

Evaluation of the Alzheimer's Australia National Quality Dementia Care Initiative (NQDCI)

Final Report

December 2014

Anita Westera

Cristina Thompson

Darcy Morris

Acknowledgements

The authors acknowledge that the evaluation would not have been possible without the contributions and cooperation of a number of groups. In particular we would like to thank the project managers and team members involved in the evaluation of the National Quality Dementia Care Initiative, as well as all members of the Alzheimer's Australia Consumer Dementia Research Network.

The support from key staff from Alzheimer's Australia is also gratefully acknowledged.

Finally, the authors acknowledge the contribution made by colleagues from the Australian Health Services Research Institute during the course of the evaluation. In particular we would like to thank Professor Kathy Eagar.

Suggested citation

Westera, A, Thompson C and Morris D (2014) *Evaluation of the Alzheimer's Australia National Quality Dementia Care Initiative (NQDCI): Final Report*. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

Table of Contents

Key messages	iv
Executive summary	v
1 Introduction	1
2 Evaluation overview	2
2.1 Evaluation Framework.....	2
2.2 Methods and data sources	3
2.3 Ethics and confidentiality	6
3 National Quality Dementia Care (NQDC) projects	7
3.1 Introduction.....	7
3.2 Background.....	7
3.3 Results	14
4 CDRN update	34
4.1 Introduction.....	34
4.2 Background on the CDRN Final Evaluation Report.....	34
4.3 Methods	35
4.4 Findings.....	35
4.5 CDRN Final Evaluation Report recommendations.....	37
4.6 CDRN developments.....	38
4.7 Future directions	40
5 Discussion.....	41
5.1 NQDC knowledge translation projects	41
5.2 Consumer involvement in research	47
6 Conclusion	50

List of Tables

Table 1	Timeline of NQDC project selection and implementation	7
Table 2	National Quality Dementia Care (NQDC) projects.....	10
Table 3	NQDC project outputs.....	11
Table 4	Consumer involvement in projects.....	14
Table 5	Priorities addressed by projects	15
Table 6	Nature and context of evidence	16
Table 7	Settings and audiences targeted by NQDC projects.....	19
Table 8	Professional behaviour change strategies used	21
Table 9	Competencies for Dementia Knowledge Translation	44
Table 10	Chronic care and public health evaluation frameworks.....	57
Table 11	Quality Evaluation strategies and frameworks.....	57

List of Figures

Figure 1	Centre for Health Service Development evaluation framework.....	2
Figure 2	Hub and spoke network model for project consortiums	8

Appendices

Appendix 1	Projects Funded.....	52
Appendix 2	Consumer Dementia Research Network Terms of Reference	53
Appendix 3	Service Provider Network Overview	55
Appendix 4	NQDCI Governance Model	56
Appendix 5	Frameworks Informing NQDC Project Evaluation.....	57
Appendix 6	Key Success Factors and Principles of Practice Change	59
Appendix 7	Recent International Developments – Dementia Knowledge Translation	61

Abbreviations

AADRF	Alzheimer’s Australia Dementia Research Foundation
CDKTN	Canadian Dementia Knowledge Translation Network
CDRN	Consumer Dementia Research Network
DCRC	Dementia Collaborative Research Centres
DoHA / DSS	Commonwealth Department of Health and Ageing (now Department of Social Services)
EBPRAC	Encouraging Best Practice in Residential Aged Care
GP	General Practitioner
KSF	Key Success Factors
KT	Knowledge Translation
NHMRC	National Health and Medical Research Council
NQDC	National Quality Dementia Care
NQDCI	National Quality Dementia Care Initiative
NQDCN	National Quality Dementia Care Network
PARIHS	Promoting Action on Research Implementation in Health Services

Key messages

Alzheimer’s Australia’s National Quality Dementia Care Initiative (NQDCI) has been an ambitious program to improve the quality of care for people with dementia in Australia. It has taken a leadership role in demonstrating the application of international developments in consumer involvement in dementia research and knowledge translation.

The Consumer Dementia Research Network (CDRN) established under the NQDCI has worked alongside researchers and service providers to identify priorities and improve processes for collaboration and involvement of consumers in research and research translation. The eight National Quality Dementia Care knowledge translation projects that have been completed addressed longstanding issues of concern for both people with dementia and carers, dementia care providers and certain areas of the health and aged care sectors more generally.

The funded projects built on existing evidence about quality care and practices by applying the evidence based recommendations or implications for practice in a range of settings including aged care, general practice, design and legal contexts. The success of the projects demonstrated that implementation obstacles can be addressed, including overcoming inter-jurisdictional boundaries and inter-sectoral barriers, and engaging diverse professional groups in collaborative quality improvement initiatives.

The NQDCI predominantly generated indirect gains for consumers, tangible and useful benefits for service providers and demonstrated to the broader aged care sector that consumers have the capacity to drive effective knowledge translation in collaboration with researchers and care providers.

These achievements were made possible through \$3.3 million funding from the J.O. and J.R. Wicking Trust, Bupa Care Services Australia, and with support from the Dementia Collaborative Research Centres (DCRCs). They build on the knowledge and commitment of CDRN members, partnerships with Alzheimer’s Australia State and Territory organisations, researchers and service providers, all of whom are committed to improving care for people with dementia and carers. The investment has represented value for money in terms of benefits for service providers and the broader sector.

The NQDCI has enhanced Alzheimer’s Australia’s credibility as an organisation that is committed to consumer empowerment, and to real and sustained changes in policy and practice that improve the quality of dementia care in Australia. In doing so, it has added weight and credibility to Alzheimer’s Australia’s significant and successful advocacy to government on these issues.

This final evaluation report discusses in detail the outcomes and learnings from the NQDCI, as well as identifying a number of key challenges for Alzheimer’s Australia to ensure the achievements are built on and sustained into the future.

Executive summary

Background

The Alzheimer's Australia National Quality Dementia Care Initiative (NQDCI) commenced in 2010 with \$3.3 million funding from the J.O. and J.R. Wicking Trust, Bupa Care Services Australia, and with support from the Dementia Collaborative Research Centres (DCRCs), as part of the Australian Government's Dementia Initiative. The objectives of the NQDCI have been to achieve changes in policy and practice that improve the quality of dementia care in Australia and to facilitate consumer involvement in dementia research and dementia research knowledge translation.

These objectives have been pursued through two core and interrelated elements: the National Quality Dementia Care (NQDC) knowledge translation projects, and the Consumer Dementia Research Network (CDRN). In total, eight knowledge translation projects were funded that met clear eligibility criteria and addressed consumer priority areas. All eight projects were effectively implemented, resulting in a broad range of outcomes including new models of care, service improvement initiatives and system improvements. The CDRN was established in response to international developments in the consumer participation environment which demonstrated the potential benefits which could arise from direct consumer involvement in research. It remains 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, as well as promoting consumer involvement in research more generally.

Purpose of the report

This report builds on previous evaluation interim reports which were, in the main, formative in nature, discussing progress, developments and issues arising within the main elements of the NQDCI. The most recent report delivered in September 2013 provided an overarching review of the CDRN and posited options for its future within the context of the latest developments in consumer involvement in dementia research and service delivery.

This report provides a summative evaluation of the NQDCI, focusing predominantly on the activities and outcomes of the NQDC projects. It also provides a brief update on progress against recommendations made within the CDRN Final Evaluation Report, and related activities.

Methods

Evaluation of the NQDCI was based on an evaluation framework developed by the Centre for Health Service Development. The framework recognises that programs aim to make an impact at three levels – consumers, providers and the system – and is based on six domains: project delivery, project impact, sustainability, capacity building, generalisability and dissemination. The evaluation employed a mixed methods approach and utilised a range of data sources including documentation review (e.g. project proposals, project selection processes, progress and final reports), project site visits, observations from other meetings and forums, and semi-structured interviews and surveys of CDRN members and other key stakeholders (including DCRC leads, Alzheimer's Australia State and Territory Associations, Service Provider Network (SPN) members, and Department of Social Services representatives).

Findings

The NQDCI has had a range of impacts and outcomes at the three levels of the evaluation framework – consumers, providers and the system.

Impacts and outcomes for consumers

The NQDCI has generated predominantly indirect gains for consumers. Each NQDC project actively involved consumers in the development and implementation of their core activities and a number of operational aspects. CDRN members were engaged in governance and advisory roles and provided important insights into the real-life context in which care of people with dementia is delivered. CDRN involvement was streamlined through the establishment of sub-committees; allowing greater oversight of the initiative as a whole, and facilitating networking and linkages between projects where feasible. The experience of CDRN members in relation to the NQDC projects was, on the whole, positive. Nonetheless, involvement was not without challenge for many members.

Underpinning the NQDCI was the objective of improving care for people with dementia and their carers, through translating evidence into practice (either by enhancing the existing evidence within the sector and extending its reach, or by taking evidence of an effective intervention in an unrelated sector and translating and / or trialling that evidence within a dementia care context). The two projects that collected consumer level data both recorded positive outcomes for the participants. The focus of the remaining six projects was predominantly on improving the capacity of those directly involved in supporting people with dementia through developing strategies and resources to enable them to deliver evidence-based interventions. However, the extent to which these interventions generated direct outcomes for consumers was out of scope of this evaluation. Each project team produced a final report that described the results of their local evaluation and compared their project objectives and corresponding results. Consequently, the program evaluation has focused on the effectiveness of the projects as knowledge translation strategies and how they have influenced consumer driven research and service provider engagement.

Impacts and outcomes for service providers

The NQDCI has generated tangible and useful benefits for service providers that have the potential to help them to improve the quality of support delivered to people with dementia and their carers. Projects sought to improve care for people with dementia and their carers by improving service providers' skills, access to resources and the application of evidence to everyday practice. The projects sought to influence care practices across a range of settings including primary health, acute care, sub-acute care (palliative) and aged care (community and residential). They also aimed to influence services and professional groups involved in design, landscape, architecture and provision of legal services to support people living with dementia.

The majority of projects worked with diverse stakeholder groups who had the capacity to improve care and support of people with dementia. The project leads were clearly cognisant of the multiple and complex factors that impact on and influence outcomes for people with dementia and their carers; this was also reflected in the governance and / or consortium arrangements and consultation processes of each project. Most project leads had a strong understanding of knowledge translation processes, the sectors and settings they were working with, the nature of change required and factors that were likely to impact on project delivery;

each employed a range of change management strategies to address their particular target audiences and contexts.

All project leads demonstrated significant expertise in the evidence that was being translated, but often had less experience of the context in which the evidence was to be applied. The consortium arrangements specified as part of the project design requirements were critical in addressing potential knowledge gaps as this approach engaged relevant stakeholders and ensured appropriate governance and / or advisory mechanisms. For example, members included representatives of academic institutions, clinical experts, professional groups, and aged care providers. Every project included consumers, relevant Alzheimer's Australia State and Territory representatives and the Alzheimer's Australia National Research Manager within their project governance arrangements. Broad stakeholder engagement and consultation processes addressed contextual factors.

Four projects sought to directly impact practice through the development of resources and provision of education and training to care providers. In their final reports they identified measureable changes in practice arising from their interventions. The remaining projects developed resources and processes that were designed to improve practice, however were not in a position to evaluate the extent to which these resources were applied in practice. Each project endeavoured to address the project guidelines' requirement for sustainability and national application.

Impacts and outcomes for the system

The NQDCI has demonstrated to the broader aged care sector that consumers have the capacity to drive effective knowledge translation in collaboration with researchers and care providers.

The key outcome resulting from the NQDCI at the system level related to collaboration. The strategies employed resulted in the development and strengthening of linkages between different sectors and professional groups involved in supporting people with dementia. The knowledge translation projects provided a practical mechanism for local State and Territory Alzheimer's Australia organisations to work with the CDRN and the Alzheimer's Australia National Office. One project also successfully influenced national design standards as a first step to achieving widespread improvements in dementia enabling design.

The stakeholder engagement strategies enhanced and extended existing networks to ensure project processes and outcomes were appropriately targeted and sustained. In addition, they facilitated linkages between disparate groups around a common agenda that is likely to continue into the future. Through these initiatives, Alzheimer's Australia member organisations have benefited in a range of ways, including access to resources, enhanced revenue streams, extension of networks and enhanced public profiles. Despite these benefits, the extent to which they have resulted in improved relationships between the Alzheimer's Australia National Office and State and Territory organisations remains unclear.

CDRN developments

The key findings relating to the CDRN and its impact on consumers, providers and the system were reported in the CDRN Final Evaluation Report. Developments since the Final Evaluation Report in September 2013 include:

- Enhanced processes and protocols for CDRN membership, meetings, and communication through the Alzheimer’s Australia secretariat and CDRN subgroups;
- A successful strategic planning workshop in August, 2014 that established strategic objectives and priorities for the CDRN for future work;
- An increased level of engagement of CDRN members in the \$25 million NHMRC Partnership Centre on Cognitive and Related Functional Decline in Older People;
- Inclusion of two CDRN on the Alzheimer’s Australia Dementia Research Foundation (AADRF) Scientific Panel to provide a consumer perspective in research grant assessment and decision making process;
- Development of priorities by CDRN members for a third round of NQDC projects in mid-2014, followed by assessment of applications and decisions to fund or establish a further seven dementia knowledge translation projects in 2015;
- Increased liaison with the National Health and Medical Research Council (NHMRC) on consumer involvement in research, and the good prospects of a significant consumer involvement in the forthcoming National Institute for Dementia Research which will play a coordinating role for dementia research in Australia.

Conclusion

The development and implementation of the NQDCI has represented a significant investment for Alzheimer’s Australia. The most successful components of the initiative have been the knowledge translation projects and the establishment and sustained operation of the CDRN. The NQDCI has predominantly generated indirect gains for consumers, tangible and useful benefits for service providers and has demonstrated to the broader aged care sector that consumers have the capacity to drive effective knowledge translation in collaboration with researchers and care providers.

Alzheimer’s Australia National Office in collaboration with the CDRN and selected Alzheimer’s Australia State and Territory organisations has been able to effectively select, monitor and support a range of national projects, implemented in diverse settings. The Alzheimer’s Australia National Office support of the CDRN priorities ensured that consumers were at the heart of, and drove, decision making processes regarding research and project funding which affect them. The eight projects addressed longstanding issues of concern for both persons with dementia and carers, service providers and the aged care sector. They demonstrated that implementation obstacles can be addressed, including overcoming inter-jurisdictional boundaries and inter-sectoral barriers and engaging diverse professional groups. Project teams have delivered on the majority of project objectives and the investment has represented value for money in terms of benefits for service providers and the broader sector.

Developments are occurring internationally in consumer involvement in dementia research and knowledge translation. Alzheimer’s Australia has taken a leadership role in demonstrating the application of these concepts and approaches to improving dementia care. The NQDCI has enhanced Alzheimer’s Australia’s credibility as an organisation that is committed to real and sustained changes in policy and practice that improve the quality of dementia care in Australia. It has also demonstrated that Alzheimer’s Australia has a strong commitment to consumer involvement in dementia research and knowledge translation.

The challenge for the Alzheimer’s Australia National Office is to capitalise on the gains achieved to date through the NQDCI by ensuring that the organisation continues to:

- sustain the relationships developed through the initiative;
- embed the national focus and consortium approach to the development and implementation of knowledge translation projects;
- engage researchers, service providers and policy-makers in the work of the organisation;
- consolidate a framework for consumer involvement in dementia research and maintain the primacy of consumers in the knowledge translation process;
- balance the perspectives of people with dementia and carers in priority setting for future knowledge translation projects; and
- collaborate with State and Territory Alzheimer’s Australia organisations to build on the successes of the NQDCI.

1 Introduction

This is the final evaluation report of the Alzheimer's Australia National Quality Dementia Care Initiative (NQDCI). The NQDCI commenced in 2010 with \$3.3 million funding from the J.O. and J.R. Wicking Trust, Bupa Care Services Australia, and with support from the Dementia Collaborative Research Centres (DCRCs), as part of the Australian Government's Dementia Initiative.

The objectives of the NQDCI have been to:

- Achieve changes in policy and practice that improve the quality of dementia care in Australia; and
- Facilitate consumer involvement in dementia research and dementia research knowledge translation.

These objectives have been pursued through two core and interrelated elements:

- National Quality Dementia Care (NQDC) Knowledge Translation (KT) projects and the;
- Consumer Dementia Research Network (CDRN).

A third element, the Service Provider Network (SPN), was also established at the outset, however was subsequently subsumed within individual NQDC project governance arrangements and related activities.

The NQDCI was overseen by an Advisory Committee comprised of key stakeholders in the consumer, service delivery, policy and research sectors. As with the SPN, Advisory Committee members were also involved in individual NQDC project governance arrangements and other related activities, and consequently their collective oversight over time came to be more on an ad hoc basis as issues arose.

This report builds on the previous evaluation reports which have, in the main, been formative in nature, discussing progress, developments and issues arising within the main elements of the NQDCI. The most recent report delivered in September 2013 provided an overarching review of the CDRN and posited options for its future within the context of the latest developments in consumer involvement in research and service delivery. Consequently, this final report will focus predominantly on the activities and outcomes of the NQDC projects and how this investment fits within the context of developments in the dementia research, policy and service delivery sectors and the field of knowledge translation. It will also provide a brief update on progress against recommendations made within the CDRN Final Evaluation Report, and related activities.

2 Evaluation overview

2.1 Evaluation Framework

The Evaluation Framework for the NQDCI was developed and refined over the period of almost twelve months, as the various elements of the Initiative became more established, and the shape and nature of the projects emerged. During that period the evaluation team worked closely with the Alzheimer’s Australia National Office team and the CDRN members to confirm strategies and priorities.

The Centre for Health Service Development Evaluation Framework, represented by a matrix with three levels of analysis on the vertical axis, was utilised to ensure that the impact and outcomes of the NQDCI were explored for consumers (including carers, their families and friends), providers and the broader aged care sector. Across the horizontal axis of the matrix are six key questions that a comprehensive evaluation should address – What did you do? (program delivery) , How did it go? (program impact), Can you keep it going? (sustainability), What has been learnt? (capacity building), Are your lessons useful for someone else? (generalizability) and Who did you tell? (dissemination).¹

Figure 1 Centre for Health Service Development evaluation framework

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

Through systematically exploring each of the six key questions posed, where possible at each level of the framework, the formative and summative requirements of the evaluation were addressed.

¹ Yeatman H, Quinsey K, Dawber J, Nielsen W, Condon-Paoloni D, Eckermann S, Morris D, Grootemaat P and Fildes D (2014) Combining Realism with Rigour: Evaluation of a National Kitchen Garden Program in Australian Primary Schools. Evaluation Journal of Australasia, 14 (2): 17-24.

While the Centre for Health Service Development Evaluation Framework provided an overarching means to review and monitor impacts and outcomes of the NQDCI, tailored evaluation questions and processes were developed for each of the different sub-elements.

The iterative nature of the activities of the NQDCI led to refinements of the framework; for example, the CDRN prioritised knowledge gaps, project leads developed strategies based on their expertise in terms of content and knowledge translation, which in turn was subject to review and negotiation between the CDRN members and prospective project leads.

Innovative programs typically set in train a sequence of events that cannot be foreseen at the commencement, requiring a capacity to be flexible and adaptive in planning the evaluation (but no less systematic or rigorous because of this). This is consistent with many innovative measures, and therefore the evaluation approach utilised a number of methods to identify the 'lessons learned' through the NQDCI and to capture any opportunistic or unintended outcomes.

Successful change initiatives hardly ever follow a simple pattern of 'thinking' followed by 'doing'. Instead, thinking informs doing and doing informs thinking throughout the process, in an iterative way.²

2.2 Methods and data sources

The Evaluation Framework aimed to assess impact at all three levels including outcomes for consumers, providers and the system however, the majority of data was expected to be drawn from activities targeted at the provider and system levels. The program logic underpinning the knowledge translation projects predominantly concentrated on the development of new information and its delivery to a third party (e.g. nurse, carer, medical practitioner) for implementation. Improved outcomes for consumers are therefore predicated on the capacity of those imparting the new knowledge to employ strategies that have been proven to effect change in behaviour.

The program evaluation of the NQDCI has utilised a mixed methods approach and utilised data from a range of sources:

- A large component of the data collected has been from National Quality Dementia Care Network (NQDCN) documentation, including project proposals, project selection processes, progress and final reports, and site visits and observations conducted by members of the evaluation team.
- Semi-structured interviews and surveys of CDRN members and key stakeholders were conducted at different time points over the life of the evaluation. Stakeholders included DCRC leads, Alzheimer's Australia State and Territory Associations, SPN members, and Department of Social Services (formerly Department of Health and Ageing) representatives.

² Iles V and Sutherland K (2001) Organisational change: a review for health care managers, professionals and researchers (Managing change in the NHS). NCCSDO, London School of Hygiene & Tropical Medicine, London.

The majority of findings have been reported elsewhere in previous evaluation progress reports, in particular the CDRN Final Evaluation Report (September 2013); this report expands on those issues as they relate specifically to the outcomes of the NQDC projects and the NQDCI overall.

2.2.1 NQDC projects - evaluation methods

In constructing the evaluation for the NQDC projects, a variety of evaluation strategies and frameworks were reviewed, including quality improvement, diffusion/dissemination of innovations, organisational change to improve healthcare and implementation of evidence-based practice and use of clinical guidelines (see Appendix 5 for detailed listing).

Most of the work undertaken by a range of organisations attempting to translate research evidence into clinical practice has focused on disseminating and implementing clinical practice guidelines, protocols and care pathways, usually in hospitals. That work has demonstrated that implementation of best practice is far more complicated than simply presenting the evidence and expecting change to occur. Changing the behaviour of clinicians is possible but this usually requires comprehensive approaches at different levels tailored to specific settings and target groups. An added complexity within residential aged care is the differing skill and educational levels of staff involved in delivering care, ranging from tertiary-educated nurses to personal care assistants and volunteers. Planning to implement best practice needs to take into account the nature of the innovation; characteristics of the staff and residents involved; and the context within which changes are being made.

In recognition of the different target audiences and contexts in which the NQDC projects were seeking to exert influence, the limitations of these established processes were soon evident. Consequently, the Centre for Health Service Development evaluation team sought to draw on lessons learnt from similar national evaluations they had previously undertaken, in particular the Key Success Factors (KSFs) that support implementation of evidence based practice.³ The KSFs were derived from the health sector literature and applied to an evaluation of knowledge translation projects in aged care under the Encouraging Better Practice in Residential Aged Care (EBPRAC) Program. They were used to inform the framework for the NQDC projects, to direct data collection and analysis; explore the links between project delivery and project impact; and assist in identifying the barriers and incentives influencing the use of evidence in day-to-day practice. As the NQDC program unfolded, it also became evident that the KSFs, and the subsequent Principles of Practice Change which arose from the EBPRAC final evaluation, would not be as applicable as anticipated, given less than half of the NQDC projects directly engaged with staff working in the residential aged care sector (1.2 Relate, Motivate, Appreciate; 2.1 ICF-D; and, 2.4 Improving Staff-family relationships).⁴

Given the range of knowledge translation activities being undertaken within the NQDC, the Promoting Action on Research Implementation in Health Services (PARIHS) framework was re-visited as a potential mechanism to assess the projects.⁵ The PARIHS framework identifies three inter-related factors that influence successful implementation of evidence-based practices:

³ Masso M and McCarthy G (2009) Literature review to identify factors that support implementation of evidence-based practice in residential aged care. *International Journal of Evidence Based Healthcare*, 7: 145-56.

⁴ Refer to Appendix 6 for more information on the Key Success Factors and Principles of Practice Change

⁵ Rycroft-Malone J (2004) The PARIHS framework--a framework for guiding the implementation of evidence based practice. *Journal of Nursing Care Quality*, 19: 297-304.

strong scientific Evidence, a welcoming environment or Context and skilled and targeted Facilitation. i.e.

Evidence + Context + Facilitation = Successful Implementation

The NQDC projects each had varying objectives and / or evidence, contexts, target audiences and proposed change mechanisms. Even where there were alignments between some of the elements, the ability to compare between projects was hampered by the fact that there was rarely a single, or even dominant set of factors which explained why some people adopt new practices and deliver improved care, or why some systems for providing care do significantly better or worse than the average on particular measures. Successful implementation is not a linear process; rather it is the interaction of Evidence + Context + Facilitation that determines whether an intervention will be successfully implemented. This is because knowledge translation is:

‘a dynamic and iterative process (that) takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user.’⁶

The Canadian Dementia Knowledge Translation Network (CDKTN) has built on the PARIHS framework to enhance the implementation of research into practice. Established in 2012, CDKTN is the national network for knowledge translation (KT) and exchange of dementia research. It identifies seven core competencies for Dementia Knowledge Translation:

- Understanding stakeholder goals and cultures
- Identifying the target audience
- Fostering collaborations between knowledge users and producers
- Translating evidence into policy and practice
- Managing information and knowledge
- Appreciating the unique features of dementia KT
- Using KT to mitigate stigma and discrimination⁷

When considered together, it was agreed that the PARIHS and the CDKTN competencies provided a contemporary and targeted platform against which all projects could be assessed.

2.2.2 NQDC projects – data sources

The major source of data for the NQDC projects evaluation was the regular six monthly progress reports of each project; the report template was structured to address the key questions of the evaluation and opportunities to reflect on practice. Site visits were conducted and opportunistic meetings (conferences, workshops etc.) were also used to capture progress and identify any issues emerging. Stakeholder interviews were conducted over several time-points throughout the evaluation and CDRN perspectives were also canvassed on a regular basis. The Final Report template was developed to capture key outcomes and outputs of projects, as well as identify

⁶ Canadian Institutes of Health Research, More about Knowledge Translation at CIHR, <http://www.cihr-irsc.gc.ca/e/39033.html#Definition>

⁷Canadian Dementia Knowledge Translation Network (2012) A guide to knowledge Translation principles, frameworks, and practicalities. <http://lifeandminds.ca>

lessons learned. Projects were also asked to record dissemination activities, however the subsequent diversity of potential target audiences and proposed project outcomes did not lend itself to robust analysis and/or conclusions for the projects overall. Dissemination activities and outcomes are discussed only where data is reliable and relevant for the discussion throughout this report.

2.3 Ethics and confidentiality

This evaluation received approval from the University of Wollongong Human Research and Ethics Committee in December 2010, with approved amendments in October 2011. In accordance with the ethics approval, where individual views and / or observations are being reported, these are presented in a de-identifiable format apart from where specific attribution was agreed and considered appropriate.

3 National Quality Dementia Care (NQDC) projects

3.1 Introduction

The NQDC projects received funding of \$2.2m to support knowledge translation projects that addressed gaps between what is known from research about best-practice dementia care, and actual dementia care practice in specific priority areas. It was initially expected that 10-15 knowledge translation projects would be funded, with budgets of approximately \$100,000-\$250,000 each.⁸

3.2 Background

The establishment of priority areas for funding, the selection process and governance arrangements of the NQDC projects has been reported more fulsomely in previous evaluation progress reports. In summary, the process and timelines are displayed in Table 1.

Table 1 **Timeline of NQDC project selection and implementation**

Stage and Activity		Time-frame
	Priority areas identified by consumers in collaboration with research experts	September 2010
Round 1 NQDC projects		
	Development of application process and documentation	September – October 2010
	Project selection processes	Shortlisting expressions of interest: November 2010 Full proposals: February 2011 Final proposals selected: April 2011
	Formal launch of first two Round 1 projects	18 May 2011
	Third Round 1 project established	2 December 2011
	Round 1 projects completed	June – December 2013
Round 2 NQDC projects		
	Clarification of objectives and priorities by CDRN members	March – July 2011
	Project selection processes	December 2011 – February 2012
	Formal launch of Round 2 projects	1 June 2012
	Round 2 projects completed	December 2013 – March 2014

It was anticipated that project governance would take a consortium approach similar to that in Figure 2.

⁸ Alzheimer's Australia National Quality Dementia Care Initiative 'Call for Expressions of Interest'.

Figure 2 Hub and spoke network model for project consortiums



3.2.1 Priorities

Priorities for knowledge translation projects were determined by the CDRN, in consultation with selected stakeholders, at its inaugural summit in September 2010. CDRN members workshopped specific evidence-practice gaps in dementia care, i.e. where there was both a significant concern about the quality of current dementia care practice, and there was a rigorous base of research evidence regarding improvements that could be made through the application of knowledge translation initiatives.

The six priorities derived from this process were:

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

At the time of the priority setting process, the view of the evaluation team was that it was inclusive and used group processes that enabled all participants to contribute. In the first

evaluation progress report to Alzheimer’s Australia, the evaluation team noted that the input of researchers present at the inaugural meeting was positively received by the consumers, the refining of the nominated priorities was democratic and the final list of priorities was well supported.⁹ Subsequent to these observations, however, the evaluation team was informed that not everyone shared the view that the priorities reflected the views of all members; in particular, several members with dementia commented that the priorities appeared to be ‘carer-driven’, i.e. addressing the needs as carers saw them, as opposed to priorities people with dementia may have chosen. As one member commented, they were ‘totally aghast’ when they joined the CDRN sometime after the inaugural summit, and did not feel they were in a position to challenge the priorities selected. The dominance of carer concerns is not surprising, reflecting the fact that the inaugural summit comprised 22 carers and two people with dementia. In addition, it was suggested that many carers were ‘quite articulate’ and in some cases effectively ‘neutralised’ the voice of the person with dementia. Alzheimer’s Australia were acutely aware of the imbalance and took a number of steps to increase the numbers of people with dementia within the CDRN (as of August 2014, 7 of 22 members have dementia), as well as introducing processes to better facilitate their involvement and participation in CDRN activities.

It is clear that the perspectives of people with dementia can be different to those of carers on some issues, particularly people with younger onset dementia who are often at different life stages at onset compared to older people. Recent research conducted by the Centre for Health Service Development for the Department of Social Services clearly indicates the priorities and preferences of people with younger onset dementia require different policy and program responses than have traditionally been provided; there are clearly many emerging opportunities for knowledge translation for this group of people with dementia, which in turn may also result in positive outcomes for older people.¹⁰ That said, the evidence is also clear that the perspectives of carers are also important in determining need and, in turn, service models for people with dementia as well as themselves.¹¹ This is likely to be an ongoing issue for Alzheimer’s Australia, particularly in terms of determining the appropriate balance between the perspectives of the two groups in priority setting for future knowledge translation projects.

3.2.2 Selection processes

The NQDCN documentation established included clear eligibility criteria against which each proposal would be assessed. In addition to addressing one of the priority areas identified, proposals were required to demonstrate:

- the potential for project outcomes to be generalisable on a national scale;
- processes to ensure inclusion of consumers (people with dementia and their families) in all aspects of the project;
- an evaluation component that aligned to the national evaluation framework; and
- the involvement of an Alzheimer’s Australia State and / or Territory organisation.

⁹ Submitted February 2012.

¹⁰ Westera A, et al. (2014) Final Report: Younger Onset Dementia Literature Review and Needs and Feasibility Analysis. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong (<http://ahsri.uow.edu.au/chsd/projects/yod/index.html>).

¹¹ Bakker C (2013) Care needs in young-onset dementia and the relationship between unmet care needs and the course of neuropsychiatric symptoms: a two year follow up study (Chapter 4 of PhD Thesis). Younger Onset Dementia, Care Needs and Service Provision. Nijmegen, Netherlands.

The first round resulted in 44 expressions of interest. Twenty of these met the key eligibility criteria and were subjected to a rigorous, multi-staged review process including:

- Expert review panels to examine the proposals’ research basis, knowledge translation strategies and costs, and to identify potential areas of overlap with existing initiatives and/or more appropriate funding sources;
- Review of proposals by all CDRN members;
- Commentary generated by both expert and CDRN membership review of proposals resulted in eight applicants being asked to submit more fulsome proposals;
- Final review by the CDRN working group, resulted in two projects being recommended for funding:
 - The Dementia Enabling Environments Project (submitted through the Western Australia Alzheimer’s Association); and
 - Training family carers to undertake Montessori activities in residential aged care facilities to help manage the behavioural and psychological symptoms of dementia (Monash University).

Following the experience of the first funding round, the second round included more explicit documentation including detailed project expectations developed by the CDRN to assist applicants in assessing the applicability or otherwise of their proposals prior to submission. Following a similarly rigorous review process, five projects were selected for funding.

In the intervening period, Alzheimer’s Australia Victoria was commissioned to develop a proposal addressing the delivery of person centred care in community settings, building on work already undertaken in Victoria. The resulting eight knowledge translation projects are listed in Table 2. Refer to Appendix 1 for details of project leads and funding.

Table 2 National Quality Dementia Care (NQDC) projects

Project	
1.1	Dementia Enabling Environments Project (DEEP)
1.2	Relate, motivate, appreciate: Restoring meaningful engagement with people with dementia
1.3	Person-centred dementia support in the community (Valuing People)
2.1	Integrated care framework for advanced dementia
2.2	Advance Care Planning for people with dementia
2.3	Heart Foundation Walking – Active Body, Active Brain
2.4	Improving staff-family relationships
2.5	Timely diagnosis and management – GPs

3.2.3 Implementation

The NQDC projects established clear project and evaluation plans to guide their implementation. Each project included an advisory or steering committee mechanism, including representatives of the consortiums involved, consumers and relevant Alzheimer’s Australia National and State /

Territory organisations. The inclusion of a range of stakeholders in these governance arrangements ensured that projects appropriately incorporated the perspectives of the different groups likely to benefit from the project outcomes, and in turn assisted in better targeting of effort and outputs to meet the needs of those groups. Importantly, each project involved at least one CDRN representative in its governance arrangements, and a number also actively sought input from the broader membership in the development of resources and delivery of associated training activities.

The Alzheimer’s Australia National Research Manager was actively involved in each project from the outset. This included working with project leads and steering committees to clarify project outcomes, processes, deliverables and budgets and facilitating networking and linkages across individual projects within the broader Alzheimer’s Australia national network.

3.2.4 Project outputs

Each of the eight projects has now concluded (albeit with some ongoing activity in some cases) and resulted in a broad range of outputs through the provision of training resources, new models of care, service improvement initiatives and system improvements. Many of these are now in the public domain, and can be found at the web addresses listed in Table 3.

Table 3 NQDC project outputs

1.1 Dementia Enabling Environments Project (DEEP)	
Website	DEEP Virtual Centre & Information Sharing Network www.enablingenvironments.com.au
Social media	DEEP Facebook page, to raise awareness dementia design through social media.
Resource development	Development of resources including book and home audit check for family carers; Collation of resources into DEEP kit, for distribution through Alzheimer’s Australia State and Territory organisations.
Audit tool development	Clarification of existing best practice environmental audit tools in health and aged care. Development of Home Environment assessment tool, and Creating Therapeutic Gardens assessment tool.
Education and training	<i>Design for Dementia</i> workshop developed for staff working in aged care; Alzheimer’s Australia State and Territory organisations supported to deliver same on commercial basis.
Curriculum development	Engagement with Schools of Architecture at various universities, including encouragement to include dementia design within curriculum.
National Design Standards	Contribution to National Standards review relating to design and accessibility.
1.2 Relate, motivate, appreciate: Restoring meaningful engagement with people with dementia	
Web-based resource development	Website includes the following elements: - Application of Montessori principles - Preparation for visits - Watching, listening, touching, smelling, and tasting activity suggestions

	<p>including step-by-step instructions, pictures and videos.</p> <p>The resources are currently hosted on the Alzheimer’s Australia’s Quality Dementia Care webpage, with plans to migrate the resources on to the main Alzheimer’s Australia website in early 2015. http://qualitydementiacare.org.au/dementia-care-projects/relate-motivate-appreciate/</p>
1.3 Person-centred dementia support in the community (Valuing People)	
Web-based resource development	http://www.valuingpeople.org.au/
Audit tool development	Organisational Self-Assessment Tool for five groups: consumers, carers, staff (direct care worker), staff (non-direct care worker) and leaders.
Resource development	Change management information, including theories and practice.
2.1 Integrated care framework for advanced dementia (ICF-D)	
Website	<p>Website established to host resources developed to implement integrated care framework for advanced dementia (ICF-D).</p> <p><i>Note: Website IP owned by HammondCare; not accessible to general public.</i></p>
Assessment tool development	Online assessment tool developed to support delivery of ICF-D allows a care worker to assess a person with dementia in residential care.
Resource development	Care planning and conversation guide.
Audit tool	Reporting and audit tool built into website to facilitate ongoing monitoring and quality improvement.
Education and training	<p>Education modules (PowerPoint slides, facilitator’s guides, participant’s guides and background reading) for eleven topics;</p> <p>Twelve video podcasts (filmed interviews of expert clinicians and family carers).</p>
Access to information	<p>Enhancements to Caresearch website www.caresearch.com.au including:</p> <ul style="list-style-type: none"> - development of dementia specific filter to allow health professionals to access up to date literature and best practice guidelines - development of residents and families page with resources to support palliative care of people with dementia in residential care.
2.2 Advance Care Planning for people with dementia (Start2Talk)	
Website	https://www.start2talk.org.au/
Social media	<p>Facebook page</p> <p>YouTube video http://www.youtube.com/watch?v=9k-JErN2HSQ</p>
Promotional material	<p>Designed to promote awareness of the Start2Talk webpage</p> <ul style="list-style-type: none"> - Introductory brochure - Emergency Contact wallet card

	<ul style="list-style-type: none"> - Posters - Print media advertisements - 30 second radio ads for paid and community service announcements - Animated video for the homepage that can be used in other social media - Pull-up banners for presentations - Online banner ad for use on websites - Television Community Service Announcements throughout Australia (November 2014).
2.3 Heart Foundation Walking – Active Body, Active Brain (HFW ABAB)	
Education and training material	<p>Online module developed for HFW Local Coordinators and Walk organisers on including people with dementia in walking activities.</p> <p>Expected to be available through the Heart Foundation website: http://www.heartfoundation.org.au/active-living/walking/Pages/welcome.aspx;</p> <p>Current information available on Alzheimer’s Australia Quality Dementia Care website: https://www.fightdementia.org.au/common/files/NAT/1630-Morley.pdf</p>
2.4 Improving staff-family relationships (Staff-family relations)	
Educational materials	<p>Online resource package for staff and families, including:</p> <ul style="list-style-type: none"> - Video presentation and case study on the importance of ‘staff-family relationships in residential aged care - Three animations on ‘Communication’, ‘Family Conflict’ and ‘Sexuality’ - Short video vignettes about the experience of family carers moving their loved one into an aged care facility - Short conversational style videos comprising twelve conversational question and answer scenarios between family members and health professionals about various aspects related to dementia - ‘Plain language’ booklet for families about how to develop and relationships with the residential aged care facility staff.
Website development	Currently under development, launch date anticipated by end of August 2014.
2.5 Timely diagnosis and management for General Practitioners (Timely Diagnosis)	
Educational materials	<p>Revision of existing resources and redevelopment into online resources.</p> <p>Timely Diagnosis of Dementia in General Practice educational resource developed for delivery at GP Conference and Exhibition events including following topics:</p> <ul style="list-style-type: none"> - Dementia Essentials - Diagnosis, tests, scans and bio-markers - Physical activity, positive lifestyle and risk factors - Complications and behavioural changes - The carer as the patient and legal issues. <p>Small group workshop materials and train-the-trainer packages.</p> <p>Self-directed e-learning modules addressing the following topics:</p> <ul style="list-style-type: none"> - Recognising dementia - Diagnosis of dementia - Developing a plan for management - Screening and case finding - Recognising and managing BPSD and physical co-morbidities - Carer, legal and end of life issues.

3.3 Results

This section integrates findings from multiple data sources to answer the questions posed in the Evaluation Framework. The diversity of projects meant there were no readily available tools or processes that could be applied to assess their progress or outcomes in a consistent and / or coherent manner. The questions which the evaluation sought to address were applied to each project, and reported against in six-monthly progress reports as well as final project reports. Additional information was obtained through stakeholder interviews and CDRN evaluation activities.

3.3.1 Processes, impacts and outcomes for consumers

The evaluation addressed the following questions regarding the impact and outcomes of the projects on consumers:

1. Were projects implemented as intended with consumers?
2. Were NQDC projects funded in line with knowledge translation priorities identified by the CDRN?
3. Has care improved?
4. What has been the experience of consumer involvement in the project?
5. Are there any unintended consequences for consumers and carers arising from the program?

Project implementation

Projects were implemented as intended. Each project actively involved consumers in the development and implementation of their core activities; this inclusion was a condition of funding, and readily facilitated by the active engagement of CDRN members in governance and advisory roles and their ability to provide important insights into the real-life context in which care of people with dementia is delivered. Consequently, projects actively sought input from consumers around a number of operational aspects including analysis of service gaps; providing advice on draft materials and proposed implementation processes; participating in governance arrangements, resource development and educational opportunities undertaken as well as contributing to project evaluation activities. As the NQDCI evolved over time, the CDRN also sought to streamline their involvement through the establishment of sub-committees to provide greater oversight of the projects as a whole, and facilitate networking and linkages between projects where feasible. Table 4 summarises consumer involvement in five key elements of NQDC project delivery.

Table 4 Consumer involvement in projects

Project	Gap analysis	Resource development	Implementation strategies	Evaluation activities	Networking and linkages
1.1 DEEP	✓	✓	✓	✓	✓
1.2 Relate Motivate Appreciate		✓	✓		✓
1.3 Valuing People	✓	✓	✓	✓	✓
2.1 ICF-D		✓	✓		✓
2.2 Start2Talk	✓	✓	✓	✓	✓
2.3 Active Body Active Brain		✓	✓		✓

Project		Gap analysis	Resource development	Implementation strategies	Evaluation activities	Networking and linkages
2.4	Staff-Family Relationships	✓	✓	✓		✓
2.5	Timely Diagnosis			✓	✓	✓

Priority projects funded

The CDRN was actively engaged in the selection of projects for funding, (refer to Appendix 2). Indeed, their primacy in this process was evidenced by their selection of only two projects out of over 40 expressions of interest received in the first funding round. The low acceptance rate was primarily due to the different perspectives regarding what constitutes a knowledge translation project. Conceptually, knowledge translation spans the distance between the point of research to the application of changed practice at the individual and / or care system level; the majority of applications received appeared to be extensions of established research priorities and project initiatives, were not aligned to the practical and targeted priority concerns of consumers, and did not have the potential to be generalisable across a range of geographic and cultural contexts and care settings.

Despite receiving significant negative feedback from a number of key stakeholders who were unsuccessful in their project bids, the decision by the Alzheimer’s Australia National Office to adhere to the decision made by the CDRN reinforced the integrity of the overall NQDCI in ensuring that consumers are at the heart of, and drive, decision making processes regarding research and project funding which affect them. As one key stakeholder noted, CDRN members:

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

Projects funded subsequently were either directly commissioned by the Alzheimer’s Australia National Office (Valuing People) to align with consumer expectations, or were the result of the subsequent funding round which included greater level of detail in the overall project descriptions being sought by the CDRN for funding.

Table 5 **Priorities addressed by projects**

Priority area	Project	
Person centred care	1.3	Valuing People – Person centred care in the community
Advance care planning	2.2	Start2Talk - Advance Care Planning for People with Dementia
Support for carers	2.4	Staff-family relationships
Timely diagnosis of dementia	2.5	Timely Diagnosis
Non-pharmacological approaches to managing behavioural symptoms of dementia	2.3	Active Body Active Brain
	1.2	Relate, Motivate, Appreciate
Palliative care for people with dementia	2.1	Integrated Care Framework – Dementia
<i>Other</i>	1.1	DEEP – Dementia Enabling Environments Project

Improved care

Underpinning the NQDCI was the objective of improving care for people with dementia and their carers, through translating evidence into practice. For some projects, the focus was enhancing the existing evidence within the sector and extending or enhancing its reach e.g. projects 1.1 DEEP and 2.5 Timely Diagnosis, while others took evidence of an effective intervention in a related sector (or in some cases, an unrelated sector) and translated and / or trialled that evidence within a dementia care context e.g. 1.2 Relate, Motivate, Appreciate, 2.1 ICF-D.

Table 6 Nature and context of evidence

Project		Primary locus of evidence	Original context	New context	Existing and enhanced (EE) or translation / trialled (TT)
1.1	DEEP	Building and environmental design	Residential aged care	Residential care, community care and home; gardens	Both EE and TT
1.2	Relate, Motivate, Appreciate	Montessori methods	Education	Residential aged care	TT
1.3	Valuing People	Person centred care	Residential aged care providers	Aged care providers; people with dementia, carers and family members	TT
2.1	ICF-D	Palliative care / end-of-life framework	Sub-acute care	Residential aged care	TT
2.2	Start2Talk	Legal issues associated with dementia	Dispersed on jurisdictional basis	Brought together (con ...) in one accessible location	EE
2.3	Active Body Active Brain	Health benefits of walking	General community activity	Residential aged care and general community walking groups	TT
2.4	Staff-family relationships	Importance of family relationships	Psychology; family therapy	Residential aged care	TT
2.5	Timely Diagnosis	Early diagnosis of dementia	Limited knowledge within General Practice	Mainstream general practice professional learning and development; medical software prompts	EE

Of the five projects that sought to translate or trial relevant evidence from other areas in dementia specific settings, three were trialling interventions directly with consumers and the remaining two targeted interventions at staff and / or organisational levels to deliver improved outcomes for consumers. Furthermore, because only two of these projects – 1.2 Relate, Motivate, Appreciate and 2.3 Active Body Active Brain – collected consumer-level data, it was only possible to address the question of consumer outcomes in these two cases.

These two projects used a combination of validated assessment tools as well as observations, which were administered pre- and post-implementation. Both projects recorded positive outcomes for the participants:

Information gathered from the pilot suggests there is decreased agitation and aggression, and some improvement in sleep, mood and energy. Primarily the perceived benefits are social – improved relationships with family and friends. Also a perceived improvement in memory – which may be a side effect of improved sleep and more energy. (Active Body Active Brain Final Report, p3)

Project 1.2 Relate, Motivate, Appreciate also used a number of assessment processes, which showed some positive results, but which were insufficient in terms of completions as well as overall numbers to be of value for the evaluation. The project website includes a number of videos on the “Activities” pages that clearly indicate the benefits of using Montessori principles when interacting with people with dementia. The site also includes a vignette about ‘Marjorie’ which concludes:

Marjorie’s sons both commented that over the ten-day period, their mother’s verbal communication increased, her facial expressions became more positive and her general level of engagement increased. ([Relate, Motivate, Appreciate Project](#))

The focus of effort for the remaining six projects was predominantly on improving the capacity of those directly involved in supporting people with dementia through developing strategies and resources to enable them to deliver evidence-based interventions. The time-frame and resourcing of the evaluation did not enable the evaluation team to investigate further the extent to which these interventions were put into practice on a general and sustainable basis (i.e. beyond the activities undertaken directly through the projects), nor whether outcomes were realised for consumers. Consequently, the evaluation includes a broader approach, assessing the evidence behind the proposed knowledge translation strategies. These are discussed in more detail in Section 3.3.2 below.

Consumer experiences

As discussed at length within the CDRN Final Evaluation Report, the experiences of consumers (CDRN members) in relation to the NQDC projects has been, on the whole, positive. From the outset, the process of seeking consumer input regarding priorities and participation in selection of projects for funding proved to be a unifying factor for a group of people who came from disparate backgrounds and experiences in project management and knowledge translation, in addition to their lived experiences of dementia. Consequently, involvement in the selection of projects and initial governance arrangements was not without challenge for many members, particularly in terms of processes (priority setting, selection of projects, monitoring progress) and outcomes (limited feedback on CDRN input).

Project leads were invited to present on progress at several CDRN meetings, however while many CDRN members found these opportunities valuable, they also noted that there was variability in the quality of the presentations, with the information in some cases not provided in a manner that was readily accessible to members. This compounded the concerns of some members that, despite initial intentions, not all projects were being implemented in the consumer-driven manner that had been anticipated at the outset. Each project included at least one consumer representative on its governance / advisory arrangements; however no mechanisms were in place to support regular sharing of information across the CDRN to ensure members were abreast of developments and / or emerging themes amongst the projects that

required their attention. The resultant dissonance between the CDRN and individual projects had the potential to be de-motivating to members whose involvement was premised on the belief that their contribution could add value to projects; the limited feedback also meant they had no opportunity to improve the content or manner of their engagement with projects. As one CDRN member noted about CDRN involvement in activities in general (not just NQDC projects):

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

More effective monitoring and communication strategies were implemented to address this issue, including the establishment of CDRN sub-committees to monitor progress and advise the broader membership of any issues arising.

From their perspective, however, it was clear that the project leads were very conscious of their obligations in regard to consumer involvement, with consumer representatives on every project governance / advisory group. As projects became more established, there was increasing recognition of the value of the consumer contributions; this was in part due to the quality and timeliness of feedback when sought, as well as the unique perspectives of people with lived experience of dementia. This enabled project refinements to address potential barriers to implementation, as well as develop more targeted processes and resources. Key outcomes included:

- Improved targeting of information to better meet the needs of the relevant audiences;
- Access to broader networks for purposes of consultation and participation in project activities; and
- Improved appreciation of the perspectives of consumers by project target audiences, through their direct participation in training processes (e.g. Timely Diagnosis) and via case studies and resources produced by projects (e.g. Relate, Motivate, Appreciate).

Examples from project final reports that demonstrate these outcomes include:

A short video was produced (project participant) Frank's story- why walking helps my dementia.

(Active Body Active Brain Final Report)

(The) active participation of consumers ... (resulted in) developing the website content largely in terms of the range of questions that consumers might ask and having website content reviewed by consumers during development.

(Start2Talk Final Report)

Consumer involvement was deeply embedded in all stages of this project. People with dementia, their carers and families were given the opportunity to meaningfully engage with the project at several levels... Provided detailed review and feedback on all web-based materials including content and 'user-friendliness' ... (and participated in) the production of short 'filmed narratives' for video linked resources representing consumer perspectives.

(ICF-D Final Report, p15)

The appreciation of consumer input to projects was clearly acknowledged in several of the final reports, including:

The people living with dementia so generously gave their time and ideas in the creation and piloting of the initiatives. Your words of wisdom and encouragement were our inspiration.

(DEEP Final Report, p23)

3.3.2 Processes, impacts and outcomes for providers

The evaluation addressed the following questions regarding the impact and outcomes of the projects on providers:

1. Were projects implemented as intended with providers?
2. What learning and knowledge gaps hindered the use of evidence-based practice?
3. Have the knowledge and skills of dementia care providers improved following implementation?
4. How is evidence used in everyday practice?
5. Has this changed since project implementation?
6. Have dementia care providers been supported in accessing and using evidence-based practice?
7. What capacity has been built as a result of the program?
8. Are improvements sustainable?
9. Are there any unintended consequences for providers arising from the program?

Project implementation

The main mechanism through which many of the projects sought to improve care for people with dementia and their carers was improving the skills of, and increasing the use of evidence in everyday practice by, those involved in providing that care. The projects sought to influence care practices across a range of settings including primary health, acute care, sub-acute care (palliative) and aged care (community and residential); as well as generic community services involved in design, landscape, architecture and legal services (refer to Table 7 below).

Table 7 Settings and audiences targeted by NQDC projects

Project		Aged care: Community	Aged care: Residential	Primary care	Sub- acute	Generic community services	People with dementia, carers and families
1.1	DEEP	✓	✓			✓	✓
1.2	Relate Motivate Appreciate		✓			✓	✓
1.3	Valuing People	✓	✓				✓
2.1	ICF-D		✓		✓		✓
2.2	Start2Talk	✓	✓			✓	✓
2.3	Active Body	✓	✓			✓	✓

Project		Aged care: Community	Aged care: Residential	Primary care	Sub-acute	Generic community services	People with dementia, carers and families
	Active Brain						
2.4	Staff-Family Relationships		✓				✓
2.5	Timely Diagnosis			✓		✓	✓

The vast majority of projects sought to influence a range of audiences who had the capacity to improve care and support of people with dementia; importantly, all ensured that people with dementia and / or their families and carers were also supported through targeted resources and activities. The project leads were clearly cognisant of the multiple and complex factors that impact on and influence outcomes for people with dementia and their carers; this was also reflected in the governance and / or consortium arrangements and consultation processes of each project.

Learning, knowledge and skills

The aim of evidence-based practice is to effectively implement an effective intervention so that positive consumer outcomes are achieved. NQDC projects were developed to address a lack of knowledge and / or access to evidence that can improve care and support for people with dementia and their carers; these improvements for consumers were predominantly sought through improving practices of those directly involved in their care and support delivery.

This required project leads to have a sound understanding of knowledge translation processes some of which were explicit:

- 1.1 DEEP utilised the Pathman approach of Awareness, Agreement, Adoption, Adherence¹²
- 1.3 Valuing People incorporated a change management consultant to embed change management principles in practice.
- 2.1 ICF-D described its approach to achieving cultural change as being through its content being accessible, engaging and interactive, and using a continuous quality improvement model that included a focus on learning and leadership.

It was clear that the majority of project leads had a strong understanding of the sectors and settings they were working with, the nature of change required and factors that were likely to impact on project delivery. Each also employed a range of change management strategies to address their particular target audiences and contexts.

The Cochrane Effective Practice and Organization of Care¹³ has developed the following taxonomy of professional behaviour change strategies have been identified as being effective in translating evidence into practice; these include:

- Printed educational materials such as clinical practice guidelines, electronic publications, educational materials;

¹² As described in Davis D, et al. (2003) The case for knowledge translation: shortening the journey from evidence to effect. *BMJ*, 327 (7405): 34.

¹³ Effective Practice and Organisation of Care taxonomy of professional and organisational interventions (2002) <http://epoc.cochrane.org/epoc-author-resources>.

- Educational meetings such as conferences, lectures, workshops and traineeships;
- Educational outreach or academic detailing, whereby a trained person meets with professionals in their practice settings;
- Local opinion leaders such as staff members identified by their colleagues as being able to influence others attitudes or behaviours informally in a positive way;
- Audit and feedback processes which use clinical performance information to improve clinical practice and / or health outcomes;
- Reminders, such as computer or paper-based prompts for staff to recall information;
- Tailored interventions, which involve planned strategies to overcome identified barriers to change; and
- Multifaceted interventions which employ a number of components to address identified barriers.

Table 8 below provides a summary of strategies used by each project.

Table 8 Professional behaviour change strategies used

Project	Printed educational materials	Educational meetings	Educational outreach	Local opinion leaders	Audit and feedback	Reminders	Tailored interventions	Multifaceted intervention
1.1 DEEP	✓	✓			✓		✓	✓
1.2 Relate Motivate Appreciate	✓	✓		✓			✓	
1.3 Valuing People	✓	✓			✓		✓	✓
2.1 ICF-D	✓	✓		✓	✓	✓		✓
2.2 Start2Talk	✓	✓						✓
2.3 Active Body Active Brain	✓	✓		✓			✓	✓
2.4 Staff-Family Relationships	✓	✓	✓	✓			✓	✓
2.5 Timely Diagnosis	✓	✓	✓	✓		✓	✓	✓

All projects developed resources and included educational meetings as part of their suite of change management strategies, and the majority also used tailored and multifaceted interventions to address the perceived barriers to implementation. The choice of strategy was outlined in the project documentation and supported by evidence in the literature; in practice, however, it appears that a mix of previous experience and pragmatism were the main reasons behind the choice of intervention. This demonstrated the flexibility of project leads to adapt to the emerging issues as they arose, for example:

- 1.1 DEEP incorporating an ‘Adapting the home’ resource in response to consumer input;
- 1.3 Valuing People reconfiguring its resources in response to early evaluation feedback; and
- 2.5 Timely Diagnosis incorporating consumer representatives at training sessions following the inability of local Alzheimer’s Australia organisations to organise concurrent community awareness activities within the timeframe needed.

All project leads demonstrated significant expertise in the evidence that was being translated, but often had less experience of the context in which the evidence was to be applied. The consortium arrangements that were integral to the project design requirements were critical in addressing potential knowledge gaps; each project included governance and / or advisory mechanisms that included a range of relevant stakeholders.

First and foremost, all projects included consumer and relevant Alzheimer's Australia State and Territory representatives and the Alzheimer's Australia National Research Manager as core members of the project governance arrangements. In addition, members included representatives of:

- Academic institutions: all projects included representatives of DCRCs, Dementia Training Study Centres and / or research collaborators associated with one or the other;
- Clinical experts: intensive care (2.2); palliative care (2.1); general practitioner and practice nurse (2.2, 2.5); behaviour management (2.3); Montessori methods (1.2);
- Professional groups: architect and landscape design (1.1), legal (2.2);
- Aged Care providers: all projects, except 1.1; and
- Other: change management (1.3); communications (2.1) software design (2.5); Heart Foundation (2.3).

Contextual factors were also addressed through consultation processes. Despite this broad stakeholder engagement approach, a number of projects experienced significant challenges because of the nature of the workplaces in which they were seeking to effect change. For example, the 1.2 Relate, Motivate, Appreciate project team found they had to reintroduce the project within organisations because of changes to key personnel in facility management roles. The Staff-Family Relationships team had a similar experience and found that changes in facility managers affected the organisational culture, staff morale and left a leadership gap which adversely impacted implementation. This project also noted that in several instances staff did not have ready access to information technology which was problematic. While these issues may be familiar to those who work in the aged care sector, it suggests there may be benefits to using a more structured approach to managing context. This is particularly important in determining the optimum change strategies to effect practice change at the local level.

Changes to practice and capacity

The nature of the NQDC projects meant that it was not possible to accurately gauge the extent of overall practice change resulting from the activities undertaken. This was because not all projects directly focused on specific practice changes and supported their implementation, several aimed to facilitate change by making the evidence more accessible for practitioners.

The four projects which sought to directly impact on practice were:

- 2.1 ICF-D: training for residential aged care staff in use of the ICF-D;
- 2.3 Active Body Active Brain: training for Heart Foundation Walk Local Coordinators and Walk organisers;
- 2.4 Staff-family relationship: education for staff working in residential aged care;
- 2.5 Timely Diagnosis: education for General Practitioners and Practice Nurses.

The final reports of these projects identified observed and / or measureable changes in practice arising from their interventions (namely the development of resources and provisions of education and training to care providers). Further detail is provided below.

2.1 ICF-D reported that ICF-D as a resource was considered user friendly, time efficient and supports comprehensive care planning and interventions. Care-workers involved in the pilot found the assessment processes ‘engaging’, and the information for families when the resident is imminently dying ‘helpful’. The video podcast modality that was developed for teaching was found to be useful.

2.3 Active Body Active Brain reported the training developed for volunteer Local Coordinators and Walk Organisers about dementia and how to respond to a person with memory loss or confusion was of benefit to those involved. Residential aged care staff of participating facilities noted a decreased level of agitation and aggression while people were involved in walking, in turn impacting on their own work practices.

2.4 Staff-Family Relationships reported that not only did staff report an increased awareness of the need to improve staff-family relationships; this was also observed in practice. Benefits were observed in interactions, communication and information provision. Staff recognised the need for improved communication with families, the benefits of which included better knowledge of the consumer and their needs. The experiences and feelings described by families in the video vignettes were described as a real ‘eye opener’ for many staff ‘and generated considerable empathy’. The final report goes on to say:

For many staff, this was the first time that they had been exposed to the hidden grief of families of people with dementia and the unexpressed hardships which many families have and continue to live with.

Staff found that by implementing the changed practice there were also benefits for their care planning as well as the workplace environment:

Since learning the names of families and addressing them accordingly, she has been able to establish a much greater rapport with families and an improved relationship with them.

Staff also perceived a reduction in their own stress associated with care-giving, and families likewise indicated a moderate reduction in their stress.

2.5 Timely Diagnosis focused on providing education and training that was linked to continuing professional development requirements. The final report noted that 519 general practitioners had participated in the training, with 72 going on to complete the learning module online. Small group workshops were run in regional areas such as Ballarat and Geelong (Victoria) and Ballina (NSW), attracting participation of 282 general practitioners. To facilitate ongoing delivery of the training, Train the Trainer courses were delivered to 14 people nationally. The outcomes of this project are expected to be further extended through the e-learning modules that went live in June 2013; within six months 206 GPs had completed all modules, and a further 612 were

working through the modules. GPs were also supported through the development of electronic software prompts that were incorporated into 2,900 GP practices nationally in early 2014. The project was not able to undertake closer assessment of the extent to which the education and resources resulted in changed practice; however, the positive feedback on the training and small group workshops, with most indicating the training entirely met their needs and was entirely relevant to their practice, bodes well for uptake and implementation more generally.

Similarly, the remaining projects developed resources and processes that were designed to improve practice, but were not in a position to evaluate the extent these were applied in practice.

1.1 DEEP developed a Virtual Information Centre (website) that comprises resources to support the implementation of its ten Design Principles. The project took a multi-pronged approach to its development of resources, targeting a range of key stakeholder groups, including consumers, aged care providers as well as architects and designers. Resources include information sheets; booklets; e-newsletters; online media / social marketing; audit tools for adapting the home environment as well as developing therapeutic dementia gardens. A professional education program was developed based on a train the trainer model to promote and assist people using the DEEP website; this is expected to be an ongoing resource for Alzheimer's Australia organisations nationally. The final component of the project was the compilation of a 12-item lending library for each Alzheimer's Australia organisation to make available for loan to interested parties.

1.2 Relate Motivate Appreciate developed a series of video and online resources, as well as a series of national workshops to support implementation. Approximately 1,000 family carers and dementia care professionals attended 24 full and half-day workshops delivered by Dr Cameron Camp in 2013. A range of resources are available on the Alzheimer's Australia national web-site and Alzheimer's Australia Victoria continues to offer activity programs based on the Montessori method for diversional therapists, planned activity group and lifestyle staff.

1.3 Valuing People is ongoing with continued funding; results were not available at the time of writing this report with the summative evaluation report due in October 2014.

2.2 Start2Talk reported that there has been a steady interest in the Start2Talk website. The overall number of visits to the site between March and September 2014 was 8,190. These have been spread evenly across Australia. There have also been visits from a number of other countries. Ongoing development and promotion of the resource has been achieved through the supporting organisations and through a range of media outlets, including a series of television Community Service Announcements aired nationally in November 2014.

Sustainability

The objectives of project outcomes being sustainable and generalisable were core assessment criteria for project selection. This was based on the recognition that the NQDCI was time-limited, being funded for only three years; it was also in response to the past history of similar programs and investments of this type, which were generally one-off and therefore limited in terms of scope, impact and cost-effectiveness. Program guidelines specifically stated that projects were to:

Have a national impact, or have outcomes that are directly applicable and generalisable on a national scale.¹⁴

This proved to be a challenge for many applicants for funding, who submitted proposals that were quite self-contained and / or built on existing research interests rather than having a practical and generally applicable outcome focus. Consequently, each of the projects selected included a range of explicit strategies, including:

- High level stakeholder engagement embedded within governance arrangements of projects to facilitate shared ‘ownership’ of project outcomes and increase the likelihood of sustainability and spread.
- Resource development in an accessible format. All projects developed and / or reformatted materials to target specific audiences, which were delivered through a range of mechanisms including website development, e-learning modules, electronic prompts and library resources.
- Education and training modules often included a ‘train the trainer’ component, to equip practitioners to continue to deliver the education over the longer term.
- National workshops and promotional activities. Several projects undertook national workshops aimed at delivering the education developed as well as raising awareness of the resources produced. Presentations at conferences and development of promotional materials were some of the key dissemination activities of projects. Social media was also used to raise awareness.
- System-level impacts. Embedding changes into policies and procedures within organisations that have a broad sphere of influence in terms of current and future practice.

As demonstrated in Table 8, most projects applied a multi-faceted approach to effecting practice change, and this was also reflected in the strategies developed to facilitate sustainable outcomes. Projects were also required to have dissemination strategies that addressed the requirement for national application and / or spread outlined in the project guidelines.

Project enablers

Each project was asked to identify the factors they found to be most helpful in achieving their goals. The most common responses were the different groups that informed the project processes, including consumers, participants and stakeholders.

A supportive host organisation has also been identified as being a key enabler for some projects. This is often found in projects where the host organisation has had a long-standing interest in the subject matter being undertaken, or where the project extends the work and investments previously undertaken by the organisation. The in-kind support was often essential, in particular when projects face unexpected costs which were not envisaged at the outset of the project. In-kind support also proved helpful in cases where there was a lag between the expenditure and the organisation’s capacity to recoup costs at a later date (if at all), for example, contracting a change management expert (Project 1.3 Valuing People).

¹⁴ Expression of Interest *ibid*.

Supportive organisations within which the projects were implemented were also seen as critical, in terms of assisting with recruitment of participants and facilitating access to training for staff. Conversely, the lack of support can prove a significant barrier, as identified by Project 1.2 (Relate, Motivate, Appreciate).

Consumer and carer input

Most project teams identified the assistance and input of consumers and carers as a major enabling factor that supported project development and implementation. The 1.3 Valuing People project team benefited from consumers reviewing the content of the O-SAT consumer module and providing advice on simplification of the language used. The 1.1 DEEP project team consulted with consumers who provided feedback and direction for development of the initiative and the “look” of the website. They also collaborated with consumers in the piloting of a workshop. The project team repeatedly noted their appreciation of contribution provided by CDRN members.

The 2.2 Start2Talk project team specifically commented on the willingness of consumers to participate in focus groups or contact the project manager directly with input. This allowed the project manager to get a broad range of consumer input that enhanced project development and delivery. The CDRN provided critical advice to this project through carefully reviewing and commenting on draft material and this improved the appropriateness of these resources for the target audience.

The 2.3 Active Body Active Brain project team felt that consultation with Heart Foundation Walking group participants (which was achieved through on-line survey, Facebook and through face-to face mechanisms) helped generate early enthusiasm and interest for the project. The feedback of these consumers was instrumental in formulating participant resources. Through working with several existing Heart Foundation Walking groups, pilot sites were more quickly established as their “parent” group was already registered and familiar with program processes.

Participant support

The level of support provided by the people involved in implementing the practice change was a positive factor for a number of projects. 1.2 Relate, Motivate, Appreciate project actively worked on its external relationships and found participant recruitment was easier when facilities were highly supportive of the project. Similarly, 2.4 Staff-Family Relationships project found that the frequent presence of a member of their team within the residential aged care facility created familiarity and built rapport with staff which assisted project implementation. 2.1 ICF-D project likewise reported high levels of interest from aged care providers and recruitment of residential aged care facilities to participate in the project was relatively straightforward. The enthusiasm of participants was a key enabler for the 2.3 Active Body Active Brain project team, who reported they were delighted to find that more sites than originally anticipated agreed to be part of the pre and post walking quality of life evaluations.

Stakeholder support

The ready availability of stakeholder expertise, advice and input into the development of resources was a key enabler of success for projects, primarily given the innovative nature of the projects, complex subject matter, and multiple audiences and/or stakeholders involved. Stakeholders provided advice around content matter, implementation and dissemination

processes, as well as infrastructure and opportunities that could enhance a projects' impact, e.g. inclusion of the established online resource (www.caresearch.com.au) for palliative care health professionals, patients and family and friends (2.1 ICF-D), change management expertise (1.3 Valuing People) and influencing curriculum development for architectural students (1.1 DEEP).

The 1.1 DEEP team worked hard to inform external suppliers about the intent of their initiative and found that some companies were prepared to support the project through reducing their usual commercial rates. Similarly, 2.1 ICF-D project found that using an external web design company provided access to all the elements needed to design a more extensive web resource and within budgeted resources. The support of Alzheimer's Australia State and Territory member organisations was also important, with the 1.1 DEEP project noting the strong support of Alzheimer's Australia Western Australia through the provision of "in-kind" support. The comprehensive consumer engagement undertaken as part of the 2.2 Start2Talk project was facilitated by Alzheimer's Australia NSW, whose 'willingness and ability to organise focus groups improved access to consumer input' was noted as being an important part of the project's success.

Supportive organisations within which the projects were implemented were also seen as critical, in terms of assisting with recruitment of participants and facilitating staff access to training provided. Conversely, the lack of support can prove a significant barrier (see below).

Dissemination

Two project teams in particular commented on the support of various groups in contributing to the promotion of the project and engagement of stakeholders. The 2.2 Start2Talk project team found meetings with the Public Guardians / Advocates and State / Territory Department of Health staff particularly useful in getting information about the initiative more widely disseminated. The strategy of engaging with national organisations that were listed as "supporting organisations" on the developed website also assisted with wider dissemination. Participating in a professional development conference provided the opportunity for 2.3 Active Body Active Brain to not only increase awareness of the project, but also to engage older people without dementia to consider walking groups as a preventative approach.

Project barriers

Project teams identified a range of factors that hindered implementation. These can be summarised as barriers relating to project resources (financial and human) and their impact on project delivery; implementation context; and legalities.

Project resources

Under-budgeted project plans and recruitment of project staff with the requisite skills – subject knowledge, project management and stakeholder engagement expertise – proved to be a challenge for several projects. The 1.3 Valuing People project team found they had inadequate administrative support during the initial stages of the project. This made additional reporting requirements, particularly from their other funding body, burdensome and impacted on the project timeline. This also meant there was no capacity to backfill the project manager role when unanticipated leave was taken, in turn impacting on the project management activities and the level of communication with pilot sites. These issues were subsequently resolved through the

securing of additional funding under the Commonwealth Government’s Encouraging Better Practice in Aged Care (EBPAC) program.

Budgets developed as part of project proposals are not an exact science, and often require some realignment once a project has become operational; in part, this is due to the innovative nature of the projects, where the activities and project outcomes have a developmental aspect to them. This was the experience of several project teams. The 1.1 DEEP project team found that they did not have the budget to recruit specific staff early in the project and this made the development process slower than anticipated. The 2.2 Start2Talk project also struggled with limited administrative support to coordinate the numerous meetings required as part of the consultation process; this responsibility fell to the project lead who then had to juggle this coordination role while in the process of visiting each State and Territory. This had a downstream effect as it made it challenging to also find time to disseminate information about the project to a broader stakeholder group.

The 1.1 DEEP project team also underestimated the costs of website development and time to find a company that could deliver what was expected within the appropriate timeframe. The team achieved a great deal in a short space of time but could see the potential for ongoing development of the concept. They felt that the two year time-frame was too short to meet their own high expectations and the team’s desire to deliver a comprehensive range of initiatives supported by high quality information.

Implementation contexts

Some of the most significant challenges arose because of the nature of the workplaces where projects were based. For example, the 1.2 Relate, Motivate, Appreciate project team (in its initial pilot phase) found they had to reintroduce the project within organisations because of changes to key personnel in facility management roles. The 2.4 Staff-Family Relationships project team had a similar experience and found that changes in facility managers affected the organisational culture, staff morale and left a leadership gap which adversely impacted implementation. The project team reported that in several instances staff did not have ready access to information technology which was problematic.

The 1.2 Relate, Motivate, Appreciate project team (in its initial pilot phase) faced a significant barrier because of carers’ experienced burden. They appeared to be overwhelmed by the amount of information that they were provided with during the recruitment phase and this resulted in approximately 50% of eligible individuals deciding not to participate in the project.

Legal issues

The 2.3 Active Body Active Brain project team identified two barriers related to legal issues. The first was an intellectual property issue that arose between the National Heart Foundation and Alzheimer’s Australia South Australia; this had a negative impact on project timelines, the budget and professional relationships. The second barrier that was not anticipated was about the legal considerations relating to persons’ capacity to sign the “walker” registration forms. Both of these issues were resolved following consultation and discussion involving management of each organisation, and with Alzheimer’s Australia National Office.

Unintended consequences for providers

Projects of this kind have typically been framed as developing ‘solutions’ to ‘problems’ associated with dementia; the NQDC projects instead have a much greater focus on enablement of the individual and enhancement of attributes and / or functionalities of current processes. The contribution of consumers has been fundamental to the direction setting for projects as well as refinement of project strategies and resource content.

Key outcomes include:

- Improved targeting of information to better meet the needs of the relevant audiences;
- Access to broader networks for purposes of consultation and participation in project activities; and
- Improved appreciation of the perspectives of consumers by project target audiences, through their direct participation in training processes (e.g. Timely Diagnosis) and via case studies and resources produced by projects (e.g. Relate, Motivate, Appreciate).

Many project leads, their respective host organisations and stakeholder networks also described the personal and professional learnings that have resulted from participation in the NQDC projects.

- Greater understanding of the real impacts of living with dementia and the associated gaps in quality of care available:
 - A clinician spoke of the profound effect of comments made by a fellow member of a project steering committee meeting, a carer of a person with dementia, about their distressing experience within the local hospital; they were subsequently able to respond by reallocating resources to better address the issue in question.
 - A stakeholder who was a member of a project steering committee noted the different emphases of consumers in terms of priority projects for funding; in discussion regarding a potential risk assessment tool for involvement of people with dementia in community activities, it was clear that:

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

- The capacity of consumers to provide constructive input to projects – the ‘value-add’ they provide:
 - The target audience for the resources produced by the DEEP project were initially aged care service providers and design schools. Consumer representatives on the steering committee were able to highlight the absence of any such resource for people living in the community, resulting in this being incorporated into the overall project plan. The outcome includes a readily accessible resource that has been well-received by family carers.
- How to work with consumers as partners in the project development and implementation:
 - The Timely Diagnosis project had planned to work with Alzheimer’s Australia organisations to conduct community awareness activities to align with their training for General Practitioners but in most cases this proved not to be feasible due to timing and resource constraints. The implementation of the project was adapted to

emphasise the consumer perspective within the context of the GP training, through the inclusion of Alzheimer’s Australia representatives, a person with dementia and / or a carer on the panel discussion component of the training.

For some, the experience of working with consumers in this capacity had ‘opened their eyes’ to appreciating them as active contributors to service provision rather than passive recipients. Others expressed greater optimism about continuing to work in the sector into the future. While it was acknowledged that working with consumers had required some adjustments on the part of project partners, there was a general consensus that the inclusion of end-users as partners in collaboration was likely to provide better targeted projects that have greater relevance to practice, and therefore are more likely to gain traction and be sustainable over the longer term.

3.3.3 Processes, impacts and outcomes for the system

The evaluation addressed the following questions regarding the impact and outcomes of the projects for the system:

1. What linkages have developed between collaborators in projects?
2. Have any improvement networks or communities of practice developed?
3. What barriers or enablers to the sustained use of evidence-based practice can be identified?
4. What needs to be done to make improvements sustainable?
5. Are the health and aged care sectors receptive to the use of evidence?
6. Have improvements in clinical care been widely disseminated?

Linkages and networks

While the primary objective of the NQDC projects was to facilitate change in practice, a secondary objective was to develop and strengthen linkages between the different sectors and professional groups involved in supporting people with dementia. In addition, it was expected that the NQDC projects could forge stronger links between collaborators and local State and Territory Alzheimer’s Australia organisations, as well as within the Alzheimer’s Australia Federation.

The extensive stakeholder engagement strategies described previously were specifically designed to enhance and extend existing networks to ensure project processes and outcomes were appropriately targeted and sustained; in addition, they facilitated linkages between disparate groups around a common agenda that is likely to continue into the future.

The most concrete of networks to be strengthened through the NQDCI overall, was the Alzheimer’s Australia national network, with three of the eight projects being directed or co-directed by a State Alzheimer’s Australia member organisation, and all projects required to liaise with relevant Alzheimer’s Australia organisations as part of their governance arrangements. The rationale for this requirement was to firstly build capacity within the network more generally, as well as enhance the federation as a whole. The participation of the Alzheimer’s Australia National Research Manager on each project’s steering committee was designed to strengthen ties within the national network, as well as provide opportunities for cross-fertilisation of

learnings between projects and related Alzheimer’s Australia national initiatives. Through these initiatives, Alzheimer’s Australia national members have benefited in a range of ways, including:

- Access to resources, such as the DEEP Lending Library that has been distributed nationally (1.1), audit tools developed (1.1 and 1.3) and educational packages (1.2, 2.1, etc.);
- Enhanced revenue streams, through receipt of funding for projects, and being able to leverage additional project funding (Alzheimer’s Australia Victoria) as well as potential ongoing revenue through the provision of consultancies utilising resources produced by the projects;
- Extension of networks, such as the regulatory, legal and consumer groups with an interest in advance care planning (2.2); and
- Public profiles enhanced, resulting from promotional activities associated with projects, e.g. launches, presentations at conferences, media interviews.

Despite these benefits, the extent to which they have translated into improved relationships between the Alzheimer’s Australia National Office and State and Territory organisations remains unclear; stakeholder interviews conducted throughout the evaluation revealed a continuing resistance to national initiatives overriding local processes and resources. For example, the requirement of prospective applicants to align themselves with Alzheimer’s Australia State and Territory members resulted in some being overwhelmed with requests for assistance and continued to be a source of contention two years after the events occurred.

Enablers and barriers

The majority of projects did not specifically identify system enablers or barriers to the uptake of evidence in practice; however a number of lessons can be drawn from project reports and experiences about high level stakeholder engagement.

Each project had several high level stakeholders in their governance arrangements and / or collaborations. In the main, this was to ensure strategies adopted were appropriately targeted for the respective audiences, and were able to be incorporated into existing systems and processes which in turn enhanced chances of sustainability of project outcomes. Each project included a representative and / or collaborator associated with the Dementia Collaborative Research Centres and the Dementia Training Study Centres. These academics, and other stakeholders with specific content expertise, contributed to the projects at the same time as potentially benefiting from the resources developed and project learnings. It is expected that these developments will be reflected in the future work of these participants, for example, in curriculum development, lectures, ongoing research activities, architecture, design and legal practices.

The NQDCI had initially included a Service Provider Network (SPN), which comprised key industry stakeholders who had the potential to influence improvements in service delivery arising from the overall Initiative (refer to Appendix 3). Members of the SPN provided feedback on project proposals, as well as participated in steering committees associated with most of the projects. Consequently, their formal role as a network was subsumed within the governance arrangements of individual projects. However, in doing so, this diluted the capacity of SPN members to oversee the initiative as a whole, identify opportunities for service improvements that could be made within their relevant organisations and professional networks, and impact on

policy and program development through their industry and regulatory roles. Similarly, the limited availability of the former Department of Health and Ageing representative and the inability to find a replacement impacted on the ability of lessons learned to be adopted at the national policy level.

Sustainability

All projects included strategies that would facilitate system level impacts through working to embed practice change as well as enhance sustainability of project outcomes beyond the life of the NQDCI. Strategies included:

- Curriculum development, through engagement of academics in projects, including nursing and medical school representatives (2.1, 2.2, 2.3, 2.4, 2.5), as well as architecture (1.1);
- Policy alignment, ranging from supporting policies of organisations delivering care and support to people with dementia (1.3, 2.1, 2.2, 2.3, 2.4) and to national design standards (1.1);
- Professional development, including building educational components into existing accreditation processes (2.5), enhancements to resource portals and sector-specific professional development channels (2.1); and
- Organisational developments, including extending remit of mainstream organisations (2.3), provision of audit tools (1.1, 1.3), electronic prompts and reminders (2.5).

Most projects acknowledged, however, that ongoing sustainability was not a foregone conclusion, and would benefit greatly from ongoing promotion and incentives.

Receptive contexts

A recurring theme amongst projects targeting aged care services was the importance of having a receptive context for change. The main factors that impinge on implementation of evidence based practice include the resourcing constraints of staff and associated stress this causes (2.4 Staff-Family Relationships; 1.2 Relate, Motivate, Appreciate), accessing information in a timely manner (2.4, 2.1), and organisational commitment and / or leadership (1.2, 1.3, 2.4).

Many of these issues were not able to be resolved within the context of the projects; indeed, they are endemic to the aged care sector as a whole. However, projects were able to develop a number of inducements for staff to adhere to changed practices, the primary one of which was using real-life examples and stories of consumers (people with dementia and carers). Where these were used (1.2; 1.3; 2.1; 2.4) all projects reported improved motivation amongst project participants.

Dissemination

The national workshops, websites and resources are expected to be promoted through the Alzheimer's Australia national network, as well as relevant stakeholder networks. This has the potential for cross-fertilisation of ideas between sectors, for example, aged care and palliative care, consumer groups and guardianship advocates, as the various target audiences are brought together to hear of project outcomes, resources and processes. Assessing these impacts was outside the scope of the evaluation timeframe.

Project representatives were involved in a number of key industry events, reaching large numbers of people who in turn have the capacity to access project outcomes and implement improved care practices. These included:

Annual DCRC National Forum:

- 2010: NQDCI overview – Alzheimer’s Australia National Research Manager and Alzheimer’s Australia National Project Officer
- 2011: 1.2 Relate, Motivate, Appreciate;
- 2012: CDRN presentation
- 2013: 1.1 DEEP

Alzheimer’s Australia National Conference 2013:

- 1.1 DEEP; 2.3 Active Body Active Brain; 1.3 Valuing People; 2.1 ICF-D; 2.2 Start2Talk

4 CDRN update

4.1 Introduction

The Consumer Dementia Research Network (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. It is a key component of Alzheimer’s Australia broader National Quality Dementia Care Initiative.

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.*¹⁵

Initially focusing on establishing priorities and selecting the knowledge translation projects funded under the NQDCI, the CDRN has evolved significantly over the last four 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 CDRN is supported by Alzheimer’s Australia with funding from the Dementia Collaborative Research Centres (DCRCs) and the J.O. and J.R. Wicking Trust.

4.2 Background on the CDRN Final Evaluation Report

The CDRN Final Evaluation Report was issued in September 2013 and provided a snapshot of the key outcomes of the CDRN, the challenges it continued to face, and options for future operations. The following sections on methods and findings relate to the CDRN at the time of submission of the CDRN Final Evaluation Report, although the CDRN has continued to function past that point in time. Developments and progress since submission of that report are included in Section 4.6 and 4.7.

Since its establishment, the CDRN participated in a multiplicity of 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 (numbers have varied over time from 20 to 27), of which two-thirds remained relatively stable over the course of the three-year evaluation period, 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 expanded over time to include a greater focus on driving research priorities, particularly through its role in the Partnership Centre for Cognitive and Related Functional Decline in Older People (established in April 2013) and also through its advocacy in key policy and political contexts.

¹⁵ Available at <http://www.fightdementia.org.au/research-publications/quality-dementia-care-initiative.aspx>, accessed 14 July 2014.

The CDRN has been characterised by passion and commitment and this has been instrumental in enabling the CDRN to function effectively within a relatively short space of time and within the constraints of having geographically dispersed membership who contribute on a voluntary basis. This has been facilitated by Alzheimer’s Australia and the support for consumer participation by leaders in the dementia research field.

4.3 Methods

The CDRN Final Evaluation Report was framed to address key questions outlined in the evaluation framework developed in the early months of the CDRN’s operations to guide the presentation of findings¹⁶. This included 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 were categorised into eight key domains: leadership and culture; role clarity and governance; resources; participation; capacity building; support; communication; and, recruitment and selection. A mixed methods approach was taken to the evaluation with qualitative and quantitative data generated through interviews, observation at workshops, and analysis of meeting documentation, surveys and activity logs.

4.4 Findings

The CDRN achieved some important in-roads in consumer contribution to research.

In summary, the evidence is found in changes that have arisen as a result of the CDRN:

- More than fifty research projects were undertaken (or are still 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 were established that implemented evidence across a range of care settings addressing priorities identified by consumers; with an additional seven knowledge translation projects scheduled to commence in late 2014 or early 2015 based on priorities of, and selection by CDRN members;
- Additional investments in dementia were 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 was 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) increased directly as a result of the activities and advocacy of the CDRN.

¹⁶ Centre for Health Service Development (2011) Evaluation of the Alzheimer’s Australia Quality Dementia Care Initiative Evaluation Framework, Version 2. Centre for Health Service Development, University of Wollongong.

A key objective of the CDRN was 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. It was not possible to ascertain the actual impact and outcomes of the CDRN activities on these groups of consumers within the context of the CDRN evaluation. That is because the CDRN did not directly engaged with the 'end-users' of their efforts, but rather their intent and efforts were mediated through researchers and care providers; the logic being that these groups, in turn, would effect change in care practice at the local level.

The NQDC knowledge translation projects represented one of the major mechanisms that the CDRN used to progress this objective.

Impacts and outcomes for consumers

The experience of members involved in the CDRN was, in the main, positive. They were a highly motivated and committed group of people, who came from a broad range of backgrounds, with differing skills and experiences, and formed a cohesive and effective CDRN with a common agenda. The mutual respect shown by members was evident through observations at meetings and the content of email communications, and was further reinforced by the opportunities that Alzheimer's Australia provided and facilitated for members to contribute. These experiences reinforced the relevance and value of their efforts to be agents of change. The networking opportunities and friendships that developed also provided a sense of support and encouragement to those who, at times, struggled with issues relating to their experience of dementia. Amongst these positive outcomes, however, a number of issues emerged that suggested there was room for improvement. These were categorised generally 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

The capacity of the CDRN to establish priorities for research and projects directly correlated with the levers of influence they have had at their disposal. The knowledge translation priorities and projects were within the direct remit of the CDRN, which at the outset provided them with an advantage in achieving their objectives. 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 were more subtle, requiring members to negotiate for changes within research processes and build relationships with researchers to take on board consumer perspectives. This was a slow but ultimately successful process resulting in considerable cultural change for the majority of researchers who had direct experience of working with the CDRN. There continued 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 system

The CDRN 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 and DCRCs were met, and expanded upon through its involvement with National Health and Medical Research Council (NHMRC) initiatives, in particular the NHMRC Partnership Centre for Cognitive and Related Functional Decline in Older People.

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. The main system areas which the CDRN aimed to influence were within the Alzheimer's Australia national network, research entities such as the DCRCs, the Alzheimer's Australia Dementia Research Foundation and NHMRC; and, the broader policy context. The CDRN 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 Alzheimer's Australia 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 Alzheimer's Australia with the capacity to do so. The outcome enabled Alzheimer's Australia 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 were 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 Alzheimer's Australia.

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

4.5 CDRN Final Evaluation Report recommendations

Some important questions about consumer involvement in research were identified during the course of the CDRN evaluation, 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. The concept of consumer involvement in research was found to be firmly embedded within the Australian dementia research sector as a direct result of Alzheimer's Australia's CDRN.

The recommendations of the CDRN Final Evaluation Report are reproduced below:

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 CDRN.
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 participate¹⁷.

4.6 CDRN developments

Since the final evaluation report for the CDRN was issued there have been several important developments and considerable progress implementing the recommendations.

4.6.1 Progress against recommendations in Final Report

1. **NHMRC resourcing of consumer involvement in research.** Alzheimer’s Australia and members of the CDRN are continuing to liaise with the NHMRC to progress this issue. The current CEO was invited in 2014 to join the NHMRC Community and Consumer Advisory Committee which has emphasised this point among several other priorities to the NHMRC CEO and Council. Alzheimer’s Australia’s incoming CEO (commencing December 2014) has been a vocal advocate on this issue in her previous role as CEO of Consumer Health Forum, and is a member of the NHMRC Council.
2. **Funding for CDRN secretariat.** Alzheimer’s Australia has continued to fund and support a secretariat for the CDRN. Since mid-2014, these duties have fallen to a more general full-time consumer secretariat role within Alzheimer’s Australia National Office that supports the CDRN and three of Alzheimer’s Australia’s four other national consumer committees. This has allowed Alzheimer’s Australia to work with CDRN members and other consumer

¹⁷ Westera A, Thompson C, Morris D, Blissett C and Navakatikyan M (2013) Evaluation of the Consumer Dementia Research Network – Final Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

representatives to improve processes for communication, membership and meeting processes, although the work is ongoing. Further face-to-face meetings will take place once or twice each year as required.

3. **Review of Alzheimer’s Australia’s consumer participation processes.** As outlined above, Alzheimer’s Australia has reviewed and subsequently revised and consolidated many of its consumer participation processes across the consumer committees and groups supported by the National Office. Given the nature of the Alzheimer’s Australia Federation, it has not been possible to do so across the State and Territory organisations as recommended by the evaluation report, although some approaches and suggestions have been made.
4. **Development of strategic directions.** With the support of a consultant and long-term supporter of the CDRN, CDRN members undertook a strategic planning workshop at their face-to-face meeting in August 2014. This process identified three key priority areas for focus of members’ time (namely, NQDC projects; the forthcoming NHMRC National Institute for Dementia Research, and the Partnership Centre). Future work and commitments of CDRN member time are being planned and directed around the outcomes of these agreed strategic directions.
5. **Development of a suite of CDRN resources.** Some progress has been made against this recommendation; however the work to develop an induction program, training resources for consumers to enhance participation in research and guidelines for researchers in maximising contribution of consumers is ongoing.
6. **Implementation of a formal recruitment process.** A CDRN membership subcommittee was formed following this recommendation and this group has developed and successfully implemented procedures for formal recruitment and selection of new CDRN members.

4.6.2 Other developments

The most significant development in this space has been the announcement in the 2014 Federal budget of an additional \$200 million for dementia research over five years. This new funding responded directly to Alzheimer’s Australia’s Fight Dementia Campaign, and includes funding for priority driven research, capacity building, research translation and a new National Institute for Dementia Research. CDRN members formed an ‘NHMRC liaison subgroup’ at their August 2014 meeting and have been corresponding with the NHMRC CEO and senior executive about their priorities and preferred methods for consumer involvement in these activities. Alzheimer’s Australia’s CEO and National Research Manager have also been working closely with NHMRC management and are working towards both a significant level of involvement of CDRN members in the new National Institute, and involvement of CDRN members in assessment and review of dementia research funding applications to the NHMRC. It is anticipated that these opportunities for involvement will eventuate early in 2015 with the development of the new Institute.

In addition, in mid-2014, on the recommendation of members of the Alzheimer’s Australia Dementia Research Foundation (AADRF) Scientific Panel, two CDRN members were invited to join the panel on a trial basis to assist with decision and review of research grant applications to the Foundation. This involvement is so far proving to be positive, and the CDRN members

involved are working with AADRF and liaising with CDRN members to establish this arrangement on a permanent basis in 2015.

Finally, at the August 2014 meeting, CDRN members met to assess and decide on applications for a third round of NQDC projects, which will commence in early 2015 with additional funding obtained by Alzheimer’s Australia National Office from the J.O. and J.R. Wicking Trust and the Department of Social Services. The decision made by CDRN members was to support four new projects to be run through Alzheimer’s Australia organisations, and to commission three additional projects through external organisations that would best meet their specific priority areas.

4.7 Future directions

One of the main outcomes of the CDRN strategic planning session in August 2014 was the clear realisation that CDRN members’ time is limited, and the current and potential future demands on that time will soon exceed their capacity to respond. Consequently, decisions were taken by the group about the three key areas on which they would focus the majority of their time and effort, these being:

1. NQDC projects
2. NHMRC National Institute for Dementia Research
3. NHMRC Partnership Centre on Cognitive and Related Functional Decline in older people.

Beyond these priority areas, CDRN members agreed that opportunities for involvement (including in current and ongoing activities and programs including the DCRCs and AADRF) would be considered on a case by case basis in view of their alignment to the overall strategic objectives of the CDRN and members’ capacity to respond.

5 Discussion

5.1 NQDC knowledge translation projects

When the NQDCI was first established, the concept of knowledge translation was still relatively new; there had been an emerging recognition of the disparity between research outcomes and their application in practice within the health and care fields, and a number of international initiatives had commenced to better clarify the most effective processes to bridge that gap (refer to Appendix 4). The majority of these developments occurred within the broader health services research context, with dementia knowledge translation expertise emerging subsequently. Consideration of the relevance of these developments in regard to the NQDC projects has been discussed previously in this report (2.2.1); it is fair to say that just as the project leads have grappled with the knowledge translation strategies for their specific initiatives, the evaluation team has been on a similar journey.

5.1.1 Recent Australian developments in dementia research and knowledge translation

The dynamic environments in which the NQDC projects have operated include developments in terms of dementia research and knowledge translation, as well as service delivery and policy.

From a research perspective, perhaps the most significant shift has occurred within the National Health and Medical Research Council (NHMRC) which has initiated a number of responses to improve the application of research findings into practice. The NHMRC Knowledge Translation Faculty was established in 2012 in response to emerging international trends with a mandate to be ‘a key advisory forum to directly help NHMRC confront key challenges for the translation of health and medical research in Australia.’¹⁸ Membership is comprised of the approximately 2,800 established researchers, primarily NHMRC-supported Chief Investigators and NHMRC Fellows. The Faculty also has fourteen Steering Groups comprising key researchers in a particular field, one of which is dementia. The Steering Groups are charged with developing a ‘Case for Action’ which is designed to identify the opportunities to bridge the gap between the research evidence and practice, as well as potential strategies to improve the gap in terms of research evidence and practice and / or policy. These ‘Cases for Action’ were all expected to be completed by mid-2014; however, the NHMRC website contained no further developments at the time of reporting.¹⁹

Likewise, the NHMRC Partnership Centres (PC) have been established as a means to broaden the research agendas and processes to reflect the diversity of stakeholder interests in health and medical research, including consumers, service providers, researchers and policy perspectives in consortium arrangements. As we noted in our final evaluation report for the CDRN, this general development, and specific choice of Cognitive and Related Functional Decline as the first PC established, occurred subsequent to the July 2011 NHMRC Knowledge Translation workshop initiated by Alzheimer’s Australia and involving CDRN members.²⁰

¹⁸ National Health and Medical Research Council, Knowledge Translation Faculty

<http://www.nhmrc.gov.au/research-translation/research-translation-faculty>

¹⁹ <http://www.nhmrc.gov.au/research-translation/research-translation-faculty/research-translation-faculty-steering-groups>

²⁰ Westera A et al., op cit p30

Funding to improve the nation’s dementia research capacity was enhanced within the Australian Government’s 2014 Budget. Funding of an additional \$200m over five years was announced, including \$50 million ‘to target, coordinate and translate the national research effort to ensure existing and new research translates into better care for dementia patients’. Following the announcement, a key stakeholder meeting was held in June 2014 to clarify the detail of the ‘Boosting Dementia Research Initiative’ and identify priorities. The process informed the principles to underpin the Initiative, which included a number that aligned strongly with the focus of the NQDCI including:

- the involvement of consumers throughout the ‘research prioritisation, development and translation processes (noting that this is more inclusive than simple consultation)’;
- a focus on research translation ‘to induce systemic change in the health system and make a significant difference for dementia patients and carers’; and
- engaging with clinicians and providers ‘so that research findings are translated to inform practice and practice informs further research.’²¹

The Initiative also includes \$50 million for the new NHMRC National Institute for Dementia Research, which will bring together Dementia Collaborative Research Centres and the Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People ‘to improve coordination and collaboration in the dementia research effort.’ The Institute is also expected to ‘form a focus for rapid translation of evidence into policy and practice.’ The Dementia Collaborative Research Centres (DCRCs) have previously included knowledge translation as a component of its activities, particularly through the Assessment and Better Care (ABC) and Carers and Consumers (CC) Centres.

In addition, the Alzheimer’s Australia Dementia Research Foundation continues to offer a range of research grants for students and early career dementia researchers, with the 2014 Dementia Grants Program including 29 grants valued at over \$2.6 million advertised in two rounds.

Because of Alzheimer’s Australia’s advocacy efforts to achieve this budget outcome, and its long-term investment in dementia research and capacity building through AADRF, and in knowledge translation and consumer involvement through the NQDCI and CDRN, Alzheimer’s Australia and its consumer networks are well placed to have a central role in the prioritisation and implementation of the new research and translation measures that will come from this funding.

5.1.2 Recent international developments

There have been ongoing international developments in the dementia related knowledge translation field that also recognise the pivotal role of consumers in dementia research. These include:

- UK Medical Research Council Dementias Research Platform (UKDP) – established June 2014;
- Bournemouth University Dementia Institute (BUDI) – est. 2012
- Dementia and Neurodegenerative Diseases Research Network (DeNDRoN)
- French National Alliance for Life Sciences and Health (Aviesan) – est. 2009
- Canadian Dementia Knowledge Translation Network – est. 2008

²¹http://www.nhmrc.gov.au/_files_nhmrc/file/media/events/2014/dementia_stakeholder_forum_outcomes_14070_1.pdf

These trends are summarised in Appendix 7. The key message that can be derived from this précis is that the NQDCI reflects international developments in dementia related knowledge translation.

5.1.3 Implications for the evaluation of NQDC projects

The international developments in dementia research and knowledge translation have assisted in better understanding the complexities associated with dementia knowledge translation, as well as providing additional ways of assessing projects of this nature.

As noted previously in Section 2.2.1, the PARIHS framework suggests that Successful Implementation of an evidence based practice is an interaction of Evidence plus Context plus Facilitation, and provides a useful mechanism to consider the outcomes of the Alzheimer's Australia funded knowledge translation projects.

- Evidence – all projects had a sound evidence base upon which their interventions were premised. Some projects were based on research evidence that had been derived from similar settings (e.g. 2.5 Timely Diagnosis) or with similar consumer groups (e.g. 1.1 DEEP) while others were seeking to apply evidence from one setting to another (e.g. 1.2 Relate, Motivate, Appreciate); and still others were seeking to develop new evidence and test its application within a particular setting (1.3 Valuing People).
- Context – all projects employed strategies to ensure they understood the context in which the evidence was to be implemented. In some cases this involved direct experience working in the particular context (2.4 Staff-Family Relationships); others used a consortium approach and/or stakeholder consultation to better understand the context in which they were proposing to work (e.g. 2.2 Start2Talk).
- Facilitation – all projects used at least three or more professional behaviour change strategies that have been shown to be effective.

Based on the PARIHS framework, each project addressed the core elements (Evidence, Context, Facilitation) and therefore had the potential to lead to successful implementation. The extent to which this was achieved, however, was very much influenced by the interaction between the three elements. For the majority of projects, this appeared to have been positive, with evaluation data providing evidence of change in practice amongst target audiences. The extent to which the changes are able to be sustained in the longer term, however, remains uncertain given the limitations in terms of strategies and timing of the evaluation methodologies used.

We also assessed each of the projects against the competencies developed by the Canadian Dementia Knowledge Translation Network. Seven core competencies or skills have been identified as being requisite for translation of dementia research.²² Table 9 lists the competencies and provides a summary of their rationale, together with a brief indicator of achievement against each by the NQDC projects.

²² Canadian Dementia Knowledge Translation Network (CDKTN) Competencies for DKT <http://dementiakt.ca/dkt-learning-centre/what-is-dkt/dkt/>

Table 9 Competencies for Dementia Knowledge Translation

DKT Competency	Rationale	NQDC Projects
Understanding stakeholder goals and cultures	'It is imperative to understand the needs of all parties with an interest in DKT, as well as the contexts in which these needs are expressed.' ²³	All projects
Identifying the target audience	The complexity of care needs means that the range of stakeholders is 'significant – persons with dementia, caregivers, long-term care providers, physicians, researchers and policy makers.'	All projects
Fostering collaborations between knowledge users and producers	The multiplicity of factors and individual preferences of the person with dementia means that multiple groups need to work together to share knowledge and build consensus. 'These collaborations embrace partnerships and multi-directional communication.'	All projects
Translating evidence into policy and practice	Importance of the evidence being accessible to decision-makers as well as practitioners.	Most projects
Managing information and knowledge	Ensuring all stakeholders remain up to date and responsive to the information available.	Most projects
Appreciating the unique features of dementia KT	Taking into account the changing definitions of dementia, the dynamic changes in cognitive and decision-making abilities of persons with dementia, and the potential for stigma and discrimination.	All projects
Using DKT to mitigate stigma and discrimination	In recognition of the role that better understanding of the biological as well as social features of dementia, delivered through targeted knowledge translation efforts to identified groups 'can mitigate this adversity and improve the quality of life of people with dementia.'	All projects

Understanding stakeholder goals and cultures

All projects incorporated a range of stakeholders within the consortium arrangements and / or engagement processes employed. The majority of projects were cognisant of the different goals and cultures of the different interested parties, resulting in often dynamic processes of engagement which significantly improved the project processes as well as outcomes. A small number of projects had limited engagement with stakeholders, and these were projects with a narrow and specific focus and target audience. These projects delivered against the specified objectives in the project plans, however the onus for practice change remained with the individual person/audience being targeted, in turn limiting their capacity to effect sustainable culture change within related services and networks.

At the broader NQDCI program level, the inclusion of so many different stakeholder groups within individual projects has facilitated a greater understanding of the goals and cultures of Alzheimer's Australia both within the National Office and in the State and Territory organisations directly involved in the projects. This has the potential to strengthen existing relationships and identify future opportunities for improvements in dementia care.

²³ ibid

Identifying the target audience

The consortium arrangements were critical in assisting the majority of projects to clarify their intended target audiences, and develop strategies and resources that had the greatest potential to be effective. In some projects, this resulted in major refinements that required additional focus of effort and, in some cases, ‘in kind’ resources from the project host organisation were drawn on to do this. A small number of projects experienced difficulties engaging with the target audiences during the project implementation, primarily due to the specific contextual barriers which were in place (in particular in residential care). On the whole, however, most projects were able to adapt their proposed strategies and outputs (resources, training materials, websites) based on feedback from stakeholders to better target the needs of their audience and overcome potential barriers to implementation.

Fostering collaborations between knowledge users and producers

Collaborations between knowledge users and producers were primarily facilitated through the consortium and/or stakeholder engagement arrangements, which in the main included a mix of consumers, service providers as well as researchers and, in some cases, policy officers. The stakeholder interviews conducted throughout the evaluation highlighted the added value that:

- Consumers can bring to the research and knowledge translation process, in terms of refining the research questions and translation objectives, recruitment and implementation strategies, and through this enhancing researchers’ appreciation of the contribution consumers can make to the research process;
- Service providers can bring to the research and knowledge translation process, also resulting in refining the research questions as well as processes to make them more relevant for the needs and context of service provision;
- Researchers and academics can bring to service provision, through access to research evidence and processes (e.g. assessment tools); as well as influencing clinicians, practitioners and other professionals of the future through the curriculum development and workforce planning initiatives.

At the broader program level, the relationships between the Alzheimer’s Australia National Office and the different stakeholder groups was not always easy; in part this was because of the innovative nature of the overall initiative (in particular the consumer driven priorities) and the processes employed in selecting the projects during the first funding round. As the selection processes became clarified and there was greater engagement with Alzheimer’s Australia and potential project applicants, there appeared to greater acceptance of the overall direction of the NQDCI and the role of the NQDC projects in particular, and consequently less concern amongst stakeholders about maintaining their authority and/or primacy and improved collaboration on a practical level. It is likely that this was facilitated by the involvement of the Alzheimer’s Australia National Research Manager in the governance arrangements of each project, which actively demonstrated the collaborative intent of the projects and the NQDCI overall.

Translating evidence into policy and practice

Each project had a different objective: a small number sought to create new evidence, some sought to adapt evidence from a different sector to dementia care, and still others developed frameworks, protocols and policies to implement existing evidence into practice. All projects,

however, resulted in the translation of evidence into practices, processes and/ or policies in some form or other. The extent to which this was achieved was in part dependent on the capacity of the project lead and the stakeholder engagement processes employed that effected a targeted focus of effort and end product; it also was dependent on contextual factors that could not be anticipated at the outset, such as operational pressures and staff changes within participating organisations.

The capacity for the national program to influence policy and practice, however, has been diluted due to the limited engagement by key national policy personnel within the Department of Social Services (formerly Health and Ageing). It is unclear why the initial engagement subsided over time, although it is likely that a combination of factors reduced the degree of interest and/or participation, including key personnel changes, as well as structural changes arising from the change of government and creation of a new agency in which dementia policy is now located. Despite this, the NQDCI and CDRN initiatives are likely to have strengthened and added credibility to Alzheimer’s Australia continued advocacy for and input into national policy and program development with respect to dementia in health and aged care settings.

Managing information and knowledge

All projects employed communication strategies to ensure immediate stakeholders (predominantly consortium members) were kept up to date with progress, with the majority actively engaged in shared decision making and problem solving. Communication between projects was primarily facilitated through the participation of the Alzheimer’s Australia National Research Manager on each of the project governance arrangements; projects otherwise operated generally in isolation from one another. In our experience this is not an unusual feature of a multi-project program, however there are clear systemic advantages in facilitating cross-fertilisation of ideas and embedding of principles across sectors through facilitating communication opportunities between project leads directly. Although CDRN members were involved with individual projects from the outset, its capacity to oversight all projects and effect translation of learnings between projects was limited. As the second round of projects became more established, strategies were developed for a more streamlined and systematic oversight of projects as a whole, in turn assisting with deliberations regarding future project priorities.

Appreciating the unique features of Dementia Knowledge Translation

The changing nature of dementia, in terms of cognition and decision making abilities of the individual, as well as the research developments in terms of treatments and models of care, were primarily addressed in the projects through the involvement of representatives from key stakeholder groups (researchers, service providers, consumers) within the governance and/or advisory arrangements. The majority of project leads were responsive to new information as it emerged, incorporating these into resources and processes in order to reflect contemporary evidence.

The Service Provider Network and the Executive Committee that operated at the outset of the NQDCI were expected to be core mechanisms for strategic oversight of the projects, as well as being a source of information about developments that may be of relevance to the projects. However, both were short-lived, primarily due to resource constraints and competing priorities both within Alzheimer’s Australia National Office and amongst individual group members. The majority of members of both groups were already involved in individual NQDC projects, mainly

in advisory and /or governance roles, and this enabled them to provide localised input regarding contemporary developments within their respective sectors. The consequent dilution of impact at a strategic level across all projects and the NQDCI overall in turn also reduced their capacity to influence their own sectors of the breadth of developments and lessons learned.

Using Dementia Knowledge Translation to mitigate stigma and discrimination

All projects were underpinned by a consumer and person-centred focus; this was evidenced in the processes used as well as the outputs and resources produced. Fundamentally, the intent was not only about supporting target audiences to provide appropriate information and support, it was aimed at demystifying the nature of dementia to mitigate against stigma and discrimination. The CDRN evaluation clearly demonstrated the impact of consumer involvement in research and the NQDC projects on researchers, many of whom indicated a heightened respect for the capacity of consumers to actively engage in the research process. The projects that targeted health professionals and service providers likewise demonstrated improved levels of awareness of the needs and preferences of people with dementia, which in turn suggests a heightened awareness of and ability to respond to the stigma and discrimination consumers face.

It is ambitious to expect that the projects were able to impact beyond those immediately involved in activities, given the relative short timeframes in which they were conducted. It is expected that their influence will broaden over time, as awareness of the resources and processes developed and their utility become more widely known. While all projects incorporated strategies to address sustainability of outcomes, most will require ongoing resources to ensure currency of information and dissemination of resources in a timely manner. In our experience of similar short-term knowledge translation projects, the outcomes are likely to be limited without additional incentive or imperative, both within Alzheimer's Australia State and Territory organisations as well as within the relevant sectors. As noted above, the members of the Service Provider Network and Executive Committee who were all key influencers within their respective stakeholder groups (service provision, research, policy) were most likely only able to impact stigma and discrimination at a local level, rather than in the strategic and systemic manner as initially intended.

5.2 Consumer involvement in research

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, the evaluation team 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 four 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.^{24,25} 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 used to evaluate the CDRN.

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

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

Alzheimer’s Australia has been conscious of the need 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 in the lived experiences of dementia within the CDRN membership, and accords with the notion that it may be more helpful to think of different consumer ‘perspectives’ rather than ‘representatives’.²⁸

Several questions about consumer involvement in research were raised in the Final Report of the CDRN, 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?’ From the perspective of the NQDCI the evidence is found in changes that have arisen as a result of the contribution of the CDRN:

- More than fifty research projects have had input from consumers that may not have otherwise occurred;
- Approximately half that number again have been directly impacted on during the past four years by CDRN members;

²⁴ Sarrami Foroushani P, et al. (2012) Consumer and community engagement: a review of the literature, University of New South Wales and Agency for Clinical Innovation <http://www.aci.health.nsw.gov.au/consumers/consumer-engagement-research>

²⁵ Williamson T (2012) Ripple on the Pond. DEEP: The engagement, involvement and empowerment of people with dementia in collective influencing. Appendix to the main report. <http://www.mentalhealth.org.uk/publications/deep-appendix-2012/>

²⁶ Ibid

²⁷ Boote J, et al. (2010) Public Involvement at the design stage of primary health research: a narrative review of case examples. Health Policy, 95 (1): 10-23.

²⁸ Ward P, et al. (2010) Critical perspectives on ‘consumer involvement’ in health research: Epistemological dissonance and the know-do gap. Journal of Sociology, 46 (1): 63-82.

- Eight major knowledge translation projects implemented 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 in part as a result of the activities and advocacy of the CDRN.

6 Conclusion

The NQDCI has made significant in-roads to achieving its ambitious objectives of improving policy and practice to improve care for people with dementia in Australia, and facilitating consumer involvement in dementia research and knowledge translation. The most successful components of the initiative have been the knowledge translation projects and the establishment and sustained operation of the CDRN. The Service Provider Network and the Executive Committee were less effective in providing the strategic oversight and influence anticipated at the outset; however the majority of members of these groups did provide localised and more focused input within individual project governance and advisory arrangements.

Key functional outcomes

What has been evident is that the Alzheimer's Australia National Office in collaboration with the CDRN, and Alzheimer's Australia State and Territory organisations has been able to effectively select, monitor and support a range of national projects, implemented in diverse settings. Project teams have mostly delivered on all project objectives and the investment has represented value for money in terms of benefits for service providers and the broader aged care sector.

The result has been the implementation of eight small but specifically targeted projects that have addressed longstanding issues of concern for both persons with dementia and carers, service providers and the broader health and aged care sectors. These projects whilst limited in scale have demonstrated that implementation obstacles can be addressed. For example 2.2 Start2Talk effectively overcame inter-jurisdictional boundaries and 1.1 DEEP provides evidence of how initiatives can cross inter-sectoral barriers and engage diverse professional groups. Often government funding bodies may recognise what needs to be done but are constrained in what they can fund because of the strict nature of procurement processes. This can result in more innovative models of care not being funded, for example the 1.2 Relate, Motivate, Appreciate project. Despite the challenges this project faced many useful lessons were learnt about working with persons with dementia, their families and carers and residential aged care personnel.

Key strategic outcomes

This report has demonstrated that international developments are occurring which support consumer involvement in dementia research and knowledge translation. Alzheimer's Australia has taken a leadership role in demonstrating the application of these methods to improving dementia care within Australia. Whilst these are small initial steps, the concepts behind the NQDCI are reflected in international developments in dementia care and research.

The NQDCI has generated predominantly indirect gains for consumers, tangible and useful benefits for service providers and demonstrated to the broader aged care sector that consumers have the capacity to drive effective knowledge translation in collaboration with researchers and care providers. The NQDCI has enhanced Alzheimer's Australia's credibility as an organisation that is committed to real and sustained changes in policy and practice that improve the quality of dementia care in Australia. It has also demonstrated that Alzheimer's Australia has a strong commitment to consumer involvement in dementia research and dementia research knowledge translation.

The federated structure of Alzheimer’s Australia produces its own unique challenges and the NQDCI presented an important strategic opportunity to enhance collaboration between the National Office and State and Territory organisations in the knowledge translation space. The major challenge for Alzheimer’s Australia is the sustainability of the outputs and outcomes of these funded projects. Whilst all projects considered how they would maintain the momentum generated through their knowledge translation project, and several projects (e.g. 2.3 Active Body Active Brain) did succeed in establishing their operations on a sustainable basis, it is unclear how sustainability will occur in practice for the majority of projects without additional funding being available. It appears the best chance for success lies where projects have close relationships with State and Territory Alzheimer’s Australia organisations and have been able to engender a sense of ownership for the initiative. This has not been achieved in all eight projects. Sustainability is similarly an issue for the CDRN, as effective networks that consist of volunteers inevitably require ongoing support and a meaningful program of work. Consequently the CDRN will require ongoing investment by Alzheimer’s Australia.

Moving forward

The challenge for Alzheimer’s Australia is to capitalise on the gains achieved to date through the NQDCI by ensuring that the organisation continues to:

- sustain the relationships developed throughout the initiative;
- embed the national focus and consortium approach to the development and implementation of knowledge translation projects;
- engage researchers, service providers and policy-makers in the work of the organisation;
- consolidate a framework for consumer involvement in dementia research and maintain the primacy of consumers in the knowledge translation process;
- balance the perspectives of people with dementia and carers in priority setting for future knowledge translation projects; and
- collaborate with State and Territory Alzheimer’s Australia organisations to build on the successes of the NQDCI.

Appendix 1 Projects Funded

Project		Project leads	Funding
1.1	Dementia Enabling Environments Project (DEEP)	Jason Burton Alzheimer’s Australia Western Australia Prof Richard Fleming NSW/ACT Dementia Training Study Centre	\$249,660
1.2	Relate, motivate, appreciate: Restoring meaningful engagement with people with dementia	Dr Eva van der Pole Monash University	\$250,000
1.3	Person-centred dementia support in the community (Valuing People)	Dr David Sykes and Chris Pappon Alzheimer’s Australia Victoria Dr Chris Hatherly Alzheimer’s Australia National Office	\$250,000 (NQDCI) \$80,000 (Alzheimer’s Australia Victoria)
2.1	Integrated care framework for advanced dementia	A/Prof Meera Agar HammondCare	\$289,842
2.2	Advance Care Planning for people with dementia	Dr Chris Shanley Liverpool Hospital	\$324,000
2.3	Heart Foundation Walking – Active Body, Active Brain	Michelle Wilson, SA Heart Foundation Lenore de la Perelle, ACH Group	\$214,456
2.4	Improving staff-family relationships	Dr Michael Bauer Australian Centre for Evidence Based Aged Care (ACEBAC), La Trobe University	\$266,196
2.5	Timely diagnosis and management – GPs	Dr Allan Shell DCRC Assessment and Better Care	\$300,000
TOTAL			\$2,224,154

Appendix 2 Consumer Dementia Research Network Terms of Reference

1. Purpose

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

2. Principle Functions

The initial functions of the CDRN will include involvement with the National Quality Dementia Care Network (NQDCN) and the Dementia Collaborative Research Centres (DCRCs). 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 DCRCs may include:

- Advising the DCRCs 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.*

Year joined CDRN	Number of CDRN members
2010	19
2011	2
2012	2
2013	4
2014	3

Appendix 3 Service Provider Network Overview

Overview

The Service Provider Quality Dementia Care Network consists of a small group of senior managers and CEOs of influential Australian aged care providers who have demonstrated commitment to and innovation in providing quality care to people with dementia over many years. They have an active role in advising on key issues in dementia care and on strategies to achieve wide-spread change in practice. The Service Provider Network was convened in October, 2010, and is the newest component of the Initiative.

Principle Functions

The initial functions of the SPN are:

- To lend support, expertise, and credibility to the Initiative and to funded activities;
- To have a voice in decision making processes and strategic direction of the Initiative including comment on priorities and proposed knowledge translation strategies;
- To complement the Consumer Dementia Research Network in promoting outcomes and findings to broader networks;
- To act as a conduit for projects and their outcomes to service managers and care workers

Membership

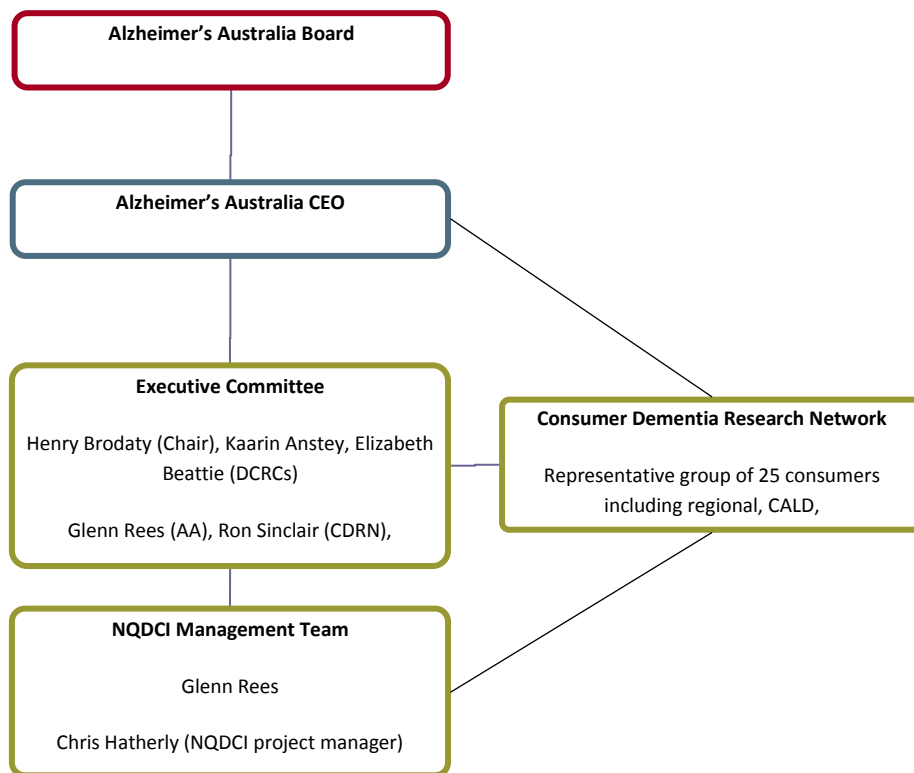
The Service Provider Network is made up of invited industry leaders with a strong interest in and commitment to improving the quality of dementia care services in Australia. The network currently includes CEOs and senior managers of nine providers representing most Australian states and territories. These organisations cover private, not-for-profit and government sectors, as well as community and residential care services.

October 2010

Appendix 4 NQDCI Governance Model

An Executive Committee, consisting of the chairperson of the CDRN, the Directors of the three Dementia Collaborative Research Centres (DCRCs), a service provider representative from Bupa Care Services, a representative from each of Alzheimer’s Australia and from the federal Department of Health and Ageing, and a knowledge translation advisor oversee the activities of the National Quality Dementia Care Initiative

The NQDCN and CDRN report to the Alzheimer’s Australia Board via the National Chief Executive Officer).



Appendix 5 Frameworks Informing NQDC Project Evaluation

The initial review of potential evaluation frameworks to inform the design of the evaluation focused on examples from the field of chronic care and public health.

Table 10 Chronic care and public health evaluation frameworks

Authors & Year of Publication	Evaluation Framework	Focus
Battersby, Ask et al. 2003; Battersby, Harvey et al. 2007	The Flinders Model originating in the South Australia 'HealthPlus' trials	Chronic care/public health
Centers for Disease Control and Prevention 1999; Chen 2001	Centers for Disease Control and Prevention – Framework for Program Evaluation in Public Health	Chronic care/public health
Feyer et al. 2003	Evaluation of the Sharing Health Care Initiative	Chronic care/public health
Hales et al. 2006	Evaluation of the Aged Care Innovative Pool Dementia Pilot	Dementia specific
Kilbourne, Neumann et al. 2007	Replicating Effective Programs Framework	Chronic care/public health
Mental Health Foundation, undated	Dementia Choices Evaluation Framework	Dementia specific
Mitseva et al. 2010	Intelligent System for Independent Living and Self-Care of Seniors with Cognitive Problems or Mild Dementia Evaluation Framework	Dementia specific
Murphy, Saunders et al. 2003; Stanford University 2007; Lorig and Laurent 2007	The Stanford Chronic Disease Self-Management Program	Chronic care/public health
Patton 1997, Williams 2010	Utilisation-Focused Evaluation	User focused
Wagner, Austin et al. 1996; Wagner 1998; Wagner, Austin et al. 2001; Bodenheimer, Wagner et al. 2002	Wagner's Chronic Care Model	Chronic care/public health

Quality Evaluation strategies and frameworks were reviewed, including quality improvement, organisational change to improve healthcare, implementation of evidence-based practice and use of clinical guidelines, and action research in health services.

Table 11 Quality Evaluation strategies and frameworks

Authors & Year of Publication	Quality Evaluation Focus
Berwick DM 2003	Diffusion/Dissemination of innovations
Dopson S, FitzGeralld L, et al. 2002	Diffusion/Dissemination of innovations
Greenhalgh T, Robert G, et al. 2004	Diffusion/Dissemination of innovations
Gustafson DH, Sainfort F, et al. 2003	Organisational change to improve healthcare
Grol R 2007	Organisational change to improve healthcare
Grol R and Grimshaw J 2003	Implementation of evidence-based practice and use of clinical guidelines
Grol R and Wensing M 2004	Implementation of evidence-based practice and use of clinical guidelines
NHMRC 1998	Implementation of evidence-based practice and use of clinical guidelines

Authors & Year of Publication	Quality Evaluation Focus
O'Brien JL, Shortell SM, et al. 1995	Quality Improvement
Rycroft-Malone J 2004	Action research in health services
Shortell SM, Bennett CL, et al. 1998	Quality improvement
Stetler CB, Damschroder LJ, et al. 2011	Action research in health services

Appendix 6 Key Success Factors and Principles of Practice Change

Key Success Factors (Masso and McCarthy 2009)²⁹

Used within the national evaluation of the Encouraging Best Practice in Residential Aged Care (EBPRAC) Program. The ‘key success factors’ provided a framework for structuring and directing data collection and analysis; to guide analysis of the links between project delivery and project impact; and assist in identifying the barriers and incentives influencing the use of evidence in day-to-day practice.

1. Receptive context for change
2. Model for change / implementation (including the role of specific change agents or facilitators)
3. Adequate resources
4. Staff with the necessary skills
5. Stakeholder engagement, participation and commitment
6. The nature of the change in practice, including local adaptation, local interpretation of evidence and ‘fit’ with current practice
7. Systems in place to support the use of evidence e.g. monitoring, feedback and reminder systems
8. Demonstrable benefits of the change

A receptive context for change includes factors such as leadership (including informal leaders), the existing relationships between staff, a climate that is conducive to new ideas and the presence of a recognised need for change.

Principles of Practice Change (Masso et al 2011)³⁰

Result of analysis of findings of the national evaluation of the Encouraging Best Practice in Residential Aged Care (EBPRAC) Program:

- Leadership - without someone to lead change it is probably not worth starting. One person might be able to start the change but it takes more than one leader to keep going. Leadership does not have to come from managers but if that is the case it is important that managers support the change.
- Staff motivation - the motivation of individuals working in residential aged care is one of the ‘keys’ to successful implementation.
- Change advocates - involving the people who will be affected by any change is important. Strong advocates for change may come from staff that would not normally be considered change agents.
- Evidence - simply having ‘evidence’ is not sufficient. Staff will want to know whether the proposed changes ‘make sense’ and will work i.e. provide benefits for themselves, their colleagues or residents.

²⁹ Masso M and McCarthy G (2009) Literature review to identify factors that support implementation of evidence-based practice in residential aged care. *International Journal of Evidence-Based, Healthcare*, 7 (2): 145-156.

³⁰ Masso M, Westera A, Quinsey K, Morris D and Pearse J (2011) Encouraging Best Practice in Residential Aged Care Program: Final Evaluation Report. Centre for Health Service Development, University of Wollongong.

- Education - education is necessary but not sufficient to change the practices of those providing care to residents. Education needs to be done in tandem with other strategies and tailored to the knowledge, skills and literacy levels of staff. A 'one size fits all' approach to education is likely to be ineffective.
- Communication - informal communication such as conversations and impromptu meetings can be just as important as more formal means of communication.
- Capacity to change - the capacity to implement evidence-based practice in residential aged care is limited, resulting in change that is likely to take place 'step by step' and in small doses rather than change on a more radical scale.
- Planning - some form of plan for implementing evidence-based practice is generally a good idea, but there is a need for flexibility to cope with unpredictable events that can upset those plans.
- Resources - resources are required, usually in the form of resources to provide education or to 'free up' at least some staff time to support change.

Appendix 7 Recent International Developments – Dementia Knowledge Translation

G8 Dementia Summit

The G8 Health Ministers met at the G8 Dementia Summit in London on 11 December 2013 to discuss how to shape an effective international response to dementia. The Summit noted the ‘importance of using existing evidence and knowledge to inform decision-making, as well as creating better and more robust monitoring and evaluation evidence’; and role that ‘research, knowledge translation and care’ can reduce its impact.³¹

French National Alliance for Life Sciences and Health (Aviesan)

Established in 2009, AVIESAN comprises stakeholders of life and health sciences in France includes objective of providing ‘a fresh boost to translational research by speeding up the transfer of fundamental knowledge to clinical application’. It’s ‘Neurosciences, cognitive sciences, neurology and psychiatry’ thematic institute has a complementary suite of objectives to ‘reduce the space between fundamental discovery and therapeutic application’, so that ‘translational research that will free up the practical application of scientific discoveries and vice versa’.³²

UK Medical Research Council Dementias Research Platform (UKDP)

Launched in June 2014, the UKDP is a public-private partnership developed and led by the UK Medical Research Council, to ‘accelerate progress in, and open up, dementias research’. The UKDP’s aims are early detection, improved treatment and ultimately, prevention, of dementias; it includes a focus on research translation as it applies to early-stage neurodegenerative disease, involving ‘intensive biomarker assessment of 24 pre-clinical Alzheimer’s disease patients, to determine whether patients would be willing to participate in future studies.’³³

Bournemouth University Dementia Institute (BUDI)

The BU Dementia Institute was established in 2012, with the objective of creating ‘an inclusive and supportive society for people affected by dementia’ through ‘high-quality research, evidence based education and staff development, knowledge translation through service evaluation and consultancy services’.³⁴ The Institute has undertaken several ground-breaking initiatives, particularly in relation to dementia-friendly communities, and includes knowledge translation as one of its research themes.

Dementia and Neurodegenerative Diseases Research Network (DeNDRoN)

Part of the UK National Institute for Health Research (NIHR), DeNDRoN focuses on translating research findings regarding dementia and neurodegenerative disorders (including Parkinson’s disease, Alzheimer’s Disease, Motor Neurone Disease and Huntington’s disease), ensuring they ‘receive the right support to make sure they are delivered successfully in the NHS’.³⁵ The

³¹ <https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-communique>

³² <http://www.aviesan.fr/en/aviesan/home/header-menu/multi-organization-thematic-institutes/neurosciences-cognitive-sciences-neurology-and-psychiatry>

³³ <http://www.mrc.ac.uk/research/facilities/dementias-research-platform/>

³⁴ <http://blogs.bournemouth.ac.uk/dementia-institute/about-us/about-budi/>

³⁵ <http://www.crn.nihr.ac.uk/dementia/>

Enabling Research in Care Homes (ENRICH) toolkit has been developed to support dementia research within care homes and by care home staff.³⁶

Canadian Dementia Knowledge Translation Network (CDKTN)

Established in 2008 through a grant from the Canadian Institutes of Health Research (CIHR), the CDKTN is a network for knowledge translation (KT) and exchange (KE) of research in Alzheimer’s disease and dementia. It brings together researchers, students, and practitioners from centres across Canada, and aims to assist researchers reach broader audiences, including families and caregivers. Resources developed include Introduction to KT; KT Planning Guide; and, Dementia KT Training site for researchers. Dementia Knowledge Translation (DKT) has been coined by the CDKTN as being ‘instrumental in the movement of research into clinical translation and the public sphere.’³⁷

³⁶ <http://www.enrich.dendron.nihr.ac.uk/>

³⁷ <http://lifeandminds.ca/>