place as a result of their direct input.25

However, the need for a dedicated resource within AA to facilitate engagement and support of members clearly continues, as indicated in feedback from members at the May 2013 meeting in Hobart, and through subsequent member surveys and stakeholder interviews. While the internal restructure within AA has enabled a more coordinated approach to the management of consumer groups, at this stage it is unclear whether this will fully address the needs identified by CDRN members.

5.7 Communication
During the early stages of the CDRN considerable attention was given to identify the most relevant communication mechanisms for members in recognition of the disparate nature of the CDRN membership, in terms of geography, expertise and capacity. A system of regular emails (monthly) supported by teleconferences and individual email and phone conversations was established and this proved to be effective for a period. However, the changes in staffing within AA have provided some challenges in ensuring consistency in terms of content and processes. It is clear from member feedback that this has resulted in some members feeling disenfranchised, particularly those who are otherwise not connected to AA initiatives and processes.

The key audiences with whom the CDRN seek to engage have predominantly focused on the dementia research leads, particularly those involved in the DCRC Carers and Consumers and DCRC Assessment and Better Care as well as the new Partnership Centre leads. In addition, CDRN members have directly engaged with a range of researchers around individual projects, and project staff involved with the knowledge translation projects. The key stakeholders interviewed in the lead-up to writing this report all indicated their strong appreciation of the contribution of the CDRN as a whole, with one commenting:

...they are an impressive bunch of people.

25 Williamson, T (2012) op cit, p 8 of 18
There continue to be some qualifications regarding the content provided by some members and the disjuncture between expectations of perceived roles; this ties in well with the desire for members to receive feedback, and with what the literature refers to as ‘reciprocity’. Researchers continue to be unclear about the exact contribution that members can make, and members are unclear about how they can improve that contribution. This is a similar position with regard to the role of the CDRN and the AA national network, and resolution could assist in enhancing the efforts of both parties, including better alignment of priorities, resources and processes. Broader consultation around the proposed ‘Guiding Principles’ would be opportune in facilitating a more open dialogue, improved relations and greater potential for partnerships to operate into the future.

5.8 Recruitment and selection

A recurring theme that is endemic to the nature of consumer groups is the composition and extent to which this is representative of the constituent group. In the case of the CDRN, the debate has been about the balance between people with dementia and carers, given the majority of members fall into the latter category. There continues to be some internal debates within the CDRN about the extent to which carers can appropriately advocate on the behalf of people with dementia, and indeed the extent to which members with dementia are representative of the broader population of people with dementia (for example, there are no members with ‘late onset dementia’). Despite this, there is genuine intent from all members to improve outcomes for people with dementia.

The issue of representativeness is an issue for the consumer movement more generally. In their review of consumer involvement in health research, the authors note that:

> Those with the economic, cultural and social capital (are) more likely to get involved in research. 26

The AA national office has been conscious to ensure that the CDRN includes a mix of people from a range of backgrounds and interests, including a mix of metropolitan and rural members, culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander (ATSI) and Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) members. These members do not seek to represent their designated ‘demographic profile’ but rather are engaged because they provide diversity within the group. Indeed, it has been argued that:

> …expecting members of the public to represent the views of others with similar life experiences places an unreasonable burden on them.27

This is an important point, particularly in light of the differences amongst lived experiences of dementia within the CDRN membership; consequently, we agree with the notion presented by Hanley et al that it may be more helpful to think of different consumer ‘perspectives’ rather than ‘representatives’.28

That said, the level of burden in terms of participation continues to be a key threat for the Network. Some of the costs associated with membership discussed in this report include the tension that is caused by competing priorities of work and caring responsibilities; it is also fair to

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26 Ibid
28 As cited in Ward et al (2010) op cit
assume that the ‘fatigue’ identified in the literature is also experienced by members.\textsuperscript{29} This may be a factor in the level of disengagement of some members over time and possibly leading to some members’ resignation (the anticipated ‘exit interviews’ of members that were planned at the outset have been difficult to realise). The ‘Guiding Principles’ document outlines some of the membership requirements that are expected to underpin the proposed new structure for the Network, but does not go into sufficient detail to suggest that a recruitment strategy goes beyond looking for certain attributes and levels of ability to engage in CDRN activities.

In order to ensure the CDRN is sustainable and functions optimally it is clear that a more fulsome recruitment and retention strategy is required, which includes induction and ongoing training, communication and support through-out members’ involvement, including:

\begin{quote}
\textit{... supporting the gradual disengagement of people who are no longer able to actively participate through sustaining contact and peer support where possible.}\textsuperscript{30}
\end{quote}

Renewal is essential for the CDRN and given that current members were engaged for a three year term, a process for reviewing ongoing membership needs to be promptly instituted. The experiences of the past three years are also likely to have provided insights into the particular attributes that are most likely to optimise members’ contributions; these should be openly discussed within the CDRN prior to undertaking membership renewal or recruitment.

\textsuperscript{29} Williamson, T (2010) op cit
\textsuperscript{30} Ibid
6 Conclusion and recommendations

The concept of consumer involvement in research is now firmly embedded within the Australian dementia research sector as a direct result of Alzheimer’s Australia’s Consumer Dementia Research Network. The recently developed CDRN Guiding Principles are based on the philosophy of ‘Research for us, with us’. This is reflected in the aims of the CDRN which are to:

- Support and promote consumers having an active involvement in all stage of the dementia research process – from knowledge generation to knowledge translation; and
- Use the unique experience and expertise of consumers to contribute to dementia research activities with the aim of improving care and outcomes for people living with dementia.\(^{31}\)

In the three years since it was established, there have been a number of constants, and a number of changes. Constant has been the commitment of AA and DCRC leaders in supporting the work of the Network, and that of the JO and JR Wicking Trust, and Bupa Care Services Australia. Likewise, the majority of members have remained involved, including the Chairperson.

The CDRN has assisted Alzheimer’s Australia in their pursuit of the objectives of its National Quality Dementia Care Initiative (NQDCI), which is:

- To achieve changes in policy and practice that improve the quality of dementia care in Australia; and
- To enable people with dementia and their carers to set priorities for dementia research and research knowledge translation.\(^{32}\)

The evidence is found in changes that have arisen as a result of the contribution of the CDRN:

- More than fifty research projects are currently underway that have had input from consumers that may not have otherwise occurred;
- Approximately half that number again have been directly impacted on during the past three years by CDRN members;
- Eight major knowledge translation projects have been established implementing evidence across a range of care settings addressing priorities that were identified by consumers;
- Additional investments in dementia have been leveraged off the activities of members, including through Commonwealth aged care funding programs and in-kind support of service provider partners; and
- The profile of dementia research has been raised within the broader political domain with the promise of additional investments in the future
- Awareness of the importance and value of consumer involvement in research (both dementia and health and medical research more broadly) has increased, with specific reference in the McKeon review of health and medical research, and new consultative

\(^{31}\) Alzheimer’s Australia (September 2013) The Consumer Dementia Research Network (CDRN): Guiding Principles (internal document).

processes within the NHMRC; both in part as a result of the activities and advocacy of the CDRN.

These are significant achievements, achieved through the foresight and commitment of an organisation to provide the framework which was then powered by the passion and commitment of a group of people who have an interest in improving quality of life for people with dementia.

The CDRN has been evaluated using a set of eight key domains which are known to be facilitators of effective networks. It is clear that there are many aspects which are operating well but there are also a number of critical factors that need to be addressed if the successes to date are to continue and are sustained. These have been raised throughout this report, and are included below as specific recommendations to be considered.

Some important questions about consumer involvement in research have been raised throughout this report, in particular around the extent, mode and timing of the involvement, implications for research practice and measures of success. The answers to these questions can be derived from the answer to one overarching, fundamental question, Why have consumer involvement in research? If consensus can be reached about this issue, then it is likely that the answers to the above questions will be more readily resolved.

Throughout the deliberations of the CDRN, the Chairperson has provided ‘progress reports’ on the status of the analogous baby elephant, Seed-Aren. At the outset, the CDRN was likened to a baby elephant, which would need to stay close to its parent, Alzheimer’s Australia. It is three years since that baby elephant took its first tentative steps; perhaps it is now time for its namesake to stand on its own feet and engage with its ‘herd’ on an equal footing.

6.1 Recommendations

1. The NHMRC be encouraged to develop options for resourcing of consumer involvement in dementia research, similar to international initiatives such as the Research Design Services of the National Institute of Health Research in the UK.

2. The CDRN is provided with adequate dedicated resources to provide an effective secretariat function to enable its independence in decisions regarding systems, recruitment and processes, including funding for face to face meetings as required.

3. Alzheimer’s Australia review its consumer participation processes across national as well as State and Territory members to facilitate alignment of priorities, processes and improved communication for those involved in providing consumer input to research projects.

4. Strategic directions be developed by the CDRN with input from key stakeholders, including researchers, State and Territory AAs and service providers to ensure its relevance and opportunities to contribute are maximised. These strategic directions should inform the composition, accountabilities, core activities and structure of the Network.

5. A suite of CDRN resources should be developed that includes core documents such as strategic directions, an induction program, training resources for consumers to enhance
participation in research, guidelines for researchers in maximising contribution of consumers and a catalogue of research initiatives in which members have been involved. These resources should be publicly available, disseminated across different stakeholder groups and supported through the provision of training for researchers in engaging with consumers.

6. A formal recruitment process is established which clarifies the attributes, skills and representative nature of CDRN membership, to ensure a balance is maintained between different demographic constituencies and provides opportunities for membership renewal. This should be supported by comprehensive skills development and training opportunities for members, ongoing communication and support from the point of induction through to the gradual disengagement of members who are no longer able to actively participate.
Appendix 1  CDRN Terms of Reference and Current Member Profile

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 (i.e. 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.
## Current CDRN Member Profile

<table>
<thead>
<tr>
<th>State or Territory</th>
<th>Number of CDRN Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Queensland</td>
<td>7</td>
</tr>
<tr>
<td>New South Wales</td>
<td>3</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>1</td>
</tr>
<tr>
<td>Victoria</td>
<td>4</td>
</tr>
<tr>
<td>Tasmania</td>
<td>2</td>
</tr>
<tr>
<td>South Australia</td>
<td>5</td>
</tr>
<tr>
<td>West Australia</td>
<td>3</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Year Joined Network</th>
<th>Number of CDRN Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>19</td>
</tr>
<tr>
<td>2011</td>
<td>2</td>
</tr>
<tr>
<td>2012</td>
<td>2</td>
</tr>
<tr>
<td>2013</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix 2  Key Activities of the CDRN

The CDRN was developed with the goal of supporting individuals with dementia and their family carers to have an active role in research and knowledge translation, and is broadly based on the UK Quality in Dementia Research Network. The CDRN is funded mainly through support provided by the Dementia Collaborative Research Centres as part of the Australian Government’s Dementia Initiative.

The network commenced in September 2010 and currently comprises twenty-five members. The group is made up of individuals from every state and territory and includes individuals from various backgrounds including CALD, Indigenous, regional/remote, gay and lesbian, and individuals with younger onset dementia. There is a mix of current family carers, former carers and individuals with dementia.

The Network has three main areas of activity:

Alzheimer’s Australia’s National Quality Dementia Care Initiative (NQDCI)
Members of the CDRN met for the first time in September, 2010 to determine the top priorities for translation of dementia care research into better care practice. These priorities formed the basis for a call for project proposals in late 2010. The CDRN invited more detailed proposals from 8 of the 44 original submissions received, and with advice from industry and research experts, subsequently selected two projects for funding.

The members met again in Brisbane in May 2011 to consider the funding priorities for the second round of knowledge translation funding. They will again be involved in the assessment of applications and in the projects when they commence.

Dementia Collaborative Research Centres
Involvement of the CDRN members in the Centres has included:

- Providing feedback on project proposals
- Representation on reference groups and the Coordinating Committee
- Providing consumer advice on methodology
- Assistance with recruitment for research projects
- Representation on a postdoctoral scholarship committee

Alzheimer’s Australia Dementia Research Foundation
Alzheimer’s Australia Research (AADRF), the research arm of Alzheimer’s Australia, administers an annual Dementia Grants program which provides research grants, scholarships and fellowships. The CDRN has identified priority areas for one of the grants funded through this program, and has included additional questions in the grant applications on consumer involvement and dissemination of findings. Members have also been involved in the assessment
process for this grant. Researchers funded through AAR have also asked for member input on projects and survey design.

In addition, members of the CDRN have been sought out for involvement in a wide variety of research projects, including presentations at workshops and conferences, and participation on research project advisory committees.

Eight members of the Network were also centrally involved in a full-day workshop Translating Dementia Research into Better Practice, jointly hosted by Alzheimer’s Australia and the National Health and Medical Research Council (NHMRC).

* Taken from Appendix B of the Submission to the Strategic Review of Health and Medical Research from the Consumer Dementia Research Network
### Appendix 3  CDRN Evaluation Framework

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Evaluation questions</th>
<th>Indicators / data items</th>
<th>Data sources</th>
<th>Who</th>
<th>Timeframe</th>
<th>Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level 1: Processes, impacts and outcomes for consumers (carers, families, friends, communities)</strong></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td><strong>Improvements in involvement of consumers in setting research priorities</strong></td>
<td>DELIVERY/PROCESS</td>
<td>Were members engaged and utilised as intended?</td>
<td>Consumer opinions</td>
<td>CDRN member interviews</td>
<td>AA</td>
<td>Start &amp; exit interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Project data</td>
<td>CDRN documentation</td>
<td>AA &amp; CHSD</td>
<td>Ongoing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Data re blog and list-server activity</td>
<td>AA &amp; CHSD</td>
<td>6 monthly</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Evaluation of national summits</td>
<td>AA</td>
<td>Mar &amp; Sept</td>
</tr>
<tr>
<td></td>
<td>IMPACT</td>
<td>Does selection of dementia research priorities reflect consumer priorities?</td>
<td>Consumer opinions</td>
<td>CDRN member interviews</td>
<td>AA</td>
<td>Start &amp; exit interviews</td>
</tr>
<tr>
<td></td>
<td>IMPACT</td>
<td>What has been the experience of consumer involvement in the project?</td>
<td>Consumer opinions</td>
<td>CDRN member interviews</td>
<td>AA</td>
<td>Start &amp; exit interviews</td>
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<td></td>
<td>Leadership and culture</td>
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<tr>
<td></td>
<td>IMPACT</td>
<td>Did consumers develop capacity?</td>
<td>Consumer opinions</td>
<td>CDRN member interviews</td>
<td>AA</td>
<td>Start &amp; exit interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>CDRN documentation</td>
<td>AA</td>
<td>Ongoing</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td>Stakeholder interviews</td>
<td>CHSD</td>
<td>May-July 2012</td>
</tr>
<tr>
<td></td>
<td>IMPACT</td>
<td>What are the enablers or inhibitors to consumer engagement?</td>
<td>Consumer opinions</td>
<td>CDRN documentation</td>
<td>AA</td>
<td>Ongoing</td>
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<tr>
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<td>Support</td>
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<td>Resources</td>
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<td>Objectives</td>
<td>Evaluation questions</td>
<td>Indicators / data items</td>
<td>Data sources</td>
<td>Who</td>
<td>Timeframe</td>
<td>Domains</td>
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<td>1f</td>
<td>IMPACT</td>
<td>Are there any unintended consequences for consumers arising from their participation in the CDRN?</td>
<td>Stakeholder interviews, CHSD, May-July 2012</td>
<td>All</td>
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<tr>
<td>Level 2: Processes, impacts and outcomes for providers (professionals, volunteers, organisations)</td>
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<td></td>
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<td></td>
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<tr>
<td>2a</td>
<td>DELIVERY</td>
<td>Were NQDCN projects and DCRC initiatives funded in line with research priorities identified by CDRN?</td>
<td>NQDCN projects, DCRC initiatives, NQDCN documentation, CHSD</td>
<td>Ongoing</td>
<td></td>
<td>Role clarity / governance</td>
</tr>
<tr>
<td>2b</td>
<td>IMPACT</td>
<td>Did DCRCs or other bodies utilise the services of the CDRN?</td>
<td>DCRC initiatives, DCRC websites, Alzheimer’s Association websites, CHSD</td>
<td>6 monthly</td>
<td></td>
<td>Leadership and culture, Role clarity / governance</td>
</tr>
<tr>
<td>2c</td>
<td>IMPACT</td>
<td>What are the enablers or inhibitors to researchers using the CDRN?</td>
<td>Stakeholder opinions, Stakeholder interviews/survey, CHSD</td>
<td>May-July 2012</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2d</td>
<td>CAPACITY BUILDING</td>
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<tr>
<td>Objectives</td>
<td>Evaluation questions</td>
<td>Indicators / data items</td>
<td>Data sources</td>
<td>Who</td>
<td>Timeframe</td>
<td>Domains</td>
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<tr>
<td></td>
<td>Have researchers been trained and resourced to respond to increased consumer participation?</td>
<td>Stakeholder opinions</td>
<td>Stakeholder interviews/survey, DCRC Websites</td>
<td>CHSD</td>
<td>May-July 2012</td>
<td></td>
</tr>
<tr>
<td>2e SUSTAINABILITY</td>
<td>Is the CDRN sustainable?</td>
<td>Project data</td>
<td>NQDCN Progress reports, DCRC websites, Stakeholder interviews / survey</td>
<td>CHSD</td>
<td>Ongoing</td>
<td>Recruitment and selection, Role clarity / governance, Resources</td>
</tr>
<tr>
<td>Documentatio n of any unintended consequences</td>
<td>Are there any unintended consequences for NQDCN projects and researchers arising from the CDRN?</td>
<td>NQDCN projects, Stakeholder opinions</td>
<td>NQDCN Progress reports, DCRC websites, Stakeholder interviews / survey, Reflective practice checklist</td>
<td>CHSD</td>
<td>Ongoing</td>
<td>All</td>
</tr>
<tr>
<td>2g How did the CDRN relate to the consumer engagement processes already underway within national, state and territory AA Associations?</td>
<td>Stakeholder opinions</td>
<td>Stakeholder interviews, AA national, state and territory websites</td>
<td>CHSD</td>
<td>May-July 2012</td>
<td>Role clarity, Recruitment</td>
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<tr>
<td>Level 3: Processes, impacts and outcomes for the system (structures and processes, networks, relationships)</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Dissemination of research findings</td>
<td>DELIVERY How has Alzheimer’s Australia disseminated the lessons learned from the CDRN?</td>
<td>Documentation Interviews</td>
<td>Alzheimer’s Australia website</td>
<td>CHSD</td>
<td>6 monthly</td>
<td>Communication</td>
</tr>
<tr>
<td>Objectives</td>
<td>Evaluation questions</td>
<td>Indicators / data items</td>
<td>Data sources</td>
<td>Who</td>
<td>Timeframe</td>
<td>Domains</td>
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</tr>
<tr>
<td>Influence of CDRN on broader policy, research and service delivery agenda</td>
<td>3b IMPACT Has there been any improvement in the opportunities for the Alzheimer’s Australia to influence policy, research or service delivery as a result of the CDRN?</td>
<td>Invitations to speak at related events Changes to program / policy / research guidelines</td>
<td>Stakeholder interviews NQDCN project documentation Alzheimer’s Australia website</td>
<td>CHSD</td>
<td>May-July 2012</td>
<td>Leadership and culture Role clarity / governance Communication</td>
</tr>
<tr>
<td>3c How did the CDRN relate to the consumer engagement processes already underway within national, state and territory AA Associations, research, service provider and policy contexts?</td>
<td>Communication with other consumer engagement processes Website reviews: AA national, state &amp; territory sites; DoHA; SPN members; DCRC sites.</td>
<td>Stakeholder interviews</td>
<td>CHSD</td>
<td>May-July 2012</td>
<td>Leadership and culture Communication</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 4  CDRN members’ ratings of evaluation questions by importance – May 2013

<table>
<thead>
<tr>
<th>Question</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Theme – Impact on Research</strong></td>
<td></td>
</tr>
<tr>
<td>1.1 Is there a consumer representative on all committees considering dementia research?</td>
<td>6</td>
</tr>
<tr>
<td>1.2 Has the work of the CDRN had a positive, permanent impact on the way researchers think about involving consumers in their projects?</td>
<td>10</td>
</tr>
<tr>
<td>1.3 What are the gaps in dementia research in Australia? Has there been an audit?</td>
<td>1</td>
</tr>
<tr>
<td>1.4 How do you achieve a situation where researchers involve consumers at the research planning phase rather than as an add-on later?</td>
<td>8</td>
</tr>
<tr>
<td>1.5 Did the network influence a consumer perspective in research projects it advised on?</td>
<td>7</td>
</tr>
<tr>
<td>1.6 Did the network influence the adoption of person centred care as the starting point for research enquiry?</td>
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</tr>
<tr>
<td><strong>2. Theme – Knowledge Translation</strong></td>
<td></td>
</tr>
<tr>
<td>2.1 What influence has the network had on the translation research projects?</td>
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</tr>
<tr>
<td>2.2 Did the network influence allocation of grants to top priority research projects?</td>
<td>7</td>
</tr>
<tr>
<td>2.3 What impact can I as a consumer have in ensuring knowledge is translated into practice and to influence future policy?</td>
<td>5</td>
</tr>
<tr>
<td>2.4 Did the network influence the uptake of knowledge translation projects by funders?</td>
<td>5</td>
</tr>
<tr>
<td>2.5 Did you understand how the term knowledge translation was used in this network?</td>
<td>1</td>
</tr>
<tr>
<td>2.6 How could the person with dementia you care for benefit from knowledge translation?</td>
<td>4</td>
</tr>
<tr>
<td>2.7 How has the CDRN contributed to research implementation?</td>
<td>7</td>
</tr>
<tr>
<td><strong>3. Theme – Impact on people with dementia</strong></td>
<td></td>
</tr>
<tr>
<td>3.1 How will our contributions at this national level make a difference to the individual living with dementia?</td>
<td>4</td>
</tr>
<tr>
<td>3.2 Has my participation in the network been of benefit to people with dementia and their carers?</td>
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</tr>
<tr>
<td>3.3 Is the network substantially contributing to improving the circumstances of people living with dementia?</td>
<td>6</td>
</tr>
<tr>
<td>3.4 How will the CDRN know what impact it has had on the care of people with dementia?</td>
<td>5</td>
</tr>
<tr>
<td>3.5 Does the CDRN contribute effectively to the actual implementation of improving lives of people with dementia and not only contribute to more research?</td>
<td>7</td>
</tr>
<tr>
<td>3.6 Will all people in Australia who are affected either, by having to live with dementia or care for a person with dementia, be improved?</td>
<td>0</td>
</tr>
<tr>
<td>3.7 Has the CDRN really improved care practices in home and residential care?</td>
<td>5</td>
</tr>
<tr>
<td>3.8 How could the person with dementia you care for benefit from knowledge translation?</td>
<td>1</td>
</tr>
<tr>
<td><strong>4. Theme – Support for members</strong></td>
<td></td>
</tr>
<tr>
<td>4.1 Has AA provided enough support to members?</td>
<td>5</td>
</tr>
<tr>
<td>4.2 Has AA provided enough resources to members?</td>
<td>1</td>
</tr>
<tr>
<td>4.3 How could support and resources to members be improved?</td>
<td>4</td>
</tr>
<tr>
<td>4.4 How have CDRN members been assisted to contribute if they have not previously had any involvement with research?</td>
<td>9</td>
</tr>
<tr>
<td>4.5 How have CDRN members been assisted to contribute if they have a cognitive impairment?</td>
<td>4</td>
</tr>
<tr>
<td>4.6 Has the information provided to CDRN members been presented in plain English?</td>
<td>3</td>
</tr>
<tr>
<td>4.7 What amount of time is required from CDRN members over the course of a year?</td>
<td>6</td>
</tr>
<tr>
<td><strong>5. Theme – Individual contributions and roles</strong></td>
<td></td>
</tr>
<tr>
<td>5.1 Would you participate in a consumer group, like the CDRN again?</td>
<td>9</td>
</tr>
<tr>
<td>5.2 Would you recommend participation in a consumer group, like the CDRN, to a friend?</td>
<td>7</td>
</tr>
<tr>
<td>5.3 How could CDRN members receive feedback about their contribution?</td>
<td>9</td>
</tr>
<tr>
<td>5.4 Do CDRN members understand their role in the network?</td>
<td>6</td>
</tr>
</tbody>
</table>
Appendix 5  Website Audit

A range of organisations have been identified that AA believes are likely to be engaged in various aspects of the National Quality Dementia Care Initiative (NQDCI) and more particularly the Consumer Dementia Research Network (CDRN). The websites selected for audit related to organisations initially involved in either the National Quality Dementia Care Initiative Executive Committee or the Service Provider Network (SPN) formed to support the NQDCI. Whilst the NQDCI Executive Committee and SPN are no longer active these organisations remain a useful barometer of dissemination about the activities of the CDRN. The websites of these organisations were reviewed in December 2011 by searching for the acronym ‘CDRN’ and the organisational title ‘Alzheimer’s Australia’.

In February 2013, the search was repeated using a wider range of search terms: “Alzheimer’s Australia”, “AA”, “National Quality Dementia Care Initiative”, “NQDCI”, “Consumer Dementia Research Network”, “CDRN” and “Partnership Centre”. The search was replicated with each of the search terms using varying punctuation such as “ ”, ‘ ’ or no punctuation surrounding the search term, which often produced different results.

In August 2013, a search was conducted of the websites of four of the projects that were successful in Round 2 NQDCI funding: HammondCare; Aged Care Research Unit, Liverpool Hospital; Australian Centre for Evidence Based Aged Care (ACEBAC); and The Heart Foundation, SA. In addition the websites of organisations listed as Dementia Collaborative Research Centres (DCRC), were also reviewed, including the Australian National University (ANU), the University of New South Wales (UNSW) and the Queensland University of Technology (QUT). The search terms used were ‘NQDCI’, ‘National Quality Dementia Care Initiative’, ‘Partnership Centre’, ‘CDRN’ and ‘Consumer Dementia Research Network’, using either varying punctuation including “ ”, and ‘ ’, or no punctuation at all surrounding the search term (refer to the table below for the search results).

The findings from this audit of websites of organisations associated with the AA National Office and therefore expected to promote the NQDCI and CDRN produced mixed results. The highest level of supporting dissemination occurred through the DCRCs, Commonwealth Department of Health and a couple of aged care service providers, for example, HammondCare. The more limited response from other aged care service providers is possibly a reflection of the decision by AA not to pursue the SPN. What is of most interest are the limited references to the NQDCI and CDRN by organisations funded through Round 2 (with projects selected by the CDRN), to implement knowledge translation projects as part of this broader Initiative.
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Website</th>
<th>Search Results – Dec 2011</th>
<th>Search Results - Feb 2013</th>
<th>Search Results – Aug 2013</th>
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<tr>
<td>Alzheimer’s Australia and State and Territory Associations</td>
<td><a href="http://www.fightdementia.org.au/">http://www.fightdementia.org.au/</a></td>
<td>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.</td>
<td>Searching “CDRN” with varying punctuation returned 81 - 134 results. The links were mainly for the application and information for second funding round which closed in Nov 2011, evaluation reports on the CDRN <a href="http://www.fightdementia.org.au/research-publications/evaluation-reports.aspx">http://www.fightdementia.org.au/research-publications/evaluation-reports.aspx</a>, and to documents on the announcement of grant recipients and staff bios. Most of the document links were duplicated several times.</td>
<td>Web-site search not replicated in August 2013, refer to February 2013 results.</td>
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<td>Searching “NQDCI” with varying punctuation returned 33-64 results. There were only two document links in the results as the search again produced multiple links to the same documents (as per CDRN above). The two documents were a funding application template and a media release from mid-2012 <a href="http://www.fightdementia.org.au/research-publications/a-new-approach-to-dementia-care.aspx">http://www.fightdementia.org.au/research-publications/a-new-approach-to-dementia-care.aspx</a></td>
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<td>Searching “Partnership Centre” with varying punctuation produced 44-575 results. Results were again duplicates of a small number of pages. The main links were to a media release from November 2012 mentioning the establishment of the Partnership Centre - Dealing with Cognitive and Related Functional Decline in Older People <a href="http://www.fightdementia.org.au/three-million-australians-will-develop-dementia-by-2050.aspx">http://www.fightdementia.org.au/three-million-australians-will-develop-dementia-by-2050.aspx</a> and a link to the AA National Office</td>
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<td>Dementia Collaborative Research Centres</td>
<td><a href="http://www.dementia.unsw.edu.au/">http://www.dementia.unsw.edu.au/</a></td>
<td>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.</td>
<td>Searching AA or Alzheimer’s Australia returned 6 results. Four were directly related to Alzheimer’s Australia as a partner in a research project and listed in the ‘outputs’ citations (<a href="http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=7&amp;search=true">http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=7&amp;search=true</a>, <a href="http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=4&amp;search=true">http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=4&amp;search=true</a>, <a href="http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=5&amp;search=true">http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=5&amp;search=true</a> and <a href="http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=8&amp;search=true">http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=AA&amp;searchtype=EXACT&amp;pid=8&amp;search=true</a>)</td>
<td>The search was repeated in August 2013 with the same search terms used in February 2013. The results were identical to the February search.</td>
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<td>CT&amp;pid=2&amp;search=true</td>
<td>The other two results weren’t relevant.</td>
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<td>CDRN and Consumer Dementia Research Network returned one result (same result for both searches) for the CDRN Project <a href="http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=CDRN&amp;searchtype=EXACT&amp;pid=1&amp;search=true">http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&amp;view=dcrc&amp;layout=project&amp;Itemid=112&amp;research_topic=0&amp;researcher=0&amp;research_type=0&amp;year=0&amp;population=0&amp;centre=0&amp;keywords=CDRN&amp;searchtype=EXACT&amp;pid=1&amp;search=true</a></td>
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<td>There were no results for NQDCI, National Quality Dementia Care Initiative or the Partnership Centre - Dealing with Cognitive and Related Functional Decline in Older People.</td>
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<td>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.</td>
<td>The acronym AA returned 203 results, none of which were specifically relevant to this audit. Alzheimer’s Australia returned 11 results, with only 3 directly related to Alzheimer’s Australia. However they were only references to scholarships or to events sponsored by AA.</td>
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<td>“CDRN” returned zero results, however “Consumer Dementia Research Network” returned 27,647 records. None were related to the CDRN.</td>
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<td>NQDCI returned zero results, whilst ‘National Quality Dementia Care Initiative’ returned 16,899 results, however none were directly related to the NQDCI.</td>
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<td><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></td>
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<td>Searching with the acronym CDRN returned 0 results, however searching with the expanded term produced 249 records, however none were relevant again.</td>
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<td>NQDCI returned 0 results, whilst the expanded term produced 249 records, however none were relevant again.</td>
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<td>Using the term ‘Partnership Centre’ returned 9,170 records, but none were directly related to the dementia specific Partnership Centre.</td>
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<td>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>.</td>
<td></td>
<td>'Partnership Centre’ returned 9,884 results, however none were relevant.</td>
<td>Searching the acronym AA returned 2,291 results, however none were related to AA. Searching with the expanded term 'Alzheimer’s Australia’ returned 21 results. A few of the results referred to Presidents of AA, scholarships or research however none were particularly relevant for our purposes. Searching with the acronyms ‘CDRN’ and ‘NQDCI’ (with variations of punctuation) returned zero results. A search with ‘Consumer Dementia Research Network’ returned 13 results, however none were related to the CDRN and there were a couple of reference to the Dementia Collaborative Research Centre. Searching with ‘National Quality Dementia Care Initiative’ returned 24 results, however none were relevant. A search using ‘Partnership Centre’ with varying punctuation returned between 2 and 5,001 results (depending on punctuation used for the search). The results however did not relate to the Partnership Centre associated with dementia or Alzheimer’s disease.</td>
<td>Searching with the acronyms ‘CDRN’ and ‘NQDCI’ both returned 0 results. A search using the expanded terms for each produced 8 records and 27 records respectively. None however were directly related to either term. Using ‘Partnership Centre’ as the search term produced up to 5,002 records but again, none were related to either dementia or Alzheimer’s disease.</td>
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<tr>
<td>HammondCare (Round 2 NQDCI Funding)</td>
<td><a href="http://www.hammond.com.au/">http://www.hammond.com.au/</a></td>
<td>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.</td>
<td>Search functionality has now been added to the website. Searching ‘CDRN’ returned one result, which was a “news” page about the NQDCI grant won by HammondCare. Searching ‘NQDCI’ returned the same result. Searching “Alzheimer’s Australia” returned 23 hits (although not all were relevant), relating to items such as: The Partnership Centre for better dementia outcomes Blog entries on International Dementia Excellence Awards (and Mr Rees’</td>
<td>Searching National Quality Dementia Care Initiative or NQDCI with varying punctuation returned 1-3 results. Only two results were relevant: 1 was the media release found in the Feb 2013 search and the other was a CareSearch NPCW Media release from 20 May 2013. Searching with ‘Partnership Centre’ returned 18 results of which 11 were relevant, however 2 results referred to the same link.</td>
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<td>Bupa Aged Care</td>
<td><a href="http://www.bupaagedcare.com.au/">http://www.bupaagedcare.com.au/</a></td>
<td>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.</td>
<td>No search function, so pages were reviewed by scanning for each of the seven search terms. The results for each are listed below: “AA” / “Alzheimer’s Australia” – 1 link to the AA homepage on the ‘Choosing a Home - Aged Care Resources’ page; further references to AA identified throughout. NQDCI – 1 reference on the ‘About Us – Partnerships’ page; and a news article <a href="http://www.bupaagedcare.com.au/staticfiles/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCare/PDFs/legends_magni%EF%AC%81e_s/BupaCar">http://www.bupaagedcare.com.au/staticfiles/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magniﬁe_s/BupaCare/PDFs/legends_magni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|                       |                               | membership on judging panel), and AA’s involvement in other awards (e.g. Care Staff of the Year)                                                                 | – Reference to statistics reported by AA (specifically about younger onset dementia)  
– On the ‘Resources’ page, it is recommended to visit the AA home page for more general information on dementia  
– Launch of the book 10 Helpful Hints for Dementia Design at Home.                                                                 | The search terms ‘CDRN’ and ‘Consumer Dementia Research Network’ produced 253 results, however only 2 of these results directly referred to the CDRN. One result related to the initial grant win and the other was a Skynews dementia discussion forum. |
| ACH Group             | http://www.ach.org.au/        | 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. |                                                                                                                                                                                                                       | Web-site search not replicated in August 2013, refer to February 2013 results.                                                                                                                                                                                   |
Searching for “Alzheimer’s Australia” also returned no results, however when searching without the apostrophe in the organisation title (“Alzheimer’s Australia”), one result was returned with a link to the Alzheimer’s Australia website for information on dementia risk reduction strategies.  
Searching with ” produced 11 results, one was a link to information on groups and counselling on the AA website http://www.ach.org.au/good-health/dementia-pathways/reducing-the-risk and the remaining results were not relevant. | Web-site search not replicated in August 2013, refer to February 2013 results.                                                                                                                                                                                   |
### Evaluation of the CDRN – Final Report

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Website</th>
<th>Search Results – Dec 2011</th>
<th>Search Results - Feb 2013</th>
<th>Search Results – Aug 2013 (NQDCI Funded Projects only)</th>
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<tbody>
<tr>
<td>Resthaven Incorporated</td>
<td><a href="http://www.resthaven.asn.au/">http://www.resthaven.asn.au/</a></td>
<td>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.</td>
<td>Searching “AA” with various punctuation returned 2-3 results. One related to the Postgraduate Research Scholarship in Dementia Care and the others were not relevant. “Alzheimer’s Australia” (with / without punctuation) returned 35-49 results. Most were links to newsletters, annual reports, foreign language information brochures and some related to the Postgraduate Research Scholarship in Dementia Care, established in conjunction with AA. “CDRN” (without / with punctuation “” or “&quot;”) returned no results, whilst “Consumer Dementia Research Network” (with or without punctuation) returned 27 unrelated / irrelevant results.</td>
<td>Web-site search not replicated in August 2013, refer to February 2013 results.</td>
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<tr>
<td>Organisation</td>
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<td>&quot;NQDCI&quot; (with / without punctuation) returned zero results.</td>
<td>&quot;National Quality Dementia Care Initiative&quot; (with / without punctuation) return approximately 37 results, however none were directly related to the NQDCI.</td>
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<td>&quot;National Quality Dementia Care Initiative&quot; (with / without punctuation) return approximately 37 results, however none were directly related to the NQDCI.</td>
<td>Searching for &quot;Partnership Centre&quot; returned zero results, however searching with either ” or no punctuation at all returned 29 results, although none were related to the Partnership Centre.</td>
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<td></td>
<td></td>
<td>Searching ‘Alzheimer’s Australia’ and ‘CDRN’ returned no results.</td>
<td>Searching “AA”, “CDRN” and “NQDCI” (with varying punctuation) all returned zero results. “Consumer Dementia Research Network” and &quot;National Quality Dementia Care Initiative” also returned zero results.</td>
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<td></td>
<td></td>
<td>Searching ‘Alzheimer’s Australia’ and ‘CDRN’ returned no results.</td>
<td>Searching for “Partnership Centre” returned 3 results, however none were relevant. &quot;Alzheimer’s Australia” returned 1 result when the apostrophe was removed from the title in the search term, however it was a link to services for older people and the link was no longer valid.</td>
<td>Web-site search not replicated in August 2013, refer to February 2013 results.</td>
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Evaluation of the CDRN – Final Report

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<tr>
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| Commonwealth Department of Health     | http://www.health.gov.au/        | Searching ‘CDRN’ returned no results. Searching ‘Alzheimer’s Australia’ returned 387 matches with documents. Those relating to the CDRN and NQDCI are as follows:  
  - NQDCI is mentioned in document titled ‘Outcome 4: Aged Care and Population Ageing’.  
  - The Address to Alzheimer’s Australia 14th National Conference (Brisbane, May 2011) by Minister Butler also refers to the CDRN and NQDCI. | Searching “CDRN”, “Consumer Dementia Research Network” and “AA” returned no relevant results. “Alzheimer’s Australia” returned 495 document matches. | Web-site search not replicated in August 2013, refer to February 2013 results. |

The search function on this website is very limited, so pages were also reviewed by scanning for the search terms. No results were found in this search either.

There were 2 results for “NQDCI” linked to the 2010-2011 Annual Report and a document titled ‘Outcome 4: Aged Care and Population Ageing’ (Section ‘Program 4.6: Dementia’), with both documents stating that ‘The department also worked closely with Alzheimer’s Australia through its National Quality Dementia Care Initiative (NQDCI) and is represented on the NQDCI steering committee.’


Seven matches were returned when the search was expanded to “National Quality Dementia Care Initiative”. Four of the matches referred to the two documents above for “NQDCI” and the other 3 were not relevant.

Searching “Partnership Centre” returned 3 results, two of which were links to Departmental Records listings for NHMRC) http://www.health.gov.au/internet/main/publishing.nsf/Content/B218D2020226DFD8CA2

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</tr>
</thead>
<tbody>
<tr>
<td>Royal District Nursing Service</td>
<td><a href="http://www.rdns.com.au/">http://www.rdns.com.au/</a></td>
<td>Searching ‘CDRN’ and ‘NQDCI’ returned no results.</td>
<td>None of the search terms (acronyms or expanded terms with / without varying punctuation) returned any results.</td>
<td>Web-site search not replicated in August 2013, refer to February 2013 results.</td>
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<tr>
<td></td>
<td></td>
<td>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.</td>
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<tr>
<td>Northern Health – Bundoola Extended Care Centre</td>
<td><a href="http://www.nh.org.au/bundoola-extended-care-centre/w1/1001208/">http://www.nh.org.au/bundoola-extended-care-centre/w1/1001208/</a></td>
<td>Searching ‘CDRN’ and ‘NQDCI’ returned no results.</td>
<td>All search terms returned zero results, except for Partnership Centre, which returned one result, however this was not related to Alzheimer’s or Dementia. There were no results for Alzheimer’s Australia (with or without punctuation).</td>
<td>Web-site search not replicated in August 2013, refer to February 2013 results.</td>
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<td></td>
<td></td>
<td>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.</td>
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</tr>
<tr>
<td>Aged Care Research Unit, Liverpool Hospital (Round 2 NQDCI funding)</td>
<td><a href="http://www.swshd.nsw.gov.au/liverpool/agedcare/research.html">http://www.swshd.nsw.gov.au/liverpool/agedcare/research.html</a></td>
<td>There was no search function associated with this site/page. There was a ‘Links’ page which contained a link to Alzheimer’s Australia and to the Department of Health and Ageing (DoHA).</td>
<td></td>
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</tr>
<tr>
<td>Australian Centre for Evidence Based Aged Care (ACEBAC, La Trobe University (Round 2 NQDCI)</td>
<td><a href="http://www.latrobe.edu.au/aipca/about/australian-centre-for-evidence-based-aged-care">http://www.latrobe.edu.au/aipca/about/australian-centre-for-evidence-based-aged-care</a></td>
<td>Searching ‘NQDCI’ with varying punctuation returned no results. Expanding the search term to ‘National Quality Dementia Care Initiative’ with varying punctuation returned 2 results. These were links to Staff Profile pages and a list of their research projects.</td>
<td>Searching for the term ‘Partnership Centre’ with varying punctuation returned 675 results, however none were relevant.</td>
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<tr>
<td>Organisation</td>
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<tr>
<td>Heart Foundation (South Australia)</td>
<td><a href="http://www.heartfoundation.org.au/Pages/default.aspx">http://www.heartfoundation.org.au/Pages/default.aspx</a></td>
<td></td>
<td></td>
<td>Searching 'NQDCI' with varying punctuation returned no results. When the term was expanded to 'National Quality Dementia Care Initiative', the search returned 2 results. Only one result was relevant and was a Heart Foundation/ACH Group media release dated 20/09/2012 on a new walking program for people with dementia (<a href="http://www.heartfoundation.org.au/SiteCollectionDocuments/120920-HeartFoundationWalkingforHeartandBrainHealthFINAL.pdf">http://www.heartfoundation.org.au/SiteCollectionDocuments/120920-HeartFoundationWalkingforHeartandBrainHealthFINAL.pdf</a>)</td>
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<td></td>
<td>Searching for ‘Partnership Centre’ with varying punctuation returned 11 results, however none were relevant.</td>
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<td></td>
<td>‘CDRN’ returned zero results, but the expanded term ‘Consumer Dementia Research Network’ returned 2 results. None however were relevant.</td>
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Appendix 6  Findings - CDRN Survey 2013 and Comparative Survey Analysis 2011 to 2013

Introduction

This survey analysis includes the results from the 2013 CDRN member survey which was issued to all members of the network in August/September 2013 (the survey tool is included as Appendix 7). This is the third time the survey has been issued and in addition to the 2013 ‘snapshot’ analysis a comparative analysis of 2011, 2012 and 2013 is included for 17 members who have responded to each of these surveys.

The snapshot analysis captures the views of all current CDRN members who responded to the survey. For several new members this is the first opportunity they have had to provide feedback on their experiences with the CDRN.

The comparative analysis in contrast focuses on long-standing CDRN members and aims to capture trends over time.

Survey implementation

This survey was administered using SurveyMonkey®, an online survey tool. All 25 CDRN members were emailed an introductory message with the survey tool (including participant information and provision for consent) on 15 August 2013. To improve the response rate, a reminder email was sent on 23 August and again on the 29 August 2013 to those members that had not yet responded. The survey collection was closed on 3 September 2013.

Response rate

In the 2013 survey, 24 (96%) out of 25 participants answered all or most of the questions. The respective number of respondents for 2011 and 2012 surveys was 24 and 21 participants.

As noted above, the comparative analysis is based on 17 CDRN members who responded to each survey across the three year period.

General background

The following results relate to general information about the survey respondents including their length of membership, time invested in the CDRN and how this has trended over the past three years.

The membership of the CDRN has been stable over the past three years. At the time of the 2013 survey the majority of participants (19 out of 24) had been members of CDRN for more than two years. Three out of 24 were members for less than one year (Figure 1).
For those members who joined the CDRN in the last 12 months, they reported that they had come to be a member of the CDRN either through involvement with State and Territory Alzheimer’s Associations, the suggestion of an existing CDRN member, or as a result of responding to an Expression of Interest or direct invitation from the National Research Manager.

At the time of the last survey the majority of participants (13 out of 24 or 54%) spent from 4 to 8 hours on CDRN activities per month. A minority of 4 (17%) participants were spending less than 4 hours per month (Figure 2).
Comparative Survey Analysis
Almost the same distribution of time spent on CDRN activities persisted over all three surveys. The majority of the core CDRN members spent 4 to 8 hours per month on CDRN activities, except in 2012 where there were similar numbers of members who spent more than 8 hours per month. The minority (1 to 4 participants) spent less than 4 hours (Figure 3).

Figure 3  Time spent on CDRN activities (core group of respondents - 3 surveys)

Roles and relationships
The results presented below focus on members’ perceived importance of the various roles of the CDRN as well as the key relationships the CDRN has forged since its inception.

Survey 2013
There are four roles that participants of Survey 2013 deemed to be the most important. Overall, these four roles gathered 54 (76%) out of a total 70 allocated votes. These roles are shown in Figure 4. The most important role appears to be “Setting priorities for NQDCI knowledge translation projects”, with “Liaison with the Partnership Centre for Cognitive and Related Functional Decline in Older People” being a close second.
A number of respondents provided comments on other ways they had participated as a member of the CDRN. These comments included providing consumer input into NQDCN projects, speaking on behalf of carers to providers and researchers, raising awareness of the CDRN among professionals and consumers, and presenting at conferences. One comment related to the changing nature of members’ role:

... As time has gone on, I think a major role we now play is to provide a consumer perspective input into knowledge translation, applied research and policy development projects. We are being sought out by researchers and policy makers from a wide range of areas to provide that consumer perspective.

Comparative Survey Analysis
Among the core group of respondents that participated in all three surveys the role of “Setting priorities for NQDCI knowledge translation projects” has consistently ranked most highly as the most important role for CDRN members.

The respondents were very consistent in their assessment of the importance of CDRN member roles over the three year interval (Figure 5). The same four roles were deemed the most important over time. The only change of note occurred with the “Liaison with the Partnership Centre for Cognitive and Related Functional Decline in Older People” role, it increased in importance from 2012 to 2013 (note, that the Partnership Centre was not established until 2012 and included in the survey from this point). Another role that was initially present in 2011 and 2012 surveys (Contributing to the direction of the NQDCI through representation on the Executive Committee) was discontinued in 2013 as the Executive Committee was disbanded.
Figure 5  Important roles of CDRN members (core group of respondents - 3 surveys)

- Liaison with the Partnership Centre for Cognitive and Related Functional Decline in Older People
- Setting priorities for NQDCI knowledge translation projects
- Advising the Dementia Collaborative Research Centres (DCRCs) on consumer priorities for research
- Assessing and monitoring knowledge translation projects
- Providing information and advice to researchers on how to improve their interactions with consumers
- Assisting with communicating findings of knowledge translation and/or research projects to the community
- Providing feedback to Alzheimer’s Australia Dementia Research Foundation
- Contributing to the direction of the NQDCI through representation on the Executive Committee
**Survey 2013**
Participants of the 2013 Survey generally consider themselves as understanding of the relationship with other initiatives (Figure 6). The percentage of participants who report understanding the relationships varied from 87% to 100%. The relationship understood best is between the CDRN and Dementia Collaborative Research Centres.

**Figure 6 Understanding of the relationship between the CDRN and other initiatives (Survey 2013)**

![Bar chart showing understanding of relationships between CDRN and other initiatives.](chart.png)

- Dementia Collaborative Research Centres (DCRCs): 24 do not understand, 1 does understand.
- Partnership Centre - Cognitive and Related Functional Decline in Older People: 22 do not understand, 2 does understand.
- Knowledge translation projects of the NQDCI: 20 do not understand, 3 does understand.
- National Quality Dementia Care Initiative (NQDCI) overall: 20 do not understand, 3 does understand.
- Alzheimer’s Australia national, state and territory activities: 20 do not understand, 3 does understand.
- Alzheimer’s Australia Dementia Research Foundation: 20 do not understand, 3 does understand.
Comparative Survey Analysis
There were no clear trends over time in understanding of relationships with other initiatives (Figure 7). The only exception is the relationship with the Service Provider Network of the NQDCI, which was poorly understood in the 2011 Survey. The Service Provider Network was disbanded in 2011.

Figure 7 Understanding of the relationship between the CDRN and other initiatives (core group of respondents - 3 surveys)
Skills and resources

The results presented in this section cover the skills/capacities and resources/support that CDRN members require to participate effectively.

Survey 2013

As reported in Survey 2013 the most important skill or capacity that enables members to participate effectively in the CDRN is considered to be ‘Experience/empathy with dementia’. The second and third in rank of importance are reported to be ‘Commitment’ and ‘Open-mindedness’. ‘Research background’ and ‘Information technology skills’ are considered of lesser importance for members of the CDRN (Figure 8).

Several respondents provided further comments in relation to the capacities required for a member of the CDRN to participate effectively, including the need for more people with dementia to participate, and the need for clear communication in plain English. ‘Experience/empathy with dementia’, ranked by respondents as most important, was expanded on by one respondent, who commented that knowledge and understanding of dementia beyond one’s own personal experience was important to be genuinely effective. The importance of the diversity of skills possessed by CDRN members was also recognised in one comment:

... People bring different skills to the Network and that is a large positive for the group to function as a whole i.e. I think that apart from Experience/empathy with dementia, we want a group that has a wide range of skills and that is exactly what we do have.
Comparative Survey Analysis
The average rank selected by members for each of the six capacities has been calculated to summarise its importance relative to the other capacities. This allows for a more simple comparison over time (as a single number summarises the importance of each capacity in each of the surveys). Members of the CDRN were very consistent across the years in their assessment of the skills and capacities that are required to participate in the network activities. The mean ranks for the five capacities under assessment show no change in time and were prioritised in the same order as in Survey 2013 (Figure 9).

**Figure 9** Ranked importance of capacities (core group of respondents - 3 surveys)

Survey 2013
CDRN members were asked which resources and/or supports are required to participate effectively. After analysis of mean ranks for each response, ‘Provision of relevant information’ is reported as the most important support for the members of CDRN in Survey 2013. ‘Support from Alzheimer’s Australia’ and ‘Available time’ were also important. 'Expert advice’ and ‘Reimbursement of expenses’ were the least important (Figure 10).
Among the few comments made by respondents in relation to resources and supports, the support provided by the two key staff members involved in the day to day management of the CDRN (the National Policy Manager, the original Manager of the CDRN, Dr Ellen Skladzien and the National Research Manager, Dr Chris Hatherly) was specifically commended. Active provision of relevant and current reading material was also noted as useful, as was being kept informed of the activities and priorities of Alzheimer’s Australia. This information assists members to understand the context within which the CDRN operates and how the Network contributes to the broader functions and operations of Alzheimer’s Australia.

**Comparative Survey Analysis**
CDRN members consistently ranked ‘Provision of relevant information’, ‘Support from Alzheimer’s Australia’ and ‘Available time’ as the most important resource or support to enable participation (Figure 11).
Achievements and impact

Below is the summary of perceived achievements of the CDRN and the perceptions of members of the impact of the Network.

Survey 2013
When asked what in their opinion were the most significant achievements of the CDRN, respondents listed a range of accomplishments. Achievements recognised by the most respondents related to the CDRN’s active involvement in the knowledge translation projects (from selection to ongoing contribution) and work with the Partnership Centre for Cognitive and Related Functional Decline in Older People.

Another achievement identified by many respondents included increasing the recognition of the value of consumer input into dementia research. Influencing knowledge translation projects based on the needs of people with dementia and their carers was also seen by several respondents as a significant achievement, as was the CDRN’s contribution of a consumer perspective of the lived experience of dementia to various Australian Government Inquiries, such as the Strategic Review of Health and Medical Research in Australia (the McKeon Review).

There were four aims of the CDRN that were assessed in the 2013 Survey. The respondents were mostly in agreement that these aims are being achieved (Figure 12). The respondents were most certain that the CDRN is empowering consumers to contribute to dementia research.
Comparative Survey Analysis
The results of the 2013 Survey were representative of all preceding surveys (Figure 13). CDRN members have consistently rated the achievement of their aims with a view that they are making most impact in empowering consumers to contribute to dementia research with least impact in improving the care of people with dementia.
Enablers

Survey 2013
When asked to list three things that have assisted the CDRN to function effectively, a range of responses were provided from which several clear themes emerged. The key enablers identified were as follows:

- Alzheimer’s Australia staff (including their dedication, enthusiasm, support, leadership and management);
- CDRN members themselves (including their passion, commitment, and mutual support);
- financial support (not only from Alzheimer’s Australia, but also funding from the JO and JR Wicking Trust, Bupa Care Services Australia and the DCRCs);
- face to face meetings; and
- open and ongoing communication.

Two clear themes were apparent from respondents’ perceptions of positive aspects of being a member of the CDRN. Firstly, being part of a group of great people was highly valued by members, with respondents describing their peers positively with adjectives such as intelligent, skilled, motivated, dynamic and supportive. The fact that the group shares goals (such as improving the patient journey through community education and improved training for health professionals) and also has a lived experience of dementia was clearly important. It is apparent that genuine friendships have developed between some members. In addition, contributing to a worthwhile cause with long term benefits for people with dementia and their carers was commonly perceived as a positive aspect of being a CDRN member. Other positive aspects identified by respondents included increased personal knowledge (for example, learning new skills and understanding the state of Alzheimer’s research and advocacy) and working with researchers and developing mutually respectful relationships with them.

Barriers

Survey 2013
Respondents identified a variety of things that have made it hard for the CDRN to function effectively. These barriers included:

- geographic separation of members;
- limited opportunities for members to meet, as well as the length of time between meetings;
- Alzheimer’s Australia staff turnover;
- CDRN membership turnover;
- lack of available time of members;
- inability to predict upcoming workload;
- limited funding; and
- issues related to communication (for example, a lack of regular teleconferences or correspondence, or on the other hand, lengthy correspondence containing difficult jargon).
Another barrier identified by several respondents related to group dynamics and the delicate balance required in such a network to have all members participate and valued equally, as illustrated by the following quotes:

- *When we do not value and respect the different points of views and experiences within the CDRN.*
- *Imbalance of carers leading to an overpowering of the voices of people with dementia.*
- *Network dominated by professionals rather than consumers....*

Relatively few respondents identified negative aspects about being a member of the CDRN, with the responses provided varying greatly. Negative aspects included:

- limitations to members’ level of involvement due to other responsibilities;
- feeling isolated or disconnected from the group; and
- feeling incapable of contributing fully (for instance due to limited skills or a lack of an academic, research or professional background).

The sensitive dynamic between people with dementia and carers was again raised, with one respondent feeling that carers dominate discussions (and consequently priorities) over people with dementia, and another feeling that carers are not as valued as people with dementia.

Difficulties directly related to dementia were also identified. For instance, difficulties participating due to suffering from dementia were acknowledged by one respondent, as were emotional difficulties (for example “opening wounds”).
Key aspects of network operation

Survey 2013

A range of 14 aspects of CDRN network operation were evaluated in Survey 2013 (Figure 14). The respondents were mostly in agreement and positive about CDRN activity, i.e. most assessments were ‘Strongly agree’ or ‘Agree’. There were only 10 ‘Disagree’ or ‘Strongly disagree’ opinions expressed of a total of 301. The statement about network operation that was most supported was “My investment (of time and effort) in the CDRN has been worth it”, and the least supported statement was “All members contribute to the work of the CDRN”.

Figure 14  CDRN members level of agreement with key aspects of network operation (Survey 2013)
Comparative Survey Analysis

There were no noticeable trends over the years in the opinions of CDRN members about aspects of network operation (Figure 15). Agreement was consistently high and positive. The same statements were ranked first and last in all three surveys.

Figure 15  CDRN members level of agreement with key aspects of network operation (core group of respondents - 3 surveys)

Future directions

Survey 2013

The ‘single biggest issue’ facing the CDRN in the future most commonly identified by respondents related to funding. The sustainability of funding is clearly a concern for members, and this is in terms of financing both the CDRN and more knowledge translation projects. Other issues facing the CDRN were the quality of future research proposals and submissions, the level of interest and importance given to dementia by researchers as well Government, and the lack
of availability of the CDRN for other activities considering the significant commitment to the Partnership Centre.

A range of views were provided by respondents in terms of what the priorities for the CDRN into the future should be. The majority of responses related to the following:

- continuing to develop the relationship with the Partnership Centre;
- continuing to work with researchers to provide consumer input into research;
- continuing to implement more quality research and projects;
- improving diagnosis and care for people with dementia and support for carers; and
- knowledge translation.

More specific priorities for the CDRN were also suggested by some respondents. For instance, respondents advocated for: increasing the focus on diverse groups such as Younger Onset Dementia and people from culturally and linguistically diverse (CALD) backgrounds; linking more with other organisations (e.g. Research Australia, DCRCs, State and Territory Alzheimer’s Associations); being more proactive in identifying research areas rather than only responding to proposals; actioning the CDRN 2012-13 work plan, and; ensuring education and support for members in dementia, dementia research and knowledge translation.

Additional reflections

Survey 2013

When given the opportunity to provide any final comments, the majority of respondents gave a short positive statement about the CDRN, including the importance of continuation. Acknowledgement of Alzheimer’s Australia staff and CEO, DCRC leads, the CDRN chairperson, the JO and JR Wicking Trust and Bupa Care Services Australia were also made.

A number of specific comments were also made. These included a suggestion of reducing the membership to twelve individuals, with at least one-third being people with dementia. Another suggestion related to Alzheimer’s Australia working with the Royal Flying Doctor Service to assist with dementia coaching in rural, remote and indigenous communities. Finally, improved structure for the way information is disseminated was requested (for instance, a monthly work in progress report using the headings Action by / Project / Type of action required / Action due date / Next stage and timing).

Conclusion

The 2013 Survey results suggest that members of the CDRN continue to be positively engaged with the Network.

Within the 2013 Survey Questions 10 (impact of the CDRN) and 15 (personal experience of the CDRN) were examined for correlations using Kendall’s tau coefficient. There were two associations identified in this data. The strongest association ($\tau = 0.70, p<.001$) was between the statement in Q 15: “I have been provided with adequate resources (e.g. financial reimbursement, information) to participate in the CDRN” and the statement “I have been provided with adequate resources (e.g. financial reimbursement, information) to participate in the CDRN.”

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33 Kendall rank correlation coefficient, commonly referred to as Kendall’s tau (τ) coefficient.
provided with adequate support (e.g. guidance from Alzheimer's Australia) to participate in the CDRN”. (This was also the strongest correlation in the 2012 survey results).

There was also an association ($\tau = 0.56, p<.01$) between the statement from Q 10 “The CDRN is empowering consumers to contribute to dementia research” and Q 15 “The direction of the CDRN is determined by members”.

**Comparative Survey Analysis**

There was no statistically significant change in the responses for any question across the three time periods. Analysis of qualitative data across time periods also identified no significant changes in members’ perceptions to the majority of questions.

A significant majority of members believe that the Network has made considerable progress over the past three years which is evidenced by the achievements of the CDRN and greater leadership of the Network by members.

While responses from each survey are overwhelmingly positive in the main, the fact that no change was evident in responses to questions related to things that have made it hard for the CDRN to function effectively, the negative aspects about being a member of the CDRN, and the biggest issues facing the CDRN, may indicate that efforts to address these areas have been inadequate or unsuccessful.
### 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).

This survey is being undertaken for Alzheimer’s Australia by the Centre for Health Service Development at the University of Wollongong, as part of the evaluation of the National Quality Dementia Care Initiative (NQDCI) and the 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.

Longer term CDRN members may have previously participated in this survey in 2011 or 2012, however it is still important to complete the survey this final time as well so we can find out if your views have changed over time. Newer CDRN members may be providing their feedback via survey for the first time. All responses will assist Alzheimer’s Australia with their future planning.

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 NQDCI, and the final evaluation report on the CDRN.

If you would like further information, or have any questions about this survey, please contact Anita Westera from the national evaluation team, on (02) 4221 3140 or email westera@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. How long have you been a member of the CDRN?**

- [ ] Less than 1 year
- [ ] 1 to 2 years
- [ ] More than 2 years
3. How did you come to be a member of the CDRN?

(Response only required from members who have joined the CDRN in the last 12 months)

4. 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.

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

- Setting priorities for NODCI knowledge translation projects
- Assessing and monitoring knowledge translation projects
- Assisting with communicating findings of knowledge translation and / or research projects to the community
- 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 Dementia Research Foundation
- Liaison with the Partnership Centre for Cognitive and Related Functional Decline in Older People

Please provide comments on other ways you have participated as a member of the CDRN.
## Consumer Dementia Research Network Final Survey for Alzheimer’s

### 6. Do you understand the relationship between the CDRN and the:

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia Collaborative Research Centres (DCRCs)</td>
<td></td>
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<tr>
<td>Knowledge translation projects of the NQDCCI</td>
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<tr>
<td>National Quality Dementia Care Initiative (NQDCCI) overall</td>
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<tr>
<td>Alzheimer’s Australia national, state and territory activities</td>
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<tr>
<td>Alzheimer’s Australia Dementia Research Foundation</td>
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<tr>
<td>Partnership Centre for Cognitive and Related Functional Decline in Older People</td>
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</tbody>
</table>

## Skills and Resources

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

### 7. 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.**

<table>
<thead>
<tr>
<th>1. Most important</th>
<th>Experience / empathy with dementia</th>
<th>Commitment</th>
<th>Open-mindedness</th>
<th>Research background</th>
<th>Information technology (IT) skills</th>
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</thead>
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<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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<td>5. Least important</td>
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</tbody>
</table>

Any other comments?

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**Page 3**
Consumer Dementia Research Network Final Survey for Alzheimer’s

8. 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.

<table>
<thead>
<tr>
<th>Reimbursement of expenses</th>
<th>Expert advice</th>
<th>Provision of relevant information</th>
<th>Available time</th>
<th>Support from Alzheimer’s Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Most important</td>
<td></td>
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<td></td>
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<tr>
<td>2.</td>
<td></td>
<td></td>
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<tr>
<td>3.</td>
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<tr>
<td>4.</td>
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<tr>
<td>5. Least important</td>
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</tbody>
</table>

Any other comments?

Achievements and impact

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

9. In your opinion, what are the most significant achievements of the CDRN?
10. Please indicate your level of agreement with the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Mixed feelings/neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The CDRN is empowering consumers to contribute to dementia research</td>
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<td>The CDRN is improving the translation of knowledge into practice</td>
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<td>The CDRN is improving the care of people with dementia</td>
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<tr>
<td>The CDRN is improving the engagement of consumers with the work of Alzheimer's Australia</td>
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</table>

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

1. 
2. 
3. 

12. 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.

13. From your perspective, what are positive aspects about being a member of the CDRN?
Consumer Dementia Research Network Final Survey for Alzheimer’s

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

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

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

The next questions give you a chance to comment on the future of the CDRN, and provide any other final thoughts.
16. What do you feel is the single biggest issue facing the CDRN in the future?

17. In your view, what should be the priorities for the CDRN into the future?

18. Do you have any other comments?

Thank you

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

The results of this survey and previous surveys will be included in the CDRN Final Evaluation Report.

If you have any questions or concerns please contact Anita Westera on (02) 4221 3145 or email westera@uow.edu.au.