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Care planning sub-program: findings from the national evaluation

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Abstract
This document is the final report for the national evaluation of the Care Planning Sub-Program funded by the Australian Government Department of Health and Ageing between April 2006 and April 2009. Thirty-three projects were funded across Australia. In this report we present an overview of the Care Planning Sub-Program, including its impacts on consumers, providers and the health system, the resources developed and the sustainability strategies employed by the projects. A companion report, Care Planning: description of projects funded to improve care planning in palliative care, provides details of each project's objectives, activities and impacts. A third report, Care Planning: report on activities of the national evaluation, addresses the deliverables in the evaluation contract.

CHSD

Centre for Health Service Development

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July 2009

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Suggested citation

Quinsey K, Williams K, Westera A and Morris D (2009) *Care Planning Sub-Program: findings from the national evaluation*. Centre for Health Service Development, University of Wollongong.

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1 Main messages

The evaluation of the Care Planning Sub-Program of the Local Palliative Care Grants Program has revealed a number of major lessons for the delivery of evidence-based, client-centred care, tailored to meet the needs of people with life-limiting conditions:

- End-of life services and care provision need to be planned and coordinated, and this requires dedicated resources. The aim of providing holistic care and support may not be realised unless there is a dedicated role responsible for organising, communicating and facilitating continuity in a person's care.

- Partnerships between providers and with carers are fundamental for people with palliative care needs. These partnerships need to be negotiated at the local level and in a defined geographic context, and require ongoing commitment, engagement and communication to ensure their sustainability.

- Palliative care is a part of the core business for residential aged care. Residents' wishes need to be actively sought and understood, and translated into practical action.

- Staff need to be provided with ongoing support to ensure their competence, capacity and confidence to engage in end-of-life discussions with residents, their families and carers.

- Staff need to be able to provide care that is evidence-based and in accordance with the residents' wishes. There is evidence emerging that appropriate end-of-life care *in situ* can significantly reduce the need for transfer to acute hospitals for the management of end-of-life issues.

This report details the evaluation findings of the sub-program, in which 33 projects were funded to improve the use of care planning to support clients to remain living at home during end-of-life care.

The projects targeted a range of settings, including residential aged care, community settings, primary care and acute care in a variety of urban and rural areas.

The National Evaluation Team supported the projects in their evaluation and project activities, and also facilitated the relationships between projects and between the projects and the broader palliative care sector.

What started out as 33 individual projects has grown into something much more than the sum of its parts, with the establishment of a community of practice in palliative care planning that is expected to continue to have an impact into the future.

The Care Planning Sub-Program has made a significant contribution in specific areas to improve the understanding of models, create shared processes and systems, and build the confidence required to improve care planning for people with palliative needs. It has also demonstrated the key attributes of program management required to support the individual projects to move from a sense of isolation to being active contributors to the broader agendas of the palliative care sector.

The findings of the sub-program clearly foreshadow the policy agenda set out by the National Health and Hospitals Reform Commission, in showing the importance of ensuring that the client's wishes and needs are at the centre of all health and care activity. They are a practical demonstration of the benefits of a multi-disciplinary approach to people with complex care needs and life-limiting health conditions. The lessons learned about how to promote best-practice in care planning, as well as program management, provide one blueprint for how the Commission's goals can be realised.

2 Executive Summary

Background
The Care Planning Sub-Program funded 33 projects across Australia to improve the use of care planning to support clients to remain living at home during end-of-life care. Projects targeted a range of settings, including residential aged care, community settings, primary care and acute care in a variety of urban and rural areas. A small number targeted specific population groups such as Aboriginal and Torres Strait Islanders, children, adolescents and young adults, people with dementia, and people with chronic heart failure.

What did the sub-program do?
A range of service models were produced that focused on providing a client-centred approach to palliative care planning, building partnerships between services and professional disciplines, and enabling smoother transitions between care settings. The models sought to build on evidence currently available, and develop education packages, resources, tools, frameworks and policies to underpin them. The activities primarily focused on building capacity of the clinicians and service providers who provide care, in order to improve outcomes for clients.

Evaluation was a mandated component of all projects in order to identify: evidence-based practice; impacts and outcomes; project lessons; the degree to which capacity has been built; and aspects which can be transferred or generalised, or sustained beyond the life of the sub-program. These activities were supported by the national evaluation, which aimed to provide an aggregated perspective on the outcomes of the program as they impacted on clients (patients/residents, their carers and/or families); providers (health, care and support) and the system (e.g. primary care and aged care organisations). Many of the project officers were experienced clinicians with little formal project management experience, and a program support function was also included within the evaluation role to assist projects with evaluation and project planning.

What did the sub-program achieve?
The major outcomes of the sub-program was an increased focus on delivering evidence-based, client-centred care, and the need for services to work in partnership to achieve this. Case conferencing and multidisciplinary team meetings were key aspects of around half of all projects, and there is now a solid body of evidence emerging to support these processes. Benefits identified include improved awareness of the range of needs of clients, improved relationships between different care and clinical providers and, particularly for generalist providers, improved understanding of palliative care issues.

Similarly, around half of all projects included a focus on end-of-life care pathways, which are critical to providing a structured approach to individualised care for people who are dying. These pathways focus on the individual (and their families and carers), using evidence-based assessment tools to develop individualised care, monitor and manage client needs, and the inclusion of end of life decision making tools, such as advance care plans or directives. Staff were supported with education, policies and procedures to give them the skills and confidence to participate in end of life discussions with clients and provide appropriate care responses. A number of aged care projects showed a reduction in the number of residents needing transfer to hospital for end-of-life symptom management due to improved use of pain assessment tools and appropriate medications.

It is not possible to estimate the actual number of people with palliative care needs who were supported by the sub-program, as that level of detail was not collected by all projects. However, evaluation findings from providers, who were the focus of much of the project activities, suggest that there were significant benefits for clients in the provision of more holistic and individualised, appropriately targeted care, and a reduction in the burden of care for carers.

Key lessons
The evaluation revealed a number of key issues which are central to improved care planning for people with palliative needs:

- Coordination of care requires dedicated resources to facilitate the processes. The reliance on general practitioners to have a primary role in care planning had mixed results; it worked well where additional resources were available in the form of a facilitator responsible for coordinating the involvement of all parties, and where responsive communication processes were in place.

- Partnerships are fundamental to the provision of holistic, planned and coordinated care for people with palliative care needs; however these must be negotiated at the local level and context. The use of formal service agreements is useful only when there is a sound relationship between service providers, and this requires ongoing commitment and engagement by all involved.

- Palliative care is part of the core business for residential aged care, and end-of-life care requires ongoing support to ensure the competence, capacity and confidence of care staff to engage in discussions with residents, their families and carers, as well as being able to provide care that is evidence-based and in accordance with the residents' wishes. Supporting care staff to provide quality end-of-life care will benefit not only the resident but also staff, as well as broader health system with reduced transfers to hospitals.

Building a community of practice in care planning
A significant achievement of the sub-program has been the development of communities of practice in palliative care planning that has the potential to continue to have an impact into the future. The national evaluation team included a focus on supporting individual projects with their evaluation and project activities, as well as facilitating relationship building among projects and with the broader palliative care sector. What started out as 33 individual projects has grown into something much more than the sum of its parts. Communities of practice have developed at the local level, with the building of partnerships through project activities such as inclusion of key players in advisory committees; the state and national levels, through the state forums and through national workshops facilitated by the national evaluators; and within service contexts, such as the aged care network established by the national evaluators.

Where to from here?
The Care Planning Sub-Program has made a significant contribution to the improvement in understanding the models, processes and systems required to improve care planning for people with palliative needs. It has also demonstrated the program management attributes which support individual projects to move from a sense of isolation to being active contributors to the broader agenda of the sector.

Within the last three years there have been a number of major changes in the policy context within which palliative care sits. At the national level, palliative care is now administered through the Office for an Ageing Australia, perhaps reflecting an appreciation of the need for older people to also be provided with the opportunity to have a good death. The National Palliative Care Strategy is being updated, the outcomes of which are likely to impact on State and Territory policies and priorities.

Significantly, there has been a change in government which has a strong reformist agenda for health and care services. The National Health and Hospitals Reform Commission's recent report has as its central theme the importance of putting clients as the focus of all health activity, and the recognition of the need for a multi-disciplinary approach to people with complex care and health needs. These echo the fundamental aspects identified through the Care Planning projects.

This final evaluation report contains a series of recommendations which seek to highlight the lessons learned from the Care Planning Sub-Program, in terms of program management, as well as best-practice care planning, which are drawn from the aggregated lessons and conclusions of the 33 individual projects, as well as through the evaluation activities undertaken by the national evaluation team. Together they provide a blueprint for future activities to support the improvement of care for people with palliative care needs.

3 Introduction

This document is the final report for the national evaluation of the Care Planning Sub-Program funded by the Australian Government Department of Health and Ageing between April 2006 and April 2009. Thirty-three projects were funded across Australia.

In this report we present an overview of the Care Planning Sub-Program, including its impacts on consumers, providers and the health system, the resources developed and the sustainability strategies employed by the projects. A companion report, *Care Planning: description of projects funded to improve care planning in palliative care*, provides details of each project's objectives, activities and impacts. A third report, *Care Planning: report on activities of the national evaluation*, addresses the deliverables in the evaluation contract.

3.1   Background

The Local Palliative Care Grants Program (LPCGP) was announced by the Australian Government in its 2005 Budget, as part of the Strengthening Cancer Care Initiative. Funding of $23.1 million was allocated over four years (2005-06 to 2008-09) and administered by the Department of Health and Ageing (DoHA). At the time of writing, the LPCGP had four sub-programs (or funding rounds), of which the Care Planning Sub-Program was the third.

The Care Planning Sub-Program aimed to improve the use of care planning to support patients who are living at home, including support for health professionals to enable patients to stay at home. It had three objectives:

1. to develop and implement flexible models of service delivery that meet the needs of each palliative patient in their local community;
2. to improve collaboration between services involved in providing care;
3. to support the smooth and appropriate transition between settings of care, e.g. residential aged care facilities, the person's home and inpatient facilities.

The 33 Care Planning projects each addressed some or all of six 'themes' associated with palliative care, which were defined by the Department of Health and Ageing:

1. Resources and tools
2. Strategies that involve carers and families in planning for care at key stages
3. Projects that develop and trial strategies or models of care that enhance care planning
4. Projects that address the needs of particular groups (e.g. residential care, children, Aboriginal)
5. Activities to support the translation of research on care planning into policy and practice
6. Projects to promote and support high-quality evaluation in the palliative care planning area

Each project was initially classified into themes by DoHA, and this classification was checked with the project officer or project manager by the National Evaluation Team (NET) early in the timeframe (at the first site visit) and again at the end (during the exit interview).

Tenders were invited in November 2005 for funding of between $100,000 and approximately $250,000 for organisations which best demonstrated an approach to improving care planning practices and resources, improving links and collaboration between health care providers and/or improving mechanisms for transition between settings of care. Approximately 138 submissions were received nationally. From these applications 33 projects were funded, totalling around $7.5

million over thee years. The Centre for Health Service Development (CHSD) was appointed national evaluator of the Care Planning Sub-Program in September 2006.

Funding was allocated to 33 projects, each of which was assigned a unique code by the NET at CHSD (Table 1).

Table 1   Coded list of Care Planning Sub-Program projects

Code	Host organisation	Project title
NSW-1	Calvary Health Care Sydney Ltd	Collaboration in trust and care: A transition model of palliative care to residential aged care
NSW-2	Feros Care Ltd	Northern Rivers Primary Palliation Response Project
NSW-3	Catholic Care of the Aged	Hunter Palliative Aged Care Collaborative Framework
NSW-4	H N McLean Memorial Retirement Village Pty Ltd	Northern New England Palliative Care Planning Project
NSW-5	Hunter New England Area Health Service	Bingara and Warialda Palliative Care Planning Project
NSW-6	Catholic Health Care Services Ltd	Catholic Healthcare – Palliative Care Plan Development
NSW-7	Mid North Coast (NSW) Division of General Practice Ltd	Mid North Coast Integrated Network Palliative Care project
NSW-8	Intereach Inc. NSW (formerly Regional Social Development Group)	Rural and Remote Palliative Care Planning Model
NSW-9	Riverina Division of General Practice and Primary Health Ltd	Rural Community Palliative Care Packages and Education
NSW-10	University of Western Sydney	Decision making frameworks in advanced dementia: links to improved care
NT-1	Top End Division of General Practice	Top End Palliative Care Planning
QLD-1	Blue Care	Fraser Coast Palliative Care Project
QLD-2	Queen Elizabeth II Health Service District	End of Life Care Pathways Project
QLD-3	Canossa Services	Collaborative approach to the planning and delivery of palliative care services for end-of-life care at Canossa Services in Oxley and in the South West Brisbane Community
QLD-4	Spiritus Care Services (formerly St Luke's Nursing Service)	Bayside Palliative Care Carers Support Group and Bayside Care4U
QLD-5	The Prince Charles Hospital	Hospital to Home: Palliation for Sick Hearts
QLD-6	The University of Queensland	Palliative Care Discharge Planning Project
SA-1	Daw House Hospice Foundation Inc	Case conferencing and care planning: an exploratory study
SA-2	Mid North Regional Health Service Inc	Mid North Palliative Care Referral and Care Planning Project
SA-3	Northern Yorke Peninsula Health Service Inc	Yorke Peninsula Palliative Care Planning Project
SA-4	Palliative Care Council of SA Inc	Metro Acute Palliative Care Resource (MAPCARE)
SA-5	South East Regional Health Service Inc	Linking palliative care services and generalist providers in the South East of South Australia
TAS-1	Tasmania Department of Health and Human Services	Multidisciplinary palliative care plans for specialist and primary care providers of palliative care and consumers
VIC-1	Ballarat Health Services	Listen up! Hearing all the voices in caring for palliative patients in a regional / rural setting
VIC-2	Melbourne Citymission Inc	Being smarter – a partnership model of palliative care
VIC-3	Monash University, School of Primary	What happens after dark? Improving after-hours

Code	Host organisation	Project title
	Care	palliative care planning in urban and rural Victoria, for patients, their carers and health professionals
VIC-4	Mornington Peninsula Division of General Practice Inc	I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)
VIC-5	Palliative Care Victoria	Way to Go project – creating partnerships to enhance access to palliative care
VIC-6	Peter MacCallum Cancer Centre	Improving palliative care services for adolescents and young adults with cancer
VIC-7	Royal Children's Hospital	A national approach to referral and care planning in paediatric palliative care
VIC-8	Wodonga Regional Health Service	A framework for supporting a patient / family centred palliative approach in a regional rural acute care setting
WA-1	Kimberley Aboriginal Medical Services Council Inc	The Renal Palliative Care Initiative, 'Finishing up?...Maybe soon…' Project
WA-2	Geraldton Palliative Care Service, WA Country Health Service trading as Midwest Murchison Health region	Midwest Aged and Indigenous Palliative Care Planning' Project

4 Methods of the national evaluation

Activities that comprise the national evaluation were described in detail in the *CHSD Evaluation Framework and Strategies* document (February 2007). To aid in understanding the evaluation report, a brief explanation of the framework, data sources and methods is provided here.

4.1 Evaluation framework

The evaluation framework drew extensively on the CHSD publication, *Evaluation and palliative care: a guide to the evaluation of palliative care services and programs* (Commonwealth of Australia 2004), and on the experiences of the CHSD in carrying out a range of other national evaluations, in particular, the Caring Communities Program, the Rural Palliative Care Program and Mental Health Integration.

The framework for the national evaluation comprises three levels of data gathering and analysis by individual projects and by the national evaluation team:

Level 1   Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)

Level 2   Impact on, and outcomes for, providers (professionals, volunteers, organisations)

Level 3   Impact on, and outcomes for, the system (structures and processes, networks, relationships)

At each of the three levels, six 'plain language' evaluation questions were posed to projects to help them consider all the relevant issues when designing their evaluations. These questions were also utilised at the program level to define the scope of the evaluation (see Table 2).

Table 2   Key evaluation issues for the Care Planning Sub-Program

'Plain language' questions	Corresponding evaluation issues
What did you do?	DELIVERY
How did it go?	IMPACT
Can you keep it going?	SUSTAINABILITY
What has been learned?	CAPACITY BUILDING
Are your lessons useful for someone else?	GENERALISABILITY
Who did you tell?	DISSEMINATION

In this report, the activities and their impacts and outcomes at Levels 1 and 2 (consumers, communities, professionals etc), are derived mainly from project-specific evaluation information; whereas the impacts and outcomes identified for Level 3 (structures, processes, relationships) are derived from a combination of project and sub-program evaluation information.

The role of the NET included regular formal monitoring of projects as well as a considerable amount of informal contact with individual project staff. Program-level activities, including three national workshops, site visits and a list server which enabled each project to share information with, and ask questions of, all the other projects, offered project officers many opportunities for training and support (see Sections 5.4 and 5.5). In addition to the traditional evaluation activities of monitoring and data collection, the NET (with the support of the program managers at DoHA) placed a strong emphasis on developing project planning and evaluation capacity within the projects, many of which were staffed by clinicians with little or no project experience. The evaluation framework, process and capacity-building focus developed for the national evaluation of the Care Planning Sub-Program is compatible with national palliative care standards and with best-practice directions identified in the palliative care literature.

Bringing together the issues of interest to the funding body with the national evaluation framework, the goals of the evaluation can be framed in terms of three evaluation questions:

1. To what extent did the sub-program, through the activities of the 33 projects, meet its objectives?

2. What impacts did the sub-program have on consumers (clients and carers), providers and the system (including any unintended consequences)?

3. What is the legacy of the sub-program in terms of sustainable processes and outcomes, capacity building, and lessons, processes and resources that can be generalised to other regions and services?

These questions have been addressed in Sections 5, 6 and 7 of this report, with key findings summarised in Section 10.

4.2 Data collection

The diagram below (Figure 1) indicates the sources of evaluation information on the effectiveness of the Care Planning Sub-Program and its achievements in sustainability, capacity building, generalisability and information dissemination.

Figure 1   Care Planning information flow chart

Project Progress Reports – six monthly

Reports provided directly to DoHA and the NET

Exit Interview Report

Exit interviews conducted at end of the sub-program.

National Workshops

Annual reports provided directly to DoHA plus information also used in NET progress reports

Project Evaluation Progress Reports – six monthly

Reports provided directly to the NET

Site Visits

Extensive information gathering/generating process

Project sustainability, capacity building, generalisability

Information gathered from the projects at initial site visits and at project completion

Project Summary Template

Draws together project specific information

NET to DoHA Progress Reports and Final Report

Draws together project and sub-program information and data Develops analysis and draws conclusions

Project Dissemination Log

Dissemination information provided at six monthly intervals to the NET

Project Final Reports

Reports provided directly to DoHA and the NET

Key stakeholder survey

Online survey of DoHA team members and other key stakeholders Report provided to DoHA

4.2.1   Project evaluation methods

Each project was required, as part of its contract with DoHA, to carry out an evaluation. Some guidance was provided; however, the scope and nature of the evaluation was not specified.

The NET worked closely with project officers, providing assistance where necessary to develop evaluation plans, and advice on sourcing or designing tools and conducting data analysis. Where possible, to maintain continuity of support and gain a deeper understanding of the projects, NET members worked with the same projects for the duration of the sub-program.

The support provided by the NET included:

- conducting an evaluability assessment (i.e. the extent project activities could be evaluated) during the first site visit
- advising on ethics and collecting information on the status of projects' ethics applications
- assisting with project and evaluation planning
- helping identify and source evaluation tools, and reviewing tools drafted by project staff
- providing a template for the evaluation plan, and templates for progress and final reporting on evaluation activities
- presenting information at national workshops
- help and advice to individuals on dealing with challenges in evaluation as they arose.

Each project (except QLD-1) received a visit from a member of the NET during the first year of the program. The one exception was a project that was in abeyance due to the resignation of the project officer, and the site visit was conducted as soon as possible after a new project officer was appointed. The site visit followed the format of an extended, semi-structured interview to ensure that a consistent set of information was collected from each of the projects. The visits and discussions took on average four to six hours to complete. Evaluation plans were discussed and an evaluability assessment conducted (the findings were reported to DoHA in our second progress report). A questionnaire, the Sustainability and Spread Tool, was administered as a structured interview during the visit (see Section 7 for details of this tool and findings). Project officers were given an electronic copy of the dissemination log and asked to complete and submit it with their progress reports at six-monthly intervals.

The evaluability assessment found that the project plans developed by most projects did not include evaluation of impacts and outcomes. Instead, they were generally limited to performance measures which indicate whether or not project activities have been completed. Projects were encouraged to review their project plans and to identify key activities that could be evaluated. In addition, projects were asked to follow the palliative care evaluation framework to consider impacts and outcomes at Levels 1, 2 and 3.

Of the 33 Care Planning projects, 19 obtained ethics approval. The remaining 14 did not apply, usually because project managers or steering committees decided it was not required. Often these projects were considered quality-improvement activities. The NET had an advisory role and could recommend obtaining ethics approval, but the final decision lay with individual projects.

Projects were encouraged to use standardised tools wherever possible, to maximise the chances of being able to compare results across the program. Ultimately, however, many projects sourced or drafted their own, purpose-built evaluation tools. The NET collated and distributed a list of tools being used by projects, and also distributed the Palliative Care Outcomes Collaboration clinical assessment instruments, which were adopted by several projects.

Progress and final reporting templates were included in the projects' contracts with DoHA. The NET also developed detailed templates for progress and final reports, which were designed to capture the information required by the evaluation framework.

The Sustainability and Spread Tool was completed again during the exit interviews which were conducted with project staff during the last month or two of each project's timeline.

Data collection methods used by projects were mainly questionnaires, interviews and focus groups or group discussions. Most of the data collected were formative; that is, they were used to inform the development of service delivery models and resources, or to identify education needs of providers. Very few projects attempted to conduct rigorous evaluations involving before-and-after measures of the impacts of their interventions. Where these types of evaluations were conducted, difficulties in recruiting participants meant that sample sizes were often so small that the planned analyses could not be conducted, or lacked power to detect effects with statistical significance. Several projects, however, had access to rich qualitative data sets.

A detailed description of the evaluation activities carried out by individual projects can be found in the companion report, *Care Planning: description of projects funded to improve care planning in palliative care.*

4.2.2   Program-level evaluation methods

The national evaluation of the Care Planning Sub-Program was designed to draw primarily on the aggregate findings of the 33 project evaluations. The activities, achievements and constraints of the projects are described below, with reference to the objectives and themes of the sub-program and the levels of the evaluation framework. In addition to this project-level information, data were also collected at a program level, via the following methods:

- Analysis of the project selection process
- Online survey of external stakeholders
- Reports on the three national workshops
- Exit interviews with project staff

A review of the project selection process was part of the overall program evaluation. The NET received a copy of the 'Assessment Process Overview – Care Planning' document from DoHA, which outlines the application process, the assessment panel composition and the four stage assessment process. Following on from this overview, the NET sent a list of questions on project selection to DoHA and received a written reply. The NET also reviewed the original application guidelines. Findings from this analysis were included in our third progress report.

The online survey of stakeholders, national workshops and exit interviews are described within this report, and findings have been reported separately to DoHA.

4.2.3   Limitations of the national evaluation

The NET had no authority to require a project to develop an evaluation plan or to carry out evaluation activities, or indeed to use the additional reporting templates provided. Although projects were required to consult the document, *Evaluation and palliative care: a guide to the evaluation of palliative care services and programs* (Eagar, Cranny and Fildes, 2004) during the program application process and its use was mandated in project contracts, the evaluability assessment indicated that six projects had not done so. Most project staff did recognise the value of conducting and reporting evaluation activities, but some were prevented from doing so by lack of time or other constraints (see Section 5.3.1 for information on the challenges faced by projects in carrying out evaluation). Despite reminders and encouragement, some projects did not have an evaluation plan. Therefore, the project activities and their impacts and outcomes have been

reported below in good faith by members of the NET, based on the information provided by projects through a range of sources, as indicated in Figure 1. In some cases, the information was limited or incomplete.

5 Activities of the Care Planning Sub-Program

This section of the report focuses on the question, 'What did projects do to achieve their goals and the objectives of the sub-program?' First, project activities are classified according to their contribution to achieving the three objectives of the sub-program and the themes identified by DoHA. Their activities are then described in terms of the three levels of the national evaluation framework. Finally, activities facilitated by DoHA and the NET at the program level are outlined.

5.1   Project activities in relation to sub-program objectives and themes

The Care Planning Sub-Program was established to target palliative patients living at home, either directly or by supporting health professionals and care providers to enable clients to stay at home, whether that was in their own private residence or a residential aged care facility. This overarching goal was defined in terms of three objectives listed above (Section 3.1). Each host organisation had a contract with DoHA that specified which of the three objectives its project was to address. In addition, DoHA classified the projects into six themes, based on the proposed activities.

These classifications were checked with the project officer or project manager by the national evaluation team (NET) at the first site visit. The program objectives and themes allocated to the project were reviewed and discussed. Project officers were asked to explain how their project objectives related to the objectives of the sub-program. Some were able clearly to articulate the connection between program and project objectives and how these had been defined in terms of specific activities in their project plans. Others were not aware of the program objectives, and this lack of knowledge was reflected in their project plans. A few project officers were advised to review their project plans to ensure that the link between the program objectives and the project plan was clearer.

As a result of discussion at the site visit, a few projects had their contracts changed to include one or more additional program objectives.

The project officers were asked during the exit interviews whether their projects had attained the allocated program objectives and themes. (Note that this does not mean that their contracts were changed to align with their comments.) As Table 3 shows, there was considerable change in the focus of projects during the course of the sub-program.

A third of the projects expanded their focus to include more program objectives than originally specified in the contracts. There was a shift overall from projects' having one objective to addressing two or three program objectives. Seventeen projects did not change the program objectives aligned to their project.

About three-quarters of the projects reported that they had developed and implemented flexible models of service delivery. The majority of the projects reported they improved collaboration between services involved in providing care, and supported the smooth and appropriate transition between settings of care.

Table 3   Sub-program objectives at project commencement and completion

Sub-program objectives	Commencement*	Completion#
Objective 1 only	2	0
Objective 2 only	2	1
Objective 3 only	2	1
Objectives 1 & 3	2	1
Objectives 1 & 2	4	5
Objectives 2 &3	5	7
Objectives 1,2 & 3	16	18
TOTAL	**33**	**33**

* *Indicates how projects were classified by DoHA in their contracts.*
# *Self-classification by project staff after activities completed.*

Overall, projects reported that they had addressed more themes at project completion than originally allocated (Table 4).

Table 4   Themes at project commencement and completion

Types/ themes	Commencement*	Completion#
1. Resources and tools for patients, families, carers or health professionals, including residential aged care staff, that assist in care planning	13	31
2. Strategies that involve carers and families in planning for care at key stages	1	28
3. Projects that develop and trial strategies or models of care that enhance care planning	26	31
4. Projects that address the needs of particular groups (e.g. residential care, children, Aboriginal)	13	18
5. Activities to support the translation of research on care planning into policy and practice	2	27
6. Projects to promote and support high-quality evaluation in the palliative care planning area	1	11

* *Indicates how projects were classified by DoHA. One project was not included in the original classification table.*
# *Self-classification by project staff after activities completed.*

By the end of the sub-program, almost all projects had developed resources or tools. These had different target groups - patients, families, carers or health professionals, including residential aged care staff – and purposes in assisting care planning, which was broadly defined. There was also a strong emphasis on developing and trialling models of care or service delivery which incorporated care planning. Most projects developed strategies to involve carers and families planning care for their loved ones.

There was one project that addressed the needs of adolescents and young adults, one focusing on paediatric patients requiring palliative care, and two that specifically consulted with, and designed materials and processes for, Aboriginal and Torres Strait Islander people. Nearly half the projects had a focus on residents of aged care facilities.

A remarkable change from the start to the end of the sub-program was the number of projects that reported (in their exit interviews) that they had implemented activities to support the translation of research on care planning into policy and practice. Additionally, more projects felt their projects had promoted and supported high quality evaluation than originally anticipated.

The sub-program was designed to meet its objectives through the activities of the 33 projects, and Tables 3 and 4 show the extent of activity in relation to each of the program objectives and themes. If the project objectives are met, and are linked clearly to the program objectives, then conventionally, evaluation logic would state that the program objectives have been met.

In practice, however, the sub-program objectives are not mutually exclusive and most of the project activities served several objectives. Similarly, the themes defined by DoHA overlap considerably and it is not possible to classify projects or activities neatly according to these themes. For example, diverse resources such as assessment tools, patient diaries and referral forms were developed and used by care planning projects to support new models of service delivery and to improve communication and collaboration between providers so that clients and carers experienced more seamless transitions between settings. Furthermore, the objectives specified in projects' contracts, and the themes assigned to them by DoHA, were not always linked explicitly to activities in project plans.

For these reasons, we do not use the objectives and themes as a framework for reporting project activities and impacts. Instead, in the following sections, we discuss project achievements and constraints in the context of the three levels of the national evaluation framework, drawing this information together to demonstrate how the combined activities of the projects served the sub-program objectives.

Specific information on the activities and impacts of each project is available from the companion report, *Care Planning Sub-Program: description of projects funded to improve care planning in palliative care*.

5.2   Project activities in relation to the national evaluation framework

The 33 Care Planning projects, most of which operated for two or three years, between them undertook hundreds of individual activities directed towards achieving their own, and the program's, goals of enhancing collaboration between services, smoothing transitions between settings of care, and developing new models of service delivery. As indicated above, many of these activities served several program objectives at once, making it difficult to classify the activities according to specific objectives. Similarly, the six themes applied to the projects by DoHA are not mutually exclusive; neither do they provide a comprehensive framework to cover the diversity of activities undertaken by projects. Given the masses of data generated by projects, another framework for classifying and organising information around project activities was required in order to present a clear picture of what they, and the program overall, have achieved.

In the following section, we have drawn on two separate classification systems in order to present information about the activities of care planning projects. The first is the three levels of the national evaluation framework - consumers, providers, system - described in Section 4.1. Use of this framework enables us to link the impacts and outcomes described in the next part of this report (Section 6) with specific types of activities.

The second is a taxonomy of organisational interventions developed for use in systematic reviews. It was designed to provide a common language for reviewers to describe and classify interventions. In its data collection checklist, the Cochrane Effective Practice and Organisation of Care Review Group (EPOC, 2007) identifies three types of organisational interventions, oriented to patients, providers and structures. These categories correspond with the three levels of the national evaluation framework, and have a number of sub-categories that are applicable to the Care Planning Sub-Program activities. EPOC (2007) also highlights professional interventions, directed at providers, and financial interventions that may be directed at providers or patients, which again are consistent with the types of activities undertaken during the sub-program. The EPOC (2007) taxonomy was adapted for a systematic review of the literature on business process redesign – which is also consistent with the change-management focus of most care planning

projects – and the tables below are modelled on data tables presented in that paper (Elkhuizen et al., 2006).

Additional categories at Levels 2 and 3 have been drawn from the evaluation of a clinical services redesign program in NSW (Masso et al., 2007). The taxonomy is a generic framework designed to apply to all types of interventions aimed at enhancing effective practice and organisation of care. In order to include detailed categories reflecting specific activities applicable to palliative care clients and their carers, the intervention types at Level 1 (Table 5) were derived from recommendations in the National Standards (Palliative Care Australia, 2005b) which define best practice in palliative care. The introduction to the Standards emphasises the need for equal access to palliative care for all Australians and identifies a number of population groups that may require the palliative approach. Where relevant to the Care Planning Sub-Program, these groups have been listed in the Level 1 table (Table 5).

The text and tables below describe the project activities in terms of the three levels of the national evaluation framework (consumer, provider, system) and the taxonomy of interventions. Information about the success (or otherwise) of implementation strategies, and the impacts and outcomes identified in the project evaluation findings, can be found in Section 6.

5.2.1 Activities targeting consumers

Care Planning projects reported a variety of activities directed at palliative care clients and carers. Consistent with the objectives of the sub-program, there was a strong emphasis on improving communication so that transitions in care settings were as seamless as possible. A common intervention type was personalised communication mechanisms in which information and future plans specific to the client and carer could be recorded. For example, to improve communication with community care, residential aged care and primary care services following discharge from hospital, the QLD-6 project devised a patient-held record folder containing an information sheet, communication log, palliative care plan (PCP) form and envelope for summaries and medication lists, with key information regarding the patient's preferred location for end-of-life care, health directives and enduring power of attorney. SA-3 adapted and evaluated a patient diary for distribution by community health services to palliative clients living in their own homes. Information attached to medical records, care planning tools and case conferences resulting in care plans also fell into this category, although clients and carers did not always participate in these activities directly.

Several projects set up systems to involve clients and carers in care planning, mainly by encouraging them to think about and write down their wishes for the future in Advance Care Plans, or by enabling them to take part in case conferences.

Provision of care based on need was a key focus for many of the projects. These activities took various forms, including improved assessment tools, referral procedures (backed up by formal agreements among services) and guidelines for best practice in care and symptom management. Systems were put in place to ensure that end-of-life care of the highest quality could be delivered in community and aged care settings. While many of these activities were implemented with providers and at the system level, their goal was to improve clients' and carers' experiences and enhance their well-being.

Carers' needs were recognised and addressed by many of the projects, an approach supported by the National Palliative Care Standards. One project (QLD-4) focused exclusively on carers, with support groups running weekly on a six-week program, assessment of carers at risk of complicated grief, and referral to other services including a specialised bereavement support program. Other projects (e.g. NT-1, NSW-2) offered practical help such as equipment, home cleaning or respite, individual psychosocial support by a social worker (NSW-8 and NSW-9), or carer training and education workshops. Implementation of care coordination systems by four projects also helped reduce the burden on both carers and clients.

A third of the projects produced materials such as brochures, leaflets and DVDs, to inform clients and carers of the services available locally, or about the palliative approach, or about specific topics such as treatment options, coping skills, symptom management and what to expect when caring for a palliative patient at home.

Clients and carers were included in consultation processes regarding proposed changes in service delivery models, along with providers (see 'Marketing' in Table 6 below). In addition to the projects listed in this category (which involved specific consultation activities), many other projects had consumer representatives on their steering committees.

It is notable that 17 of the 33 Care Planning projects were based in regional or remote areas and addressed issues of service delivery and care planning that face clients and carers who live outside the metropolitan areas. Nevertheless, the focus of most projects was on the general population of palliative clients and carers, rather than particular demographic or diagnosis groups.

Table 5   *Interventions directed at clients and/or carers (Level 1)*

Intervention category	Project numbers	Examples of activities
Consultation regarding service delivery	QLD-1 QLD-6 SA-2 SA-3 VIC-3 VIC-8	▪ Clients were surveyed regarding knowledge of palliative care and needs for service provision. Community need was assessed through public forums. This information was used in the development of a regional model. ▪ In-depth interviews with clients and carers to inform development of new discharge processes from hospital ▪ Carer's group advising on new processes and tools ▪ Semi-structured interviews with clients and carers regarding their care and services utilised, including need for after-hours services ▪ Activities aimed at identification of issues and opportunities (obtained through stakeholder interviews and focus groups, literature search and site visits)
General information	NSW-3 NSW-4 NSW-5 NSW-8 NSW-9 NSW-10 TAS-1 VIC-3 VIC-4 WA-1 WA-2	▪ Pamphlet on coping skills, and the promotion of the course 'Seasons for Growth', which was delivered by the local Catholic Diocese ▪ Brochure outlining Palliative Care Planning Coordination Services, and a comprehensive local resource guide ▪ Community information pamphlet about the project and the palliative approach to care ▪ 'Caring at Home' booklet ▪ Pamphlet on weight loss in advanced dementia ▪ Fact sheets for consumers (22 topics were covered) ▪ Brochure focusing on expectations of after-hours care and emphasising the importance of using these services when needed ▪ A booklet for families and carers about the provision of palliative care in RACF ▪ Culturally appropriate kidney educational resources including posters, booklets, a brochure around kidney disease prevention and treatment options, developed in cooperation with members of the indigenous communities ▪ DVD and brochure which targeted the broader Aboriginal community and carers of people with palliative care needs (in draft form)
Personalised information and communication mechanisms	NSW-4 NSW-5 NSW-7 NSW-8 NSW-9 NT-1 QLD-1 QLD-6 SA-2 SA-3 VIC-6 VIC-7 WA-1	▪ Care plans based on Guidelines for a Palliative Approach in Residential Aged Care (2006) ▪ Home-based record of care folder plus patient diary and carers resource box ▪ Case conferences (but not involving patients/carers) resulting in multi-disciplinary care plans ▪ Patient card (two-way communication mechanism) and Yellow Envelope containing key information about a client's assessed needs and treatment strategies ▪ 'Home Notes' ▪ Diamond Register and Palliative Care Partnerships established with GPs caring for palliative patients and their family carers ▪ 'My Health Diary' for palliative patients, based on one developed in Adelaide Hills Rural Palliative Care project (used by several Care Planning projects)

Intervention category	Project numbers	Examples of activities
		▪ A patient-held record folder containing an information sheet, communication log, palliative care plan (PCP) form and envelope for summaries and medication lists, with key information regarding the patient's preferred location for end-of-life care, health directives and enduring power of attorney ▪ Diaries distributed to patients via GP surgeries or via community health service visits ▪ Care planning tools and guidelines for children with a life-limiting illness and their families ▪ Communication tools incorporated into patient medical records, including a sticker, summary form, health service transfer form, case conference form and family meeting form
Client and carer involvement in care planning	NSW-1 NSW-3 NSW-4 NSW-6 SA-1 VIC-1 VIC-4 WA-1	▪ Advance Care Planning ▪ Case conferences with patient/carer participation, resulting in multi-disciplinary care plans ▪ Patient Information Form to share information between providers and engage patients and carers in the care planning process
Psychosocial support, practical help and education for the primary caregiver	NSW-2 NSW-8 NSW-9 NT-1 QLD-4 WA-1 WA-2	▪ Two tiers of equipment and services: low care package (over toilet support, four wheel walker frame with seat, shower chair with supports, bed stick and lambs wool rugs) and high care package (above plus electric bed, overlay or pressure air mattress, bedside commode, and incontinence protection products) and carers pack ▪ Carer education workshops ▪ Individual psychosocial support by social worker ▪ Coordination of carer respite and home and domestic assistance and referral to support services ▪ Systematic assessment and immediate referral to Carers NT when the palliative patient was referred to the specialist service, plus resource kits and practical help (e.g. respite, home cleaning) ▪ Carer support groups meeting weekly for six weeks ▪ Bereavement support model including assessment, support groups, telephone support, home visits and referral for counselling if required ▪ Respite care for carers to enable them to attend the support groups ▪ Carer support group ▪ Aboriginal Carer's Training Package based on two existing resources and tailored to the specific needs of the Aboriginal people of Geraldton ▪ Carer's Picnic and Recognition event during Carers Week, and two carer training sessions ▪ Information and gift bags for the participants of the National Respite Carer's 'Caring for our People' training program
Access to care based on need	QLD-4 SA-5 VIC-4 VIC-6 VIC-7	▪ Assessment of bereaved carers at risk of complicated grief, followed by bereavement support and referral ▪ Regional model of service delivery which directs the provision of health care resources according to patient needs, by primary care providers, the specialist service, or a combination of both ▪ Increased use of pain assessment tools and pain charts for residents of RACF who received Specialist Palliative Care Consultancy ▪ Use of various assessment tools to better describe and understand the population of adolescents and young adults with cancer ▪ Assessment tool and pain and symptom management plan included in PaedPallCarePlan suite of care planning tools and guidelines
End-of-life care (including symptom management and psychosocial support, after-hours access to health professionals)	NSW-1 NSW-2 NSW-3 NSW-4 NSW-7 NSW-8 NSW-9 NSW-10 QLD-2 QLD-5	▪ End-of-life care pathways for RACF ▪ A 1300 number for all incoming calls during business hours and after hours, provided to all patients on their home file, available in the service brochure and in large print on fridge magnets. ▪ Additional funding for existing after-hours telephone support service ▪ Carer support and information available 24/7 through telephone support ▪ Medication imprest system in RACF ▪ A home intravenous frusemide pathway to support the use of this technology in heart failure patients' homes, enabling them to live in

Intervention category	Project numbers	Examples of activities
	TAS-1 VIC-4 WA-2	the community and have their symptoms adequately managed ▪ Inpatient integrated end of life pathway ▪ Development of a policy and guide for storage of essential palliative care medications in RACFs to prevent transfers of residents to hospital ▪ Four symptom management frameworks – pain, constipation, weight loss and agitation - for residents of aged care facilities
Care coordination to reduce burden	NSW-6 NSW-7 NSW-8 NSW-9	▪ PallCare Packages (flexible, specialist care planning tools and interventions including case management by social workers)
Building community capacity to respond to the needs of clients and carers	NSW-5 QLD-1 VIC-8	▪ Use of community services in production of resources e.g. local 'Men's Shed' bound the patient diaries; community information sessions held in local club, and launch of pain DVD in local theatre ▪ Awareness raising activities such as stalls at fairs and conferences, posters, brochures and leaflets ▪ A project launch was conducted using a 'hypothetical' format, facilitated by a local well-known comedian/actor and attended by 40 people, including participation from commonwealth, regional, cross-border and local services, and carers and past consumers. ▪ Community and public health initiatives (health promotion) involved the coordination of community 4 funerals in One Day (play) planning group, and Pilotlight Dying to Know books)
Interventions targeting non-malignant illness	NSW-10 QLD-5 WA-1	▪ Dementia: development of symptom management frameworks ▪ Advanced heart failure: end-stage symptom management protocol ▪ Renal failure: improved care planning for patients
Interventions targeting Aboriginal and Torres Strait Islanders	QLD-1 SA-3 WA-1 WA-2	▪ Aboriginal Health representative on steering committee, presentations to Aboriginal health service and active efforts to recruit Aboriginal patients into the trial ▪ Improved care planning for people living in the Kimberley region with End Stage Renal Disease (ESRD), the vast majority of whom are Aboriginal ▪ A number of activities were undertaken to address the needs of the local Aboriginal clients with palliative care needs, working in partnership with the Geraldton Regional Aboriginal Medical Service
Interventions targeting children and adolescents	VIC-6 VIC-7	▪ Adolescents and young adults: integrating palliative care planning within a cancer care hospital setting, including specialised assessment and proactive follow-up ▪ Children: six care plans for children with life-limiting illness and their families
Interventions targeting residents in rural and remote areas	NSW-4 NSW-5 NSW-8 NSW-9 QLD-1 SA-2 SA-3 SA-5 VIC-1 VIC-3 VIC-4 VIC-8 WA-1 WA-2	▪ Models of service delivery ▪ Communication mechanisms such as patient diaries
Interventions targeting residents of aged care facilities	NSW-1 NSW-3 NSW-4 NSW-5 NSW-6 NSW-7 NSW-10 QLD-2 QLD-3	▪ Symptom management frameworks ▪ End-of-life care pathways ▪ Case conferences ▪ Appointment of a specialist palliative care nurse consultant to support RACF ▪ Introduction of a medication imprest system

Intervention category	Project numbers	Examples of activities
	SA-2 VIC-4 WA-2	

5.2.2 Activities targeting providers

It is fair to say that most of the activities generated by Care Planning projects, and much of the time and energy expended by project staff, were directed at changing the behaviour of providers. There appeared to be a prevailing view that the key to making the palliative approach available to whomever needed it, wherever they happened to live, was to empower providers in various settings to take responsibility for delivering that care at the highest possible standard. As Table 6 shows, most projects organised education events and/or developed educational materials for providers including: general practitioners; nurses, allied health and care workers in residential aged care and community care; and medical and nursing staff in acute settings. Many of these materials and programs were produced after consulting providers regarding their needs, and this consultation often continued during the writing of the materials, with feedback from providers incorporated into the final versions. Some projects delivered education in practice settings or provided the resources and encouragement for generalist nurses to undertake placements in palliative care.

Almost all the projects used local opinion leaders by including them in steering committees or advisory groups. This was a key change management strategy (more details in Section 7.1 on partnerships). Another important strategy was identification of individuals within participating organisations who could be trained and supported to lead change among their colleagues. These 'change champions' were often nurses in RACFs, and it was generally expected that their role would continue beyond the end of the project, providing a means for sustaining the innovations (e.g. end-of-life care pathways) that had been implemented.

As well as utilising the skills and strengths of key personnel, project officers drew on existing data collections, and the knowledge and experience of providers, to inform the design and implementation of new service delivery models. More than a third of projects conducted audits of client records and/or current tools and processes to provide a baseline for their activities and identify areas for quality improvement. Surveys, interviews and group discussions were undertaken to involve providers in identifying gaps in service delivery and education needs. Analysis of needs and gaps in service provision, and consultations on the barriers to change and how these might be overcome, should theoretically provide a foundation for successful implementation and enhance the prospects for sustainability (see Section 7 for more details). Seeking feedback on draft project materials – such as symptom management guidelines, clinical indicators, end-of-life care pathways and information resources – enabled providers to participate in discussion and consensus processes, ensuring quality control as well as increasing their sense of 'ownership' of the projects' goals and outcomes.

In order to direct practice according to need, several projects introduced new data collection procedures in the form of standardised assessment tools. These included a prognostic tool used to identify patients suitable for transfer from a palliative care unit to RACF (with appropriate support; NSW-1); and assessment tools designed especially for adolescents and young adults with life-limiting illness (VIC-6).

A variety of activities were implemented in order to encourage closer collaboration among providers and enhance continuity of care for clients. The most popular mechanism was the care plan, drawn up following case discussion by multidisciplinary teams or case conferences. These meetings also provided opportunities for education and skill development. To encourage general practitioners to take part in case conferences, several projects ensured documentation conformed to the requirements for reimbursement through Medicare Enhanced Primary Care items.

(Financial incentives were also highlighted for RACFs. For example, the implementation of end-of-life care pathways designed by the QLD-2 project provided participating facilities with opportunities to claim complex health care funding under the Aged Care Funding Instrument.)

In some cases, formal links were created with external (specialist) services to provide support and education to generalist staff and/or general practitioners. Two projects (QLD-1, VIC-4) resulted in the creation of a new role for a specialist palliative care nurse to provide this support.

A number of projects made resources available to providers via websites and other mass media strategies.

Table 6   Interventions directed at providers (Level 2)

Intervention category	Project numbers	Examples of activities
Service guides	NSW-2 NSW-5 SA-4	▪ Service directory for GPs and local services ▪ A map showing the locations of specialist palliative care services and community based supports throughout SA
Educational and decision-support materials (including practice guidelines, in print or on websites, DVDs)	NSW-2 NSW-3 NSW-4 NSW-5 NSW-6 NSW-7 NSW-10 NT-1 QLD-2 QLD-3 QLD-5 SA-1 SA-2 SA-3 SA-4 SA-5 TAS-1 VIC-1 VIC-3 VIC-4 VIC-7 WA-1 WA-2	▪ MAPCARE website ▪ DVD on management of pain in RAC residents, plus Certificate IV training pack ▪ Resource Packs for primary care, developed in consultation with an international palliative care researcher/educator ▪ End-of-life care pathways ▪ Multi-disciplinary team meeting toolkits ▪ Laminated flowchart outlining procedures for admission to local hospital ▪ Decision-making frameworks for people with advanced dementia living in RACF, targeting four symptoms: pain; constipation, weight loss and agitation / confusion ▪ Residential aged care end-of-life care pathway based on components of existing pathways including the Liverpool Care Pathway (UK) and the NSW Central Coast Collaborative Pathway ▪ An end-of-life care pathway, a symptom management tool (which included the Abbey Pain Scale for clients who cannot respond verbally) and a syringe driver checklist, supported by a resource folder ▪ End-Stage Heart Failure Management Protocol including pathways, care plans and guidelines for use in inpatient settings, outpatient clinics, general practice, residential aged care facilities and community care ▪ A package and template for use by palliative care services, describing the most effective aspects of case conferencing and care planning, with supporting training materials ▪ Resource folder containing flow charts/pathways: in-home management plan; after-hours support for regional primary health care professionals; referral process for palliative care services; assessment and care planning for regional palliative care clients (all developed with reference to PCA National Standards). ▪ Home-Based Record which included an alert sheet; medication therapy sheet; information summary; health care plan; emergency care plan; client consent form; and progress notes ▪ Website (www.mapcare.org.au) designed to provide accessible, current information for acute health care providers including criteria for referral, checklists of actions to consider when making decisions, and practical assistance in planning care and discharge ▪ Hard copy version of MAPCARE resources (200 printed and distributed), plus CD, presentation and poster ▪ Revised the referral form used by services in Adelaide ▪ CD resource which directs generalist providers to evidence-based materials that support best practice in palliative care ▪ Palliative care information package for use in the regional general hospital medical ward ▪ Nine multidisciplinary care management guidelines which provide details on the initial assessment and management of conditions – posted onto website of Tasmanian Department of Health and Human

Intervention category	Project numbers	Examples of activities
		Services
		• Inpatient integrated end of life pathway
		• Formulary for adult palliative care: an alphabetical quick reference medication guide
		• A 'summary of procedures' sheet was developed to support the use of the patient information form
		• DVD focusing on utilisation of EPC items, advance care plans and multidisciplinary team communication. A small pilot evaluation was undertaken which informed the production of a web site version
		• A protocol on pain and symptom management in residents of RACF and a suite of resources to support the use of syringe drivers in residential aged care
		• Flow chart and accompanying guidelines for multidisciplinary palliative care telephone case conferences plus an age-appropriate fact sheet on palliative care for adolescents and young adults
		• The PaedPallCarePlan, a unique suite of web-based tools to assist health professionals plan palliative care for children with life-limiting conditions and their families
		• Renal resource package with information about kidney disease as well as palliative approach, in a culturally appropriate medium plus training and orientation materials for staff to introduce them to new policies and procedures
		• A Guide to Aboriginal Culturally Appropriate Care for Geraldton RACFs' was developed for use as an induction tool for RACF staff and carer volunteers
		• Palliative Approach Pathway was developed to assist medical staff and care workers understand when palliative care can be introduced to a terminally ill patient, such as in the early stages of diagnosis
		• GP information folder and website
Educational meetings (including training, lectures, workshops, conferences)	NSW-1 NSW-2 NSW-3 NSW-4 NSW-5 NSW-6 NSW-7 NSW-10 QLD-2 QLD-3 QLD-5 SA-2 SA-3 SA-5 VIC-1 VIC-2 VIC-4 WA-1	• Participation of RACF staff in training at Calvary Hospital
		• Training talks provided at RACF staff changeover on use of end-of-life care plans
		• Workshops for staff on grief and bereavement
		• Five workshop education sessions convened by an international expert during Palliative Care Week
		• Education program was developed based on feedback from staff survey of perceived training needs
		• Two 16-hour education packages directed at nursing and care staff of Catholic Healthcare
		• Conference for Catholic Healthcare aged care providers
		• 'Train the trainer' education package for RACF
		• Two full days of free training for 28 senior staff of high-care RACF on the use of symptom management frameworks
		• Educational needs analysis followed by curriculum development for educating RACF staff and general practitioners on End-of-Life Care Pathways
		• Full-day workshop on managing change in the workplace, attended by 20 selected clinical and management staff
		• Workshop on 'Breaking bad news in the palliative care setting' attended by 40 GPs
		• Aged care nurses were asked to complete a survey assessing their knowledge and skills in end-of-life care and results were used to identify training needs
		• A home intravenous frusemide pathway was developed, with a training program and consent forms.
		• Three seminars to raise awareness among doctors of the non-medical needs of patients with end-stage heart failure, and to provide training in breaking bad news
		• Education sessions on the new referral and care planning processes were delivered to primary health professionals and nurses in hospitals, community health and RACF
		• Support package and induction process to promote use of new resources
		• Principles of symptom management, referrals to palliative care, and the needs-based model of palliative care were topics covered in a study day for clinicians from RACF and acute wards

Intervention category	Project numbers	Examples of activities
		- Education for GPs focused on referrals to the specialist palliative care teams based on need, symptom assessment and management, and available evidence-based information resources. Graduate nurses received training on similar topics - Training in the use of the patient information form on personal/hand-held computers was provided to nurses and GPs - Workshops for medical staff and for nursing and allied care staff - A total of 80 inservice education programs to 36 RACFs; seven programs to GPs; and three presentations to practice nurses and acute care staff in the Mornington Peninsula region - NT-1 GP education programs
Educational outreach (visits in practice settings, distance education, placements)	NSW-1 NSW-4 NSW-5 NSW-9 NT-1 QLD-5 SA-5	- Visits by palliative care specialists to RACF - GP Practice visits - One-to-one practice visits to three-quarters of GP practices in the Top End, plus online and written resources on palliative care 15 registered nurses working in the acute and community sectors in the South East region took part in a 10-week distance education course in palliative care - PEPA placements
Local opinion leaders (use of influential leaders identified by colleagues)	All projects	- Participation by key stakeholders in steering committees, reference and advisory groups - Clinical leaders advocating for project - Expert advisory group - Contact with national and international experts - Presentation of project at state forum - Guest speaker at stakeholder meeting - Endorsement of resource by international expert - Launch of resource by local State MP, and subsequent inclusion into Hansard - State health representatives on steering committees - Inclusion of specialist by telephone for family conferences
Change champions (clinicians trained and supported to provide local leadership)	NSW-5 NSW-6 NSW-8 NSW-9 NSW-10 QLD-2 QLD-3 QLD-5 VIC-4	- Link nurses in six RACF were supported via bi-monthly meetings, site visits at least weekly by the project officer (enabling opportunistic training and monitoring of evaluation activities), telephone support and a full-day workshop - Resource nurses or 'nurse champions' were given three days' training in palliative care at a metropolitan specialist palliative care service and met regularly for ongoing encouragement and education and to build relationships with nurses from the palliative care unit. - Establishment of a palliative care special interest group for GPs and reinvigoration of a similar group for RACF staff - Train the trainer model
Audit and feedback (use of existing health care information to reflect on and improve performance)	NSW-1 NSW-4 NSW-5 NSW-6 NSW-7 NSW-10 QLD-3 QLD-5 QLD-6 VIC-2 VIC-5 VIC-6 VIC-8 WA-2	- Audits of clients' notes - Collection and submission of PCOC data - Retrospective audit of existing care plans and review of care pathway documents already used in a RACF - Review of ten hospital charts of patients who had died in the previous 12 months. - Client chart audit and review of existing discharge processes from Royal Brisbane and Women's Hospital Review of death statistics for the northern metropolitan region of Melbourne - Audit of existing care planning and decision support tools in general practice and palliative care - Retrospective audit within a comprehensive cancer centre to examine referral patterns and end-of-life care and establish baseline items for later comparison - Collection and reporting of PCOC data to allow comparison of the population of adolescent and young adult cancer patients with other palliative care populations - Development of a case audit tool 'Transition audit' to assess the main issues, including barriers to supporting palliative care provision in RACFs - Pre and post-implementation resident file audits to assess patient outcomes with the symptoms targeted by the framework
Marketing	NSW-5	Gap Analysis was undertaken based on the National Palliative Care

Intervention category	Project numbers	Examples of activities
(identifying barriers to change via group discussion or surveys, and design of an intervention that overcomes barriers)	QLD-1 QLD-6 SA-2 SA-3 SA-4 VIC-2 VIC-3 VIC-5 VIC-6 VIC-8	Standards and the Australian Council of Health Standards (ACHS) EQuIP 4 standards ▪ Local health care providers were surveyed to identify existing and optimal approaches to palliative care and end of life care provision ▪ A survey of GPs, and six focus groups involving 21 hospital staff and five community health staff informed development of new care planning and discharge processes from hospital ▪ Regional services were invited to compare themselves with what should be delivered according to the PCA National Standards and identify where the gaps were. A workshop was held in Port Pirie, with a guest speaker to provide guidance. ▪ Pre-implementation questionnaires were sent to 110 and returned by 91 service providers, including volunteers, general practitioners, palliative care specialists, community, Aboriginal and allied health workers and hospital staff ▪ Analysis of the demographic and socio-economic profiles of the catchment area and review of current service delivery arrangements ▪ Focus groups were conducted at 11 sites, including staff from public and private hospitals, transition and residential aged care facilities (RACF), with a total of 152 participants, and their feedback was integrated into resource ▪ Comparison of existing services against PCA Standards ▪ Semi-structured interviews and questionnaires for palliative care nurses and GPs, exploring the challenges of providing after hours care for people receiving palliative care at home ▪ Service mapping and identification of gaps, before developing strategies to address these issues (but strategies were not piloted due to timing constraints) ▪ Consultation with GPs including focus groups and interviews, plus interviews with providers in inpatient settings and allied health professionals ▪ Focus groups looking at barriers to palliative care referral in a comprehensive cancer centre and identifying intervention strategies ▪ Activities aimed at identification of issues and opportunities (including stakeholder interviews and focus groups, literature search and site visits).
Local discussion and consensus processes (around identification and management of problems)	NSW-1 NSW-4 NSW-5 NSW-10 QLD-2 QLD-5 SA-4 TAS-1 VIC-1 VIC-7 WA-1	▪ Draft symptom management frameworks circulated to medical and nursing staff; allied health professionals, RACF managers for comment prior to piloting ▪ Draft RACF end-of-life care pathways reviewed by an expert advisory group and national and international experts, then by a link nurse group ▪ A set of indicators for end-stage heart failure approved by the project steering committee and feedback was sought from representatives of general practice, the Heart Foundation, and a specialist group, the Southside Heart Failure Palliation Collaborative. The clinical indicators were also presented at a state-level heart failure meeting. ▪ The first draft of MAPCARE was reviewed by steering committee and other stakeholders and feedback incorporated into the resource, which was then piloted at 30 sites (wards/areas) in metropolitan Adelaide ▪ An expert panel of palliative care medical specialists convened to draft the initial management guidelines. The drafts were circulated widely amongst the three regional palliative care teams for comment ▪ The draft version of the patient information form was reviewed through an action research process ▪ Forty-four health practitioners were interviewed to determine the relevant items and issues that needed to be included in the PaedPallCarePlan care planning tools. The prototype web address was then emailed to 53 health practitioners with a request for anonymous feedback via an e-survey ▪ Consultation with indigenous groups on the development of culturally appropriate information resources.
Patient-mediated	NSW-1 NSW-2	▪ Prognostic tool to identify patients suitable for transfer to RACF from hospital

Intervention category	Project numbers	Examples of activities
(collection of new clinical information to inform practice)	NSW-4 NSW-6 SA-5 VIC-1 VIC-4 VIC-6	▪ Referral feedback form faxed to providers who refer to a palliative care service ▪ Case management assessment procedures pack for use with all new referrals ▪ Care Planning Guidance Tool ▪ Palliative care clinical assessment summary form (all symptoms and their severity recorded on one page with management strategies on the reverse) ▪ Patients referred to the palliative care service are assessed using standard tools. This comprehensive assessment is included in the patient's case notes, with documents recording the patient's needs and future care plans ▪ Assessment tools used to describe and understand the population of adolescents and young adults with cancer ▪ Patient Information Form
Cooperation with external services, or communication and case discussion with off-site professionals	SA-2 VIC-6 WA-1	▪ Royal Adelaide Hospital formally agreed to provide the Mid-North region of SA with after-hours palliative care support, and education for specialist and primary care professionals on a routine scheduled basis ▪ Extension of hospital-based specialist palliative care into the community to up skill and support community service providers
Revision of professional roles or changes in skill mix	NSW-8 NSW-9 NT-1 QLD-1 VIC-4 WA-1	▪ Role delineation and support for health professionals regarding prescribing end-of-life medications ▪ Recommendation for appointment of a palliative care service delivery officer, funded by state government ▪ Appointment of a specialist palliative care nurse consultant to support GPs, RACF and specialist palliative care services ▪ Inclusion of palliative care elements into position descriptions for the new Kimberley region renal service
Introduction or facilitation of clinical multi-disciplinary teams	NSW-6 NSW-7 NSW-8 NSW-9 QLD-6 SA-1 SA-5 VIC-6 WA-1	▪ Multi-disciplinary team meetings ▪ Case conferences ▪ Weekly interdisciplinary meetings provide a forum for client discussion, education and care planning ▪ Weekly meetings at a large GP clinic, attended by palliative care staff and focusing on care planning and symptom management ▪ Development of clinical partnerships with community care providers (GPs, community palliative care) through case conferences and frequent liaison ▪ Cross specialisation skill development within the multi-disciplinary teams ▪ Inclusion of specialist clinicians by telephone, service providers and community members in family meetings
Continuity of care (via case management or follow-up processes)	NSW-1 NSW-3 NSW-4 NSW-7 NSW-8 NSW-9 NT-1 QLD-6 SA-1 VIC-1 VIC-4 VIC-6 VIC-7 WA-1	▪ Follow-up by hospital staff after client transferred to RACF ▪ Case management by a social worker ▪ Multi-disciplinary care plans prepared with or without input from clients and/or carers ▪ Advance Care Plans ▪ 'Diamond Register' facilitating client access to palliative care via GPs, supported by specialist service ▪ A move from crisis-based management to proactive follow-up ▪ Six care plans for children with life-limiting illness and their families: i) Diagnosis of a life limiting condition; ii) Stable Phase; iii) Deterioration or crisis; iv) Transition between care settings; v) End of life care; and vi) Bereavement care.
Satisfaction with conditions of work (including interventions to boost confidence	NSW-3 NSW-6 QLD-3 VIC-4	▪ No staffing problems during the time of the project, indicating improved satisfaction of staff with changes introduced by the project ▪ Facilities where link nurses were consistent for the period of project also had greatest level of staff participation in education ▪ Empowerment of nursing and care staff to provide palliative approach in RACF ▪ Specialist palliative care nurse consultant had regular meetings with

Intervention category	Project numbers	Examples of activities
and morale)		key RACF staff which were used to review tools and templates used in palliative care, eg pain management charts and Advance Care Plans
Recruitment and training of volunteers	NSW-1 NSW-3 NSW-4 NSW-9 SA-2	▪ Volunteers trained to assist in the provision of pastoral support to RAC residents and families in latter stages of disease process but prior to terminal phase ▪ Training was provided for volunteers to assist them to support terminally ill patients and carers at home ▪ After it was identified that some clients had difficulty completing the diaries, palliative care volunteers were invited to attend a training session enabling them to assist clients
Financial incentives (including access to fee-for-service)	NSW-6 NSW-7 NSW-9 NT-1 QLD-2 QLD-6 SA-1 VIC-3 VIC-4	▪ Multidisciplinary care plans were developed, utilising the Medicare MBS Multidisciplinary Care Planning Form, which allowed the GP to contribute to the care plan and claim on the Medicare items ▪ MBS flow chart for palliative patients and carers ▪ End-of-life care pathway for RACF enables facilities to gain complex health care funding for residents under the Aged Care Funding Instrument (ACFI) as the pathway documentation allows for easy validation that the requirements have been met. The pathway also provides sufficient documentation to enable GPs to claim payment via an Extended Primary Care (EPC) item in the Medicare MBS ▪ Documents used for case conferences conformed to Medicare requirements for reimbursement ▪ DVD on access to EPC items when providing after-hours care, and contributing to advance care plans and multi-disciplinary team communication ▪ Guide to use of MBS in providing services in RACF
Mass media communication (including websites, booklets, posters etc)	NSW-2 NSW-3 NSW-6 SA-4 VIC-4 VIC-7 WA-1	▪ Website with tools and resources which support a palliative approach in aged care: http://pc.catholiccare.org.au/ ▪ Education modules being redeveloped to include on TAFE website ▪ Website (www.mapcare.org.au) designed to provide accessible, current information for acute health care providers including criteria for referral, checklists of actions to consider when making decisions, and practical assistance in planning care and discharge ▪ Redevelopment of Peninsula General Practice Network website with palliative care page http://www.pgpn.org.au/page.php?base=35 ▪ The PaedPallCarePlan tools are located at http://www.paedpallcareplan.org.au ▪ A national program of awareness-raising and professional education about the PaedPallCarePlan will include distribution of brochures and postcards developed by the project ▪ Chronic kidney disease protocol, kidney disease pathway poster, kidney disease care planning poster, palliative approach poster and palliative approach power point presentation ▪ NT-1 put resources in TEDGP website

5.2.3 Activities targeting organisations and the health care system

Interventions at Level 3 of the national evaluation framework are directed at organisational and system change. The overlapping program objectives of implementing service delivery models, enhancing collaboration between services and ensuring smooth transitions between settings of care were most often addressed by projects by negotiating formal service agreements or Memoranda of Understanding between host organisations and other stakeholders. Other project activities in this category were the establishment of a triage and referral service (NSW-7 and NSW-8/9), a regional network of community members and providers interested in palliative care (QLD-1), and a partnership model of palliative care with five defined levels of care, ranging from primary palliative approach to direct, ongoing or complex care and bereavement care (VIC-2).

A few projects set out to change the scope of services provided to clients, by piloting new service delivery models or by contributing to the establishment of a new service (informed by project findings, but not funded by the project).

The new models of service delivery designed by projects typically included changes to clinical information management, such as the introduction of home-based or client-held paper records, or implementation of secure electronic records systems. Some also included changes to the sequence or organisation of processes such as assessment and referrals. Quality management procedures – particularly 'Plan-Do-Study-Act' cycles – were incorporated into the model by four projects.

Another group of interventions at the organisation level targeted the availability and use of resources such as staff, equipment and medications. Five projects involved physical changes to the care setting, including introduction of a medication imprest system which was key to providing high-quality end-of-life care in RACF (QLD-2), and equipment loans and/or purchases. One project developed a model to enable delivery of palliative care in RACF settings for clients suitable for discharge from the specialist palliative care service (NSW-1). Other projects resulted in the appointment of new staff to provide support for providers and/or care coordination for clients, or altered staffing arrangements to ensure palliative care expertise was incorporated into multi-disciplinary care for clients in acute care settings (VIC-6, WA-1).

Table 7 *Interventions directed at systems, structures and processes within and between organisations (Level 3)*

Intervention category	Project numbers	Examples of activities
Formal integration of services (through, for example, service agreements or Memoranda of Understanding)	NSW-1 NSW-4 NSW-5 NSW-7 QLD-1 SA-1 SA-2 SA-5 VIC-1 VIC-2 VIC-4 VIC-7 VIC-8 WA-2	▪ Relationships between specialist and generalist services formalised via Memoranda of Understanding ▪ Triage and referral service ▪ PallNet - a network of community members and health care professionals to promote coordinated, accessible care and support at the end of life. ▪ Memoranda of Understanding by local healthcare providers to facilitate transitions and referrals between settings ▪ Following the gap analysis and regional workshop, service agreements were signed between regional health services and the palliative care service. ▪ Memorandum of Understanding between Royal Adelaide Hospital and Mid-North Regional Health Service set the scope for the regional model. ▪ Memorandum of Understanding between the specialist and primary care providers set out the model of care and framework, services provided, referral procedures and expectations of the education and support to be provided by the specialist service to primary care providers as needed ▪ Memorandum of Understanding between project partners ▪ Partnership model of palliative care with five levels of care: primary palliative approach; interdisciplinary consultation and liaison; episodic care; direct ongoing/complex care; and bereavement support
Changes in the scope of benefits or services provided to clients	VIC-6 VIC-7 WA-1	▪ A 12-month pilot of a new service delivery model, during which time specialist palliative care was routine for all onTrac@petermac patients with a palliative goal of care ▪ A five-month pilot of a set of care planning tools and guidelines for children with life-limiting illness ▪ Project findings fed into establishment of new renal service for Kimberley region
Changes in clinical record keeping and information management	NSW-2 NSW-5 NSW-7 NSW-8 NSW-9 NT-1 QLD-5 SA-2 SA-3 SA-5	▪ Patient-held records, patient diaries ▪ Home-based records for community care providers ▪ Revised current record management software to allow for easier tracking of patients ▪ Use of secure clinical information systems ▪ The electronic information system for the heart failure services in Queensland was modified to include information that identifies patients in end-stage heart failure, allowing better estimates of the number of patients requiring symptom palliation and care planning.

Intervention category	Project numbers	Examples of activities
	VIC-1 WA-2	▪ Patient Information Form to share information between providers in the Grampians Health Region, entered onto personal and hand-held computers – form completed on admission to palliative care service and faxed to GP, updates available to service providers each weekday on patient's condition ▪ 'Yellow envelope' developed for transfer from RACF to hospital
Changes in process sequences or organisation of processes	NSW-7 NSW-8 NSW-9 SA-5 VIC-4 WA-1 WA-2	▪ Common intake, assessment and consent processes between organisations within a region, with the unit of care being the patient and carers ▪ Pathway for referral of RACF residents to palliative care services
Presence and organisation of quality monitoring mechanisms	NT-1 QLD-3 VIC-6 VIC-8	▪ Brief questionnaires for staff after resident's death in RACF ▪ Plan-Do-Study-Act cycles with quality manager ▪ Development of criteria for sustainable activities that meet accreditation guidelines
Staff organisation	NSW-2 NSW-7 QLD-1 VIC-4 VIC-6 WA-1	▪ Appointment of a palliative care case coordinator ▪ Appointment of part-time MDT coordinator ▪ Appointment of a service development officer for the Fraser Coast region ▪ Appointment of a specialist palliative care nurse consultant to provide support to RACF and GPs ▪ Early integration of palliative care into multidisciplinary care of young cancer patients achieved by inclusion of palliative care nurse position in onTrac@petermac and removing the need for referral ▪ Inclusion of palliative care elements into position descriptions for the new Kimberley region renal service
Moving services to another setting	NSW-1	▪ Support provided to RACF to care for palliative patients once discharged from Calvary Hospital
Physical changes to the health care site, facilities or equipment	NSW-1 NSW-7 NSW-8 NSW-9 QLD-2 WA-2	▪ Loan of equipment from Calvary Hospital to partner RACF caring for palliative patients, and assistance with application for equipment funding under Round 4 of LPCGP ▪ Loan of equipment – syringe drivers – from private nursing service to RACFs ▪ Equipment loans to clients living in the community ▪ Medication imprest system for RACF ▪ Policy and guide for storage of essential palliative care medications in RACFs

5.3 Factors contributing to, and limiting, project activities

In the following section, we consider the difficulties encountered by project officers while attempting to carry out project activities. These included: staffing and management issues, defining project scope, building productive relationships with stakeholders, lack of evaluation skills and experience, and other issues that affected referrals and the timely production of project materials. We then discuss factors that helped projects overcome these difficulties, and those that contributed to the success of projects ('enablers'). The analysis is based on data from the project summaries, which in turn was derived from notes taken during initial site visits, projects' progress and final reports, exit interviews and informal discussions with project officers and managers. Themes and quotes are also drawn from the exit interview report, *Care Planning Sub-Program: Exit Interview Report* (Quinsey et al., 2009). The barriers and strengths described here have been identified by the project officers themselves, by their managers, and through our observations over the past three years.

5.3.1 Inhibitors

Issues relating to project staff and host organisations
By far the most significant problem facing Care Planning projects was the recruitment and retention of project officers. Altogether, 14 of the 33 projects had a delayed start because initial efforts to advertise and interview for the positions were unsuccessful and at least two other project managers have commented on the difficulty of attracting the right candidate. Ideally, project officers would have both clinical experience in palliative care and the ability to plan and manage a project, develop tools, write reports and other project documents, engage stakeholders and carry out evaluation activities. This skill set proved difficult to obtain for many of the projects. When faced with a choice between specific clinical expertise and more general project expertise, project sponsors have, with a few exceptions, tended to lean towards recruiting clinicians. A large number of these clinician project officers have subsequently sought additional training and support in project management.

There are advantages to this approach, one of which is that it builds evaluation and project management capacity in the clinical workforce. Another advantage was summed up succinctly by one project sponsor, who said that the selection of an expert clinician and provision of project management support 'enabled the project officer to be creative'.

One disadvantage is that experienced clinicians may feel a certain amount of pressure to provide a consultative or supervisory role in the host organisation. Indeed, clinical work represents a 'comfort zone', whereas project work may be less satisfying because the tasks are ambiguous and the benefits are not immediately apparent.

The alternative approach – recruiting a professional researcher or experienced project manager – was adopted by a small minority of projects, while a similar number were staffed by someone with both palliative care and project skills.

In addition to these initial recruitment difficulties, at least seven projects were suspended for some period of time because the project officer left and there was a delay in recruiting a replacement. In one case this was a temporary delay because the project officer was on maternity leave. One project was in abeyance for approximately five months.

For some project officers, working alone on a self-contained project was a new experience. Those recruited specifically for the project had to learn about the host organisation's systems and dynamics, obtain administrative support and build relationships with managers. Some felt there was a lack of leadership and understanding of the research process, although several successfully established connections with research mentors outside the host organisation. Isolation and unfamiliarity with project work were significant risks for project officers' leaving their roles to return to clinical or other work.

Some project officers were faced with disruption caused by restructuring and reorganisation of the host organisation during the lifetime of the project.

Size and scope of projects
The second major issue for projects has been the problem of defining the scope of project objectives and tasks. This was mentioned by at least a third of the project officers. It was common for project activities to take much longer than expected. In many cases, project officers faced a challenge in trying to understand the background and the goals of projects when they were new to the host organisation and had not been involved in designing the grant submission. Those who had been part of the original team did not always find it an advantage, however. A few project officers have struggled to contain wide-ranging projects and to accept that these projects, with limited timeframes and funding, could not be expected to address all the issues that were identified in the original submission.

Projects in regional areas often faced the problem of trying to build relationships, formalise service provision and establish new processes and documentation across huge geographic areas. Some of these projects had quite ambitious and detailed plans which were not achievable. For example, one project planned to establish a volunteer workforce, develop and disseminate resources and provide education in a very large region with many different service providers. Similarly, another project tried to address a number of issues identified in a regional review of palliative care services, by establishing new assessment and referral processes and providing education. Both projects were forced to compromise on some tasks and to trim plans back to a more realistic level. Overall, about one in five project officers identified excessive workloads and difficulties in role definition as project inhibitors.

During the exit interviews, 19 project officers indicated that the time frame for the projects had not been realistic. Of these, five project officers would have liked more time to 'bed down' sustainability strategies, and four felt more time was needed to influence practice change. Nevertheless, 26 of the 33 project officers believed the funding provided by the project grant from DoHA was sufficient.

Stakeholder engagement, resistance and turnover
Engaging stakeholders was a time-consuming aspect of project officers' work and was complicated by staff and management turnover in partner organisations. In one case, the partner organisations had such fundamental differences in philosophy and approach that they had great trouble coming to an agreement on the new model of service delivery, causing delays in project implementation.

Numerous project officers lamented the difficulty of engaging GPs. Their involvement in several types of care planning strategies is crucial; for example, they are needed to prescribe medication for aged care facility residents who have been placed on end-of-life care pathways, and they are key participants in the process of case conferencing. Part of the problem is the workforce shortage in some areas, which means GPs have large workloads and may be reluctant to take on additional responsibilities. Appropriate strategies for involving GPs was the topic of a talk by Geoff Mitchell at the second national Care Planning workshop. Dr Mitchell, who was a key investigator on the QLD-6 project, is a GP and has undertaken PhD work in palliative care case conferencing. After the workshop he took on a mentor role to several project officers seeking to involve GPs in care planning.

For one project, the difficulties associated with engaging GPs were compounded by the entrenched negative attitudes and pessimism of the palliative care service. It appeared that the service had given up on trying to get GPs involved and regarded the project as all too hard and not worth the bother. This sense of hopelessness manifested as strong resistance to change from both the specialist service and GPs. The project officer tried to build relationships by working part time at the specialist service and part time at the local division of general practice, and by approaching GPs one-to-one with training and capacity-building opportunities.

Several projects sought to engage the local indigenous community, with mixed success. One encountered resistance from the manager of the Aboriginal health service, leading to a lack of referrals from that service. During the exit interview, another project officer reflected that the community engagement model may not have been appropriate, due to cultural differences around the issue of 'finishing up'. This project officer speculated that culturally specific and freestanding programs may have served the needs of the indigenous community better than the whole-of-community approach. Nevertheless, some projects found Aboriginal health services very receptive and were able to build productive relationships.

Staff and management turnover in stakeholder organisations, particularly RACFs, also presented problems for projects trying to implement changes to practice. One strategy employed by projects was the selection and training of link nurses or nurse champions, to provide a consistent point of contact for other staff. If these key staff were lost to the project, more investment of time and

energy was required to recruit and train replacements. The cultural diversity of RACF workers meant that many had difficulty reading project documents such as pathways and protocols in English.

Active resistance by stakeholders and even project partners has been encountered by a small minority of project officers. In one case there were problems over access to data; in others, there appeared to be disputes about territory (e.g. a community care provider moving into the area of palliative care). Steering committees, which were set up to engage and involve stakeholders, did not always work well. In some cases, key members left and were not able to be replaced, or members were rarely available to meet or to comment on draft project materials. In the worst cases, there was conflict between members which led to stalled or obstructed project activities. One project reported that it had been impossible to convene a collaborative forum, as planned, because established networks resisted the concept of the project (community based, early intervention palliative care). Only in the second year of the project was there a recognition that the project did not seek to duplicate existing services, and the project officer was invited to join the local network.

One project faced staff resistance to the use of new technology (hand-held computers) to handle patient records, while another tried to implement standard documents across a region that previously had comprised three area health services and found that staff were unwilling to change to the new methods and preferred to stay with the system they had been using, despite its inadequacies.

Projects also ran into difficulties despite having engaged with a key stakeholder (e.g. the Area Health Service - AHS) in the planning stages, including signing a Memorandum of Understanding. The representative on the steering committee did not have line responsibility for the community nurses delivering care, and therefore had no influence to dispel any perceptions that the project was duplicating existing services. The project was subsequently undermined by the AHS when it introduced its own version of a patient-held record, in addition to that introduced by the project.

During the exit interviews, several NSW project officers mentioned difficulties experienced in trying to work with area health services, however, no project officers in other states specifically identified problems in dealing with area health services.

Relationships between projects and stakeholders were sometimes complicated, creating confusion regarding roles and referral pathways. For example, having a project lead by one organisation, with its service delivery component is undertaken by another organisation, is difficult for service users and service providers to understand, let alone those not directly involved. This type of arrangement also means that the project cannot directly control the nature or quality of service provision.

Evaluation issues
It was clear at the first national workshop and the initial site visits that many project officers felt intimidated by the evaluation requirements. These project officers needed considerable support from the NET to conceptualise and plan their project evaluations. In the final reports it was clear that some project officers lacked the skills to be able to present and interpret the data they had gathered, while others simply ran out of time and energy after working intensively on implementing their projects and were able to provide only very basic evaluation information.

Some project officers remarked in the exit interviews that their managers were not particularly supportive of evaluation activities and preferred them to concentrate on project implementation. Evaluation was sometimes seen by management as a distraction, a waste of time. Others viewed it as a judgmental and potentially threatening process, despite extensive and sustained efforts by the NET to explain the purpose and positive uses of evaluation data. One comment from the exit interviews captures the views of those project staff who had not thought clearly about evaluation during project planning:

> *The project team was not really prepared for evaluation. There were too many components of the project to evaluate and as a result we have ended up with too much information. Pulling the evaluation data together has been an additional task which was not factored into the original funding application. The team recognise that evaluation is crucial but it is also represents a lot of work. The project activities continue in the background as does the evaluation. The evaluation needs to be realistically funded and timed.*

During the exit interviews, a little under a third of the project officers said they did not have dedicated evaluation funding in their budgets, which meant that the evaluation was not planned or budgeted. One project commented that there was no mention of evaluation in the original tender documentation, which could be a recommendation for future programs. Another said there had been insufficient time during tender writing to consider the evaluation plan properly, and suggested that projects be funded in a two-step process: applicants would first be asked to write a project plan and then selected applicants would develop an appropriate evaluation plan. Another project officer suggested that it would have been helpful to have a (national) evaluation framework set up before the projects commenced.

Six project officers said they experienced difficulties in having to develop their own evaluation tools, as those in the CHSD toolkit (Eagar, Senior et al., 2004) were not suitable for all projects.

Ethics approval
At least nine projects had issues with ethics applications and approvals. For several projects, the implementation phase was delayed while they awaited approval or resubmitted applications. Preparing and submitting an ethics application was a new experience for many of the project officers and some found it quite daunting. However, it was also seen by some as an opportunity to refine and clarify the objectives and methods of the project and its evaluation, and to learn from the feedback provided by the ethics committees.

The main impact of delays with ethics approval was of course restriction in the time available to complete project tasks, but for some projects the effects were more profound. For example, one project was forced to submit ethics applications in three stages, which entailed six separate applications (three each to two committees). This process, and the ensuing delays, limited the ability of the project officer and steering committee to be creative in solving problems that arose in the meantime. It may have been more efficient for the project to pilot and implement one framework at a time in RACF, rather than trying to do all four at once in the final stage of the project, but this option was not available due to ethics limitations.

Participant recruitment
A common difficulty, particularly with the evaluation activities, was the inability to recruit enough clients and/or carers who met eligibility criteria and were willing to take part in care planning activities. Some projects were forced to broaden recruitment criteria as patients were being referred very late in their illness and quickly became unable or unwilling to participate or to complete evaluation procedures due to deterioration in their condition.

Getting health professionals to complete surveys or take part in interviews or focus groups for evaluation purposes also posed a challenge for projects. Large workloads and time pressure meant many were too busy to look at project evaluation materials.

The language of palliative care
The word 'palliative' was often misunderstood by clinicians and was also identified as too confronting for clients and carers. Different understandings of 'palliative' – including a belief that

this refers only to the terminal phase of an illness – created difficulties in recruitment as clinicians identified patients at too late a stage for their inclusion in the projects.

One project officer expressed regret that the word 'palliative' had been used on project materials, as many clients and carers were not yet ready to discuss issues around dying and end-of-life care, while the project officer lacked bereavement training and expertise in dealing with anticipated grief.

Lack of evidence or agreement on evidence
A few projects attempted to translate evidence on best practice management of symptoms for specific groups (e.g. dementia, heart failure) of palliative patients into user-friendly guidelines for clinicians and health workers in community and aged care settings. However, the evidence was not always clear, and opinions differed among reference group members and other experts informing the project. Seeking expert advice from busy clinicians took time, as did drafting materials to the required standards for publication.

5.3.2 Enablers

Many of the limitations on the projects, listed above, were matched or countered by building on the strengths of the host organisation, the project officer and stakeholders. The vast majority of project officers were well supported by their host organisations, through one or more of the following factors:

- Regular, supportive contact with the project manager or sponsor
- Access to resources such as project planning materials, administrative staff, information technology support, library
- Access to expertise in project management and/or research
- Control of the budget by the project officer
- Involvement of the host organisation's quality manager in documenting the project
- Strong commitment by the host organisation to achieving project objectives

For example, one project officer remarked that the project required a high degree of commitment from the host organisation and would not have been possible without the organisation's experience and senior clinical expertise.

Many project officers were also able to establish support systems for themselves beyond the host organisations, often by connecting with other care planning projects via the national workshops and state forums. A few had the advantage of regular contact with a research mentor from a university or research institute.

Strong partnerships with stakeholders
At least half the projects succeeded in establishing or consolidating relationships with local stakeholder groups. In many cases, projects have engaged stakeholders by inviting them to appoint a representative to a steering committee or advisory group. Strategies to keep these groups actively involved in the project included presenting project materials for review and discussion, regular email contact for those who cannot attend meetings, and consultation on proposed new models of care or service agreements. Clearly defined roles and expectations of steering committee members also helped ensure these groups remained productive.

A committed and effective advisory group or steering committee was a significant asset to the project and a major source of support for the project officer. For example, one project officer reflected in the exit interview that:

> *Members (of the advisory group) not only undertook their roles and responsibilities effectively but they took their support of the project officer further by offering personal and professional mentorship. A collegial relationship developed which will last beyond the life of the project.*

Several projects were able to establish close working relationships with local divisions of general practice, which facilitated broader engagement of GPs in their projects' activities. Others were able to enlist the help of expert presenters who provided their services at no cost for education sessions, including a carers' support group and a conference on the palliative approach.

Turning negatives into positives
One project was able to turn the loss of a key stakeholder into a positive outcome for the region in which it was operating. After the local domiciliary care provider on the Fraser Coast folded due to financial problems, Queensland Health approached the palliative care network established by the QLD-1 project to work out how unspent funds could be allocated. The network devised a stable model of service delivery for the region with a service development officer responsible for building palliative care capacity. Queensland Health also provided funds to establish a small palliative care consultative team at the local hospital.

Similarly, the loss of the incumbent palliative care service coordinator and subsequent downgrading of this position to part time initially created difficulties for the WA-1 project. To get around this lack of local expertise, the project officer established links with a palliative care consultant from a hospital in Perth, who agreed to participate in meetings, either in person or by phone, every second month. This assisted in building stronger engagement and networking between the specialist palliative care service in Perth and the local renal services.

The project officer for NSW-3 found that project activities overlapped with a concurrent project funded by the State government. Rather than seeing this as a conflict, both projects were able to turn this to their advantage and worked together with great success, raising the profile of palliative care and advance care planning in RACFs at both jurisdictional levels.

Strong working relationships were forged between several care planning projects, the national workshops having helped establish initial contact between the project officers. For example, NSW-4 and NSW-5 found they were operating in the same geographic area. They addressed this potential problem by working closely, leading one project officer to comment, in the final report, that the partnerships provided 'a supportive and stimulating environment that has led to exponential increases in achievements'. The two project officers brought complementary expertise to the partnership, thus producing 'outcomes for each project way beyond what may have been achieved singly'.

Sensitivities around 'turf' issues were addressed by some projects with clever branding of their new processes and documentation. For example, the use of the name PallCare Packages by two NSW projects (working together) helped differentiate the projects' case management model from clinical palliative care services in the area. According to one project report, this 'decreased anxiety in the community, and amongst some clinicians' regarding the project activities.

Project officer's skills and networks
The particular skill set of the project officer, and their existing networks and relationships, could also be seen as a valuable asset to several of the projects. In particular, a combination of clinical (palliative care) experience and research skills was advantageous. Some project officers have undertaken training to develop project management skills. In one case, the project officer was offered a structured orientation program, which they believed was extremely worthwhile.

Where the project officer had been recruited from within the host organisation, she or he may have been involved in writing the original submission and thus had a clear idea of the aims and scope of the project. This could, however, be a mixed blessing. For example, one project officer was also working part-time as coordinator of the regional palliative care service. This was advantageous in that it meant changes instigated by the project were directly transferred to clinical practice. However, it also generated some negative human resources issues and complicated team management.

Project and evaluation planning

About one in five projects were based explicitly on previous work in palliative care planning. For these project officers, knowing where the project sits in an established stream of research and what it may contribute to existing knowledge was a motivating factor and a source of valuable information in planning and conducting the project. Another useful mechanism for establishing a strong base for a project was a formal needs analysis. This process involves stakeholders in appraising existing service provision, identifying gaps and designing improvements to be implemented by the project.

Evaluation activities were viewed by some project officers as useful and beneficial. In addition to highlighting project achievements, evaluation evidence could be used to demonstrate why some project goals could not be achieved, and to advocate for needed resources. Project officers tended to be most positive about the evaluation process where it had been built into project activities from the beginning, as an integral part of the project plan. A number of other project officers remarked, in retrospect, that it would have been better to have a more specific and detailed plan earlier, preferably linked to project activities. It is likely that for these project officers, a well-designed plan would have made the evaluation a more positive and productive experience. (It should be noted that the NET provided considerable guidance and encouragement but had no authority to require projects to produce evaluation plans.)

External evaluators proved a good investment for several projects. One project officer reported that 'the recruitment of a project advisor was crucial to the success of the evaluation'. Another felt in hindsight that the evaluation should have been externally managed and made the following recommendation during the exit interview:

> *A high quality evaluation should be carried out externally and independently. The project officer is too close to the details of the project and it is difficult to step outside the project to evaluate it.*

Some project officers who may have found formal evaluation activities daunting were nevertheless able to carry out a series of quality projects, or 'Plan-Do-Study-Act' cycles, which provided valuable feedback to inform project development.

5.4 Program-level activities

The planned activities of the NET were described in detail in the CHSD Evaluation Framework and Strategies (February 2007) document, as well as the Care Planning Sub-Program Communication Plan (February 2007). This section describes the processes and outcomes of the activities which were conducted.

5.4.1 Project officer support

A major aspect of the NET's role was the provision of support to project officers in terms of their project planning and implementation, as well as evaluation issues, and general support as required. This was provided in a number of ways, some structured and articulated in the communication plan, and some which evolved as the sub-program progressed.

The major activities of the NET in supporting projects were the site visits, and provision of regular telephone and email contact. To facilitate timely and accessible support the NET identified staff members as first point of contact for each care planning project. These were:

Karen Quinsey: NT–1; TAS–1; VIC 1 – 8; NSW–10
Kathryn Williams: QLD 1 – 6; SA 1 – 5
Dave Fildes: NSW 1 – 9; WA–1 and WA–2 (until March 2007)
Anita Westera: NSW 1 – 9; WA–1 and WA–2 (March 2007 - project end)
Darcy Morris: all projects for administrative support

Site visits were, in the main, conducted by the NET staff member allocated to the relevant project. The focus of the site visits was to provide advice and support with: project planning and management; evaluation strategies and data analysis; and report writing.

All projects had at least one formal face-to-face meeting with their NET representative, as well as follow-up phone and email communication as required. For a number of projects, their particular NET member was an important resource and contact point for thinking through issues about ethics, evaluation, evaluability, what tools to use, engaging stakeholders and so on. As the projects progressed through the implementation phase to evaluation, project officers increasingly sought advice about data management, analysis and reporting.

Seventy site visits were undertaken by the NET during the three-year evaluation period. The NET made 33 site visits during the first year of the sub-program; 16 in the second, and 20 in the third. These numbers do not include the large number of additional, informal visits and meetings also conducted. The timing of the initial and subsequent visits was negotiated with project officers to suit their support needs.

In addition to the formal site visits, members of the NET took advantage of other opportunities to meet project officers face-to-face at gatherings such as conferences, state forums and the care planning national workshops. Such meetings were generally of one to two hours' duration. Approximately two-thirds of project officers have received this additional one-to-one support.

Feedback from project officers at the time suggested that they found the visits, and follow-up support, very helpful. This was confirmed in the exit interviews which were conducted with each project (details of the exit interviews were provided to the DoHA separately: *Care Planning Sub-Program: Exit Interview Report* (Quinsey et al., 2009). At this time, three project officers specifically mentioned the benefit of the face-to-face contact, in terms of building a relationship with their NET member, which assisted in making subsequent telephone and email contact much easier. In addition, three also indicated that the site visits enabled them to keep focused and their projects on track. The ongoing support following the site visits, by phone and email, was also noted as particularly useful by many projects.

The timing of the initial site visit was raised by a number of projects. During the exit interview four projects noted the importance of having the first site visit occur very early in the project. However, two project officers thought that it occurred too early, in relation to the newness of the project, which made it overwhelming.

Additional support was provided in direct relation to the needs of the individual project officer. In a small number of cases, there was relatively little additional support required, as projects were being managed by experienced project officers with sound project and evaluation plans, governance arrangements and support at the local level.

The majority of project officers, however, required regular ongoing support. The reasons for support varied, but tended to primarily relate to the experience of the individual in project management, evaluation and stakeholder management. We estimated that approximately two-thirds of the project officers were novice project managers, most being experienced clinicians, who had taken on the project work in addition to or as a secondment from their clinical work; some were newly employed and had no history with the organisation or involvement in the initial funding submission; while others had complex and/or remote governance and support arrangements.

Feedback from the project officers regarding the support provided by the NET was generally very positive. In the exit interviews, all respondents felt that the NET had carried out their role very well, and members of the NET were described as enthusiastic and encouraging. It is clear project officers appreciated the involvement of the NET, and the ongoing nature of their support. No suggestions for improving the role of the NET were provided.

5.4.2 National workshops

The NET facilitated three annual national workshops for projects. The location chosen was the Novotel Brighton Beach, Brighton Le Sands, NSW because of its central nature and easy access to the airport for those travelling from interstate. The workshops went for two days, and the aims were:

1. to increase participant knowledge of the sub-program
2. to increase participant understanding of project and sub-program evaluation
3. to foster and promote networks between the 33 projects comprising the sub-program

Two representatives from each of the 33 projects participated in the workshops, as well as representatives of the DoHA, and the NET. Each workshop was organised by the NET in consultation with the projects, and DoHA, with the agenda tailored to meet the needs of the projects at the particular point in time, and facilitated by Professor Kathy Eagar, Director, Centre for Health Service Development (CHSD). Evaluations were undertaken of each workshop, and findings presented to DoHA as well as informing the activities and processes of subsequent workshops.

The first workshop was held on 27-28 November 2006, and was attended by 63 participants including 54 project representatives, DoHA staff and members from the NET. Presentations included an introduction to the Care Planning Sub-Program, core aspects of project management and evaluation, and reporting requirements for the sub-program evaluation. Resources were provided to support projects in topics such as ethics applications, evaluation tools and contact details for key staff in both DoHA and the NET. Feedback from project officers during exit interviews was generally positive, although some felt it would have been better to have held the workshop sooner and closer to the start of their project and to be of three days' duration.

The second workshop was held on 26-27 June 2007, attended by 74 participants including 65 project representatives, DoHA staff and the NET. The focus of the workshop was on project implementation, evaluation and reporting, including presentations by individual project officers regarding the focus of their projects and evaluation strategies, as well as providing opportunities to network and share information. Key stakeholders such as Care Search, PCOC and Palliative Care Australia were also invited to participate and present to the workshop on current initiatives. The NET observed there was greater engagement between the projects, with some alliances starting to form around common target groups and/or issues, e.g. aged care projects decided to set up an information sharing network, and projects began to share literature review findings. Overall, the feedback from participants was quite positive, with many appreciating the opportunities to network and collaborate, and the majority of participants indicating that the workshop met its aims and objectives.

The third and final workshop was held on 28-29 July 2008, attended by 61 participants including 48 project representatives, DoHA staff and the NET, as well as representatives from other stakeholder organisations, including the Program of Experience in the Palliative Approach (PEPA), Palliative Care Australia (PCA) and NSW Health. This workshop had two additional aims to those of the first two, which included providing opportunities for projects to publicly present their project findings and share lessons learned, and to facilitate a greater sense of coherence within the sub-program which had the potential to be sustained into the future, once projects have finished. Over 50% of projects presented at the workshop, providing not only an opportunity for others to hear

about project outcomes and be encouraged by the lessons learned, but it also gave less experienced presenters a 'safe' environment in which to develop and test their presentation skills.

The NET observed that there was an increased level of engagement between the projects in this final workshop, probably due to the project officers being more confident about their roles, and having their projects more fully developed. There were some very strong partnerships which developed over the course of the sub-program, and this was evident in the general rapport during the final workshop, the willingness for projects to present, and the free-flowing discussions in the breakout sessions.

At the exit interview, all projects indicated that they found the annual workshops very useful. The benefits of the annual workshops most commonly noted were:
- Provided a good forum for networking
- Provided a great opportunity to share resources and information
- Provided a forum for finding out what other projects were up to
- Enabled the project officers to feel part of a very supportive team (or program)
- Provided information and support for the project evaluation
- Placed the sub-program in its national context

Four project officers found the first workshop a bit intimidating and overwhelming, stating they felt out of their depth. Conversely, six project officers or managers felt that the first workshop was less useful than the others. This highlights the varying needs of the project officers, which were acknowledged by NET, and which we attempted to accommodate in the planning of the workshop.

A number of recommendations can be made arising from comments from participants made at the workshop and in evaluation form responses, subsequently in the exit interviews, and observations made by the NET. In summary, these are:

- Program workshops should be held on a regular basis, with the initial workshop taking place at the commencement of project funding.

- Workshop programs need to be established in close collaboration with key stakeholders, particularly project officers, as well as DoHA and the NET.

- Workshop dinners should be included as part of formal part of workshop programs to enhance networking opportunities.

- Promotion of workshop procedures and findings is vital.

5.4.3 Stakeholder survey

The Care Planning Evaluation Framework included an undertaking to conduct interviews with key informants and stakeholders, to complement the common and customised evaluation tools and processes being utilised across both the individual project and program levels.

An on-line survey of key stakeholders and informants was conducted during February to April 2008 to gauge views on the projects' delivery, impact, sustainability, capacity building, generalisability and dissemination. In addition, views were sought on the level of engagement and awareness of the sub-program and/or with the projects, and effective ways to communicate progress and findings from the projects and the sub-program

In total, 46 stakeholders were emailed the survey, including representatives from the primary, palliative, acute and specialist health care sectors, as well as aged care sector, government, consumers and carers, and professional groups. Thirty responses were received to the survey, representing a 65% response rate.

The level of awareness of the sub-program by those who responded was generally high; this was not surprising given that palliative care is a relatively small and emerging field of health care. Despite this, however, only half the survey respondents indicated that they had assisted Care Planning projects to implement capacity building strategies. Only just over half of the respondents indicated they had been informed about the progress of the sub-program &/or projects. This was despite the efforts of individual projects at the local level, and the NET at the systemic level, to make the findings and project resources known.

Importantly, approximately one third of respondents were not convinced that the project outcomes could be sustainable without additional funding. This was consistent with the NET's observations, and subsequent recommendations in a number of project final reports.

In the 18 months since the survey was undertaken, there has indeed been a far greater effort by projects on dissemination activities. Many projects have presented at state, national and international conferences; uploaded resources onto web-sites of industry and related organisations; and, prepared to write journal articles. Consequently, we expect that the awareness within the broader sector will be much higher today than it was at the time of the stakeholder survey.

That said, however, the survey provided clear lessons about the opportunity to develop more active engagement with key stakeholders and informants around the objectives, opportunities, processes and outcomes of the sub-program, to facilitate a more receptive context to the work being undertaken at the local level by individual projects, and enhance the potential for project outcomes to be sustained beyond the life of the program.

A full report of the stakeholder survey was provided to DoHA in September 2008, and findings have been incorporated throughout this report.

5.4.4 Project officer exit interviews

The Care Planning Evaluation Framework included an undertaking to conduct exit interviews with each of the 33 project officers at the conclusion of their project. The aim of the exit interviews was to investigate the projects' perspectives on the delivery, impact, sustainability, capacity building, generalisability and dissemination of their projects and of their involvement in the sub-program.

Interviews were conducted predominantly over the telephone, with the majority of participants having been involved with the project since its inception, responsible for identifying service gaps and remedial strategies, negotiating with key stakeholders and building partnerships, and articulating these processes on a regular basis through their reporting requirements. The interview provided the opportunity for participants to reflect on what they gained, learnt, did best and the difficulties they experienced in running the project.

The two major lessons learnt by project officers arising from their experience running a palliative care project were around the capacity of the sector and the importance of partnerships. Many projects identified the enhanced capacity of the sector to better deal with palliative care clients as a result of the education and training provided by the projects, and the policies and procedures developed to support care planning.

The importance of partnerships in providing good care for people with palliative care needs was emphasised. One of the key partners in care planning processes is the GP, however, many of the projects had mixed findings relating to the success of engaging GPs in a collaborative approach.

A number of project management lessons were also identified through the exit interviews regarding project planning, evaluation, reporting and skills development.   Over half commented that there was not enough time to either embed the changes and/or ensure sustainability. In a number of cases this was due to the initial project plan being overly ambitious, and not realistic

given the timeframe or the budget; consequently, some projects had to renegotiate their contracts to reduce the scope of the project.

Almost a third of projects did not initially plan to conduct a project evaluation, and therefore factoring in evaluation in terms of timeframes, budgets and skill sets proved problematic for some. However, the interviews suggest that many did see that evaluation had merit, and a number of suggestions were made regarding future projects, including recommending evaluation tools and suggesting alternative methodologies.

The final project report template developed by the NET proved to be a challenge for some projects in terms of the skill set of the project officers and the time allocated to produce the reports. But even with these challenges, the projects that did complete the final reports were positive about both aspects of the process and the outcome – a report on their project which tells the story of what they did and how it went.

The interviews confirmed that for a large number of projects, the ability to acquire project management, evaluation and stakeholder engagement skills was a significant outcome. However, some of the project officers felt overburdened by the challenges of managing a project. The report concluded that in view of this, future programs should consider facilitating a greater focus on project management training for the project officers as required, e.g. evaluation methods, data analysis and/or report writing.

A full report of the exit interview was provided to DoHA in August 2009, and findings have been incorporated throughout this report.

5.4.5   State forums

As the Care Planning Sub-Program progressed, the NET highlighted to DoHA the importance of fostering networks amongst the projects. This was based on our experience with other, similar initiatives which demonstrated that individual projects benefit from meeting with others to problem solve, share learning, and provide a valuable support network for those who may feel isolated, either professionally or geographically.

In mid 2007 DoHA provided additional funding to facilitate the development of state forums (networks), with NSW, Victoria, South Australia, Western Australia and Queensland being allocated one-off funding for these purposes. At the request of the projects, the NET actively engaged with the forums since their establishment, including assisting with agenda development, organising participant lists (i.e. linking network organisers with relevant State Office representatives of DoHA, State Health Department officials, and State Palliative Care Association representatives), as well as presenting, and in some cases chairing, at some of the forums. In addition, state forums also met during Day 1 of the third national workshop, with the NET in attendance, and time was allocated on Day 2 for brief presentations to the workshop by State representatives.

The NET's involvement in the state forums was not included as part of our contracted obligations to DoHA. However, we believed that our investment was worthwhile as the networks had the capacity to add value to the individual projects, the Care Planning Sub-Program, and the broader palliative care sector.

There was no formal evaluation of the state forums, and therefore we included questions about them in the exit interviews. On the whole, project officers found the forums a very positive initiative, describing them as providing an excellent opportunity to share ideas and network. The state forums were seen by some as an essential part of the program. A number of seminars of particular value were noted by respondents, for example on project management and also sustainability. However, some project officers felt they were a repetition of annual workshops and that grouping projects by geographic area did not necessarily mean they had anything in common

with each other. Nevertheless, project officers commonly expressed appreciation of the usefulness of the forums as opportunities for communication at a state level.

Although additional funding was provided by DoHA to support the forums, three respondents noted that the process of organising the forums was burdensome and time-consuming, in addition to their scheduled project work. As Northern Territory and Tasmania had only one project each they were not provided with additional funding, and it was felt that their 'exclusion' from this potential source of support led to a greater feeling of isolation.

Through the exit interviews a number of suggestions emerged for improving the concept of state forums in the future. These included providing more direction and leadership to make them a more worthwhile process; providing clearer guidelines for the use of the funding; improving communication (e.g. keeping everyone informed about future meetings); and reimbursing project officers involved in the organisation of the forums.

5.5   Communication within the sub-program

As part of the Communication Plan the NET undertook to make available to projects a range of materials, such as: relevant workshop presentations; useful resources identified by projects and the NET; information bulletins, and details of protocols/guidelines and resources developed by projects. Such information was distributed to projects via the website and list server, which also provided opportunities for project officers to communicate directly with one another.

In addition to the nominated NET contact officer (described in Section 5.4.1 above) the communication systems established included:

- A dedicated Care Planning list server

- Information bulletins to provide useful project development information from the NET to all projects (see Table 8)

- A dedicated and password protected communication forum, the 'Care Planning Forum' http://careplanning.informe.com/

- A dedicated Care Planning web location on the CHSD website http://chsd.uow.edu.au/care_planning.html

5.5.1 List server

The list server was developed and used to promote information exchange and discussion between the NET, DoHA and each of the 33 projects. The list server proved a useful communication tool. Its main uses were for the NET team to correspond with all projects, for distribution of relevant information and resources to projects, and for project officers to ask questions and receive replies. There were 213 emails sent to the list server from its establishment in mid-December 2006 to the end of May 2009. As of the end of May 2009, this list server had 92 members. Feedback regarding the list server, from site visits, exit interviews and also the list server itself, has all been positive.

Projects were supported to use the list server during the initial site visits, with NET demonstrating how to access and use the technology. The NET also posted items on the list server on behalf of project officers who continued to lack confidence.   During exit interviews, project officers commented that the list server was a great way to share information, and also that it created a sense of connectedness to the sub-program, and alleviated feelings of isolation. However, a small number of project officers indicated they did not use the list server, either due to continued unfamiliarity with the technology (lack of computer skills), or a lack of time. Nonetheless, members that did not regularly use the list server found value in just following the discussions, reading comments or responding to relevant questions.

Another list server was developed to facilitate information exchange and discussion on issues relating specifically to aged care, following a NET facilitated discussion group at the second national workshop. Although this list server had comparatively little traffic, with developments in aged care such as the introduction of the Aged Care Funding Instrument in March 2008, it has proved a useful mechanism for dialogue and discussion. There were 40 emails sent to the list server following its establishment in August 2007 to end of May 2009. As of the end of May 2009, this list server had 20 members.

Also, on the request of a number of project officers from NSW-based projects, an additional list server was established for NSW projects specifically. However, this list server was hardly used, with only four emails sent since it establishment in November 2008 to the end of May 2009. This underuse may have been due to timing, as most projects were getting close to completion at this stage. At the end of May 2009 this list server had 14 members.

5.5.2 Information bulletins

Information bulletins have been developed by the NET and distributed to all Care Planning projects, via email list server and also posted on the website: (http://chsd.uow.edu.au/care_planning_resources.html) (Table 8).

During exit interviews, nearly all project officers indicated that they felt the information bulletins were a useful resource, providing concise and practical information. Project officers commented that they felt like the bulletins kept them on track and made them feel like part of a national program, with the bulletins often being referred back to. Two project officers said they did not read them due to time constraints. One suggestion was that the first bulletin should have been on project management, focusing on how to start a project and what tasks are needed to be done.

Table 8   Care Planning Information Bulletins

No.	Title	Date issued
-	Care Planning - a guide to developing your evaluation plan and project progress reports	14 Dec 2006
1	Qualitative Research Methods	24 Jan 2007
2	The Literature Review	24 Jan 2007
3	Workshop 2 Follow-Up	13 Aug 2007
4	Update from Care Planning NET	28 Nov 2007
5	Dissemination Update	21 Feb 2008
6	Update from Care Planning NET	23 April 2008
7	Workshop 3 Follow-Up	7 Oct 2008
8	Care Planning Stakeholder Survey – key results	23 Oct 2008
9	NET 4th Evaluation Progress Report Summary	3 Dec 2008
10	Care Planning Dissemination Update	9 Dec 2008
11	Care Planning: What now? What next?	2 March 2009

5.5.3 Forum

In 2007, the NET set up an online Care Planning Forum. During the sub-program it became apparent that this communication tool was under-used, possibly due to the effectiveness of the list server as a communication tool. After suggesting to projects the prospect of discontinuing this Forum, all of whom agreed, and receiving approval from DoHA, the Forum was shut down in August 2008.

5.5.4 Website

The NET provided continual support for the Care Planning website (http://chsd.uow.edu.au/care_planning.html) for the duration of the sub-program. The CHSD hosted website was regularly updated with relevant documents, reports and resources for projects. The NET was active in placing resources on the website (http://chsd.uow.edu.au/care_planning_resources.html), which assisted projects, as well as the palliative care sector more generally. These include: the evaluation progress reporting template, the final evaluation report template, the dissemination log, PCOC related clinical assessment tools, Care Planning Information Bulletins, and various other resources. Presentations from the three Care Planning National Workshops were made available, as was the *Care Planning Third National Workshop Report* (Quinsey et al., 2008b). Furthermore, project summaries were also made available (http://chsd.uow.edu.au/care_planning_summaries.html).

A count of web hits and document downloads from the Care Planning website was submitted in the second, third and fourth progress reports, which had showed high levels of usage. However, the reliability and accuracy of these statistics was later put into question due to technical problems with the web-based counting system used at the University of Wollongong. It was therefore decided not to include statistics in this report, but anecdotally, project officers have commented on the usefulness of the website and the resources provided therein. Fortunately, the University of Wollongong has recently changed to a new web-based counting system which will be able to provide much more accurate statistics in the future.

6   Impacts and outcomes of the Care Planning Sub-Program

This section discusses the impacts and outcomes of the interventions across the 33 Care Planning projects as described in their final evaluation reports and their exit interviews, and interpreted by the NET.

As discussed in Section 4.2.1, not all projects had the capacity to undertake a comprehensive evaluation of their project. In some cases, projects reported judgements about the efficacy of the projects which were not necessarily reflected in the data collected, or evidenced in the final report. This is likely because, as Hurteau et al (2009, p. 311) remind us, 'conflicting claims regarding a program's quality, value, or importance often serve as strong indicators that stakeholders are using different standards for judgement.' This was certainly true in a number of cases with the care planning projects where, in the absence of clearly defined evaluation criteria, methods and data, the project officers sometimes had different interpretations about the value or impact of their project than that of the NET.

6.1   Impacts and outcomes on palliative care clients and their carers

All projects were designed to have an impact on palliative care clients and carers, however, the majority of effort was on improving the capacity of the sector to deliver improved care – e.g. through establishing new service types, improved processes and providing education for staff. Twenty-six of the projects reported on activities which had a direct impact on clients and carers. The estimated reach of these projects is difficult to ascertain but from the evidence provided in the final reports, nearly 2000 clients, carers and families were directly impacted upon by the projects. However, this number is heavily qualified by the fact that not all projects collected patient-level data in their evaluations.

The major impacts and outcomes on clients and carers described by the projects were in improved coordination of services; end of life care; assessments; service provision; access to information; involvement in care and confidence; reduced burden of care; and increased community involvement. These reflect the interventions of the projects discussed previously in Section 5.2.1.

6.1.1   Improved co-ordination and communication

Approximately one third of projects instigated formal mechanisms to improve coordination of services for clients and their carers, through the introduction and/or provision of multidisciplinary team (MDT) meetings, case conferencing, case management, patient held records and referral protocols. In the majority of cases, a number of these aspects were contained within the one project. While the systems and processes of each of these activities were quite different, the outcomes for clients and their carers were the same, in that their clinical and care needs were considered in a more holistic, planned and coordinated manner.

Typically, the MDT meetings and case conferences involved a range of key clinicians and service providers meeting and communicating with each other about the care needs of clients. Decisions were documented in a care plan, the key elements of which were forwarded to the relevant agencies or clinicians, and the overall care plans were reviewed as clients' conditions and/or circumstances changed. A key principle of the MDT/case conference processes was the inclusion of the client and/or their carer in the discussions. Projects reported a range of positive outcomes from these processes including improved care for aged care residents through the provision of multidisciplinary participation (NSW-4), increased confidence and capacity of clients and carers to be involved in decisions about treatment (QLD-6), improved discharge planning leading to reduced length of stay in acute services (VIC-4), and families being better prepared for the death of their family member (NSW-6).

Patient-held records (PHRs), or diaries, were also developed as a resource for clients and carers to facilitate improved coordination and communication between clinicians and providers involved in addressing their clinical and care needs. The target group for PHRs was people living in the community, and these documents typically contained personal and clinical details as well as a care plan and advance care directive, if one had been developed. The record remained the property of the client, and was used as a communication tool when clients had appointments with their general practitioners or specialist, or when admitted to hospital. It also was used by clinicians and care providers to document their activities, and communicate with each other.

Benefits of the PHR reported by the projects include an improvement in client care and communication with service providers (NSW-5, SA-2, SA-3, QLD-6), the reduction in the need for clients to repeat information (SA-2), improved communication for those living in cross border areas where service outlets and the client's GP may be in different states (NSW-5), and less time spent on hospital appointments (QLD-6). Two projects highlighted the benefit of the record for the client's family through improving communication (SA-2) and also as a record of a family's health history which can continue to assist carers and other relatives after the client is deceased (SA-3). On the whole, the projects reported a good uptake of the concept of a patient held record. However, one project noted that the diary was not used at all by one group of clients, due to poor literacy (SA-3).

Case management strategies were also used as a means to improve the coordination and planning of care for clients and carers. The majority of clients benefiting from these strategies were living in the community, where assistance was required to navigate the complex clinical and care services that might be required. This was usually undertaken in conjunction with the case conference/MDT processes. Care planning was also undertaken for residents in aged care facilities; however this was generally in terms of enhancements to existing practices.

The key to this model of care was to ensure sound assessment and planning, service provision to meet immediate needs, and discussions regarding future care needs and approaches e.g. advance care directives. The final reports note that benefits arose from the reduced stress levels for clients and carers in having their immediate, practical needs met (NSW-2), and from not having to negotiate the range of issues and services that were involved in organising palliative care in a rural context (NSW-9).

Four projects had a focus on case management and/or care coordination strategies (NSW-8, NSW-9, NSW-2 and VIC-4). The NSW-8 and NSW-9 projects were essentially an extension of each other, with NSW-9 being funded to implement a case management and care coordination package, which was delivered by the NSW-8 project and used by that project to articulate a case management model of care for people with palliative needs. The case management approach included the development of a flexible and individualised package of care, supported by additional funding for the brokerage of services, resources and equipment as required. The model was underpinned by case conferencing and education which targeted staff and carers alike. A total of 150 clients and a further 200 primary care givers were provided with supportive care and access to services by these combined projects in the Riverina district of NSW (NSW-8 final report). The most commonly required support supplied by the project was personal care and end of life care discussions. Equipment was also important, with 58% of clients requiring items such as electric beds, mattresses, walking sticks, bed sticks, sheepskins, toilet commodes, wheel chairs and incontinent aids. Respite, domestic assistance and personal care services were required by 40% of the clients (NSW-9). Similarly, the NSW-2 project was able to supplement its case management with early referral to and resourcing of relevant services from within the organisation's community care service network. The final report notes that 105 clients were assisted with between 0.5 and 2 hours a week of palliative care assessment, coordination and planning services by the project, and a further 2.5 hours assistance depending on their needs e.g. home care, personal care and equipment.

Case management or care coordination models also facilitated ready access to specialist support. One project noted that the triage facility associated with the case management resulted in palliative care clients being able to be seen by practice nurses sooner, or early appointments were made to the general practitioner (NSW-8). Another project reported that 370 residents received specialist advice and support from the project palliative care consultant, and even more benefited as a result of the education and support provided to the workforce implementing a palliative approach to care (VIC-4). In the community context, the access to 24-hour support which was part of the case management role resulted in carers feeling 'well supported' and community nurses observing that this was a key factor in empowering the carers in their caring role (NSW-8).

A key outcome of the many interventions designed to improve coordination and communication was the facilitation of smoother referrals between services for clients and carers. This was often inherent in the MDT meetings and case conferencing, where the relevant service provider or clinician was often directly involved in the case discussion, and there was a raised awareness of available services and resources. Projects reported a broad range of referrals resulting from the coordination strategies, addressing clinical, personal care, equipment, counselling, accommodation and transport issues.

A number of resources and protocols were also established to facilitate and formalise improved referral processes for clients. These include the establishment of the triage and referral service (NSW-7), referral protocols (e.g. NSW-2, SA-5) and processes (SA-2, VIC-5). Examples of the benefits of improved referral processes include VIC-6, where the 58 patients in the onTrac@petermac program received palliative care involvement at earlier phases of care than prior to the project. The final report also noted that there had been an increase in access to palliative care for adolescent and young adult cancer patients from one patient to almost three patients per month as a result of the project. Similarly, the NT-1 project noted that prior to the project's commencement no carers of palliative clients from the Territory Palliative Care Top End Service (TPC) were referred to the Carers NT for support; however by the end of the project they accounted for 17% of Carers NT referrals.

6.1.2   Improved end of life care

A major outcome of the Care Planning Sub-Program has been improvements in end-of-life care, particularly for residents of aged care facilities. This was a focus of over half of all projects, and included specific activities to develop end of life care plans (e.g. advance care plans) as well as through the development of resources, frameworks, assessment and management strategies and after hours access to health professionals and equipment. These activities were often supported by a strong educational component targeting staff to better work with clients and carers in the end of life planning processes and stages.

One of the expected outcomes of the end-of-life care planning initiatives was that clients would be able to receive all the necessary clinical care and support to enable them to die in their place of choice. This would be demonstrated by a commensurate reduction in the numbers of clients being transferred to hospital for management of end of life issues such as pain management. A major finding by a number of projects was that this had indeed been achieved, particularly for residents of aged care facilities participating in the projects. VIC-4 reported an increased number of residents were able to die 'in comfort and dignity' in their place of choice.

Good evidence of the effectiveness of end-of-life care pathways came from the QLD-2 project which reported that prior to implementation, 21.7% of dying residents were transferred to hospital. After implementation, this fell to 1.7% of the residents who were started on the end-of-life care pathway being implemented by the project, while the transfer rate among those not placed on the pathway remained the same (21.5%). Similarly, the NSW-4 project reported an estimated reduction in transfers of residents of HN McLean Village to Inverell Hospital of around 75% resulting from the activities of its project. This was based on the findings of an audit of medical records at the local Inverell Hospital which was undertaken prior to the project commencing, and a

subsequent audit later on in the project's timeframe, which revealed only five transfers for acute needs over a three-month period, compared to 20 previously.

For those who did require transfer between settings during the end-of-life stages, a number of projects reported that these transitions were smoother (QLD-3, NSW-6), and that the incidence of readmission to the acute setting was reduced (VIC-4) as a result of the advance care plans.

Despite the success demonstrated, and the effort on end-of-life care planning by a significant proportion of projects, particularly in residential aged care, there were mixed reports about the uptake of advance care plans (ACPs). Some projects were very clear about the utility of the ACPs, with one project reporting that the relevant section of the resource guide it had produced was 'well utilised' (NSW-4). Similarly, the NSW-3 project cited the example of one of its partners, a 132-bed facility, which saw an increase in the number of its residents with ACPs rise from three at the outset, to 119 by the end of the three-year project. However, the NSW-9 project reported that an audit of files and patient-held notes revealed that while advance care planning was mentioned regularly, this did not translate into the development of formal ACPs, with only one completed and one partially completed. QLD-2, which had as its primary focus the development and implementation of end-of-life care pathways in RACFs, also found that uptake was less than anticipated, with only 47% of dying residents placed on a pathway during the project's implementation phase. The evaluation of this project included a survey of bereaved relatives, which indicated that satisfaction with care was very high throughout the whole period of the project, with no discernible changes from pre- to post-implementation (QLD-2).

The NSW-1 project focused on supporting clients and carers as they transferred from a large palliative care hospital setting (Calvary Hospital) to RACFs for end-of-life care. Sixty-seven clients and their families were assisted through the project, which sought to improve end-of-life care through a number of strategies, including psychosocial support to the clients, education to facility staff, and the enhanced use of predictive tools by the acute setting staff. Through the processes implemented by the project, there was a significant improvement in the survival times of residents following their admission to aged care from Calvary. Initial research revealed that only 33% survived at least three months following transfer; however this had increased to 50% by the time the project activities ceased. The evaluation showed a high level of satisfaction on the part of clients and their families, the key aspect of which was the continuing connection to Calvary, in particular the regular follow-up by the social worker and volunteers after the transfer to the aged care facility.

6.1.3 Improved assessment and management

Fundamental to the provision of good end-of-life care is the appropriate assessment and management of symptoms. Nearly two thirds of the projects undertook activities to address this need, including through the development and/or promulgation of assessment tools, education, protocols and care planning. Again, the outcomes of these activities were primarily reported on in terms of their impact on health providers, and therefore there is little evidence provided about the impact of such initiatives directly on clients, apart from providers' perspectives that these issues had been better addressed as a result of the interventions. These are discussed further under Section 6.2.

6.1.4 Access to information

All projects were involved in sourcing and/or developing and distributing information or supporting documentation for the systems, strategies or approaches being implemented. The majority of resources overall were targeted for health professionals and those involved in coordinating or providing care. Approximately half of all projects also distributed resources to support clients and carers. These included using pre-existing resources that were sourced and distributed, or tailored to suit the local context or needs of particular client groups, and the creation of new resources that met an identified need, e.g. pain management, end stage renal disease in Aboriginal clients. The

resources tended to have a dual purpose: to inform clients and carers, as well as empower them in decision-making regarding their care needs.

The resources took the form of pamphlets, brochures, booklets, posters, educational packages and DVDs. Some of the interventions described above, such as the PHRs and care plans, were designed to inform clients as well as give them control over the care they were receiving. Information on the dying process, supporting the use of advance care plans, symptom assessment and management strategies, and bereavement were typically included in the suite of resources provided to clients and carers (e.g. NSW-5, NSW-6, NSW-8, VIC-4).

6.1.5   Involvement in decision-making

A recurring theme in the project reports was the impact of improved coordination and the provision of information on the confidence of clients and carers to actively participate in decisions regarding their care and treatment.

The process of including clients and carers in multidisciplinary team (MDT) meetings, case conferences and care planning discussions appears to have had benefits in terms of enabling them to be prepared for the future. One project noted that patients and their carers were generally satisfied to very satisfied with their inclusion in the planning process and the level of service they received from the palliative care service (VIC-1). Another noted that being involved in care coordination activities had given clients an active voice in healthcare decisions; 'they felt listened to and involved in the decision-making by the healthcare team' and added that 'patients felt their knowledge of their illness was viewed as useful and important, and all felt able to ask questions, and to talk about feelings' (SA-1). In its evaluation of the implementation of the patient-held record, another project reported that hospital nurses had noted that clients were better able to share with family and friends about their illness, and were more involved in treatment decisions (QLD-6).

This was a particularly important finding of processes developed to improve end-of-life care for Aboriginal people with end-stage renal disease. The final report noted that prior to the project implementation people did not seek out information once diagnosis of renal disease had been made. The project introduced family meetings and also developed a series of culturally appropriate educational resources, resulting in greater engagement of clients and their families in the ongoing management of the disease (WA-1).

However, not all were successful in engaging clients and carers in the discussions. One project which had a strong focus on MDT meetings reported that despite the invitation being extended to clients and carers to participate in the discussions, none took up the offer (NSW-7).

The process of engaging with clients and carers regarding end-of-life decisions was also found to be important in building confidence in clients and carers, particularly in residential aged care. One project reported that staff felt that the introduction of advance care planning had empowered residents to have a say in, and ownership of, their care. The report went on to note that staff had observed that the end-of-life discussions had encouraged families to talk amongst themselves so they were better prepared for the death of their family member (NSW-6). Another project reported that results from surveys of residents' families and carers revealed that they felt more confident that the resident was in receipt of a higher quality of care (NSW-4).

6.1.6   Reduced burden of care

A key outcome of the processes described above was a reduction in the burden of care experienced by carers of people with palliative care needs. This was evidenced through evaluation strategies undertaken by a number of projects, involving feedback directly from carers themselves, as well as perceptions of staff and providers. The support provided to carers differed according to the needs identified by the individual projects, and included the provision of education

and support groups, development of resources, case management, referral and direct service provision.

Several projects undertook specific activities focused on providing support to carers through the provision of education packages and support groups (e.g. NSW-5, QLD-4). The education programs typically covered topics such as the dying process, carer resources, grief and loss, carer resources, and self care. One project developed a brochure on coping skills, and promoted a grief and loss course which was being provided by the local church diocese (NSW-3). Another developed its own support groups, resulting in 96 carers receiving education and support through the provision of twelve carer support groups and four bereavement support groups. Three key themes emerged from the evaluations: participants understood that grief was a process; they no longer thought they were 'going mad'; and they wished they'd had access to the information earlier (QLD-4).

A number of projects provided direct support to carers through the provision of case management and coordination, and respite. One project reported that carer stress and uncertainty regarding care were the most frequently cited reasons for assistance, leading to the development of emergency care plans. This project also noted that in addition to the case management role, carers appreciated the brokerage of services and equipment, end of life pathways, counselling and bereavement care provided by the project (NSW-9). Another project noted the importance of assessing the capability of the caregiver to manage and support the client (VIC-2). Carers appreciated being recognised in their own right, and in being referred to and provided with practical support (NT-1).

The establishment of an Indigenous Women's Cancer Support Group (IWCSG) was also supported by one of the projects. The IWCSG was an initiative funded by the local hospital, and the project was able to provide administrative support to the group, facilitate meetings and organise a public function (WA-2). A number of other resources were drafted to support indigenous carers, including an educational package, community development DVD and brochure, however due to budget decisions by management, these were not able to be fully developed.

6.1.7 Community capacity

The benefits arising from the projects were not limited to clients and carers, but also impacted on the general community. This was particularly evident in projects working in rural and indigenous communities, where community participation and facilities were used in the development of resources and undertaking of project activities. One project used the local theatre for a launch of its resources, which had been developed by the local 'Men's Shed' and included donated resources from local industry groups (NSW-5). Another reported that the community engagement of the project and resource development resulted in an increased level of understanding of kidney disease, the kidney disease pathway, and care and management for patients and their families (WA-1). Yet another reported that over 100 people from the local district had indicated an interest in completing an advance care directive following community consultations on the subject (NSW-4).

Projects working in cross-border areas were required to be quite creative in their engagement of the broader community. One project developed a community cross-border palliative care planning group and delivery of a play which, amongst other things, resulted in increased community knowledge (of 54 survey respondents 61% learnt new information and 85% indicated they were more prepared to talk about death), and additional financial resources and goodwill for continued activities (VIC-8).

6.2   *Impacts and outcomes on health professionals and care providers*

The major outcome for health professionals and care providers as a result of the Care Planning Sub-Program has been an increased capacity, competence and confidence to provide palliative care. This was predominantly achieved through education, changed care practices, access to

specialist services and resources, as well as improved relations between service providers which resulted from project activities.

6.2.1 Increased capacity of staff resulting from education

Nearly every project was involved in developing and/or delivering some type of training and educational activity. There were three broad audiences for educational activities targeting providers in the following care settings: RACFs, community care services, and health services (primary, acute and specialist). A number of projects also targeted general community groups, and these were typically projects in rural locations. While a number of projects had staff from within their host organisation as their primary target group, the final audiences included a much broader representation of the local service system.

The subject matter covered in the education sessions was focused on aspects of end-of-life care, including pathways, assessment and management of symptoms. The standard of the educational materials was high, with many basing their information on the *Guidelines for a Palliative Approach in Residential Care – Enhanced Version* (Palliative Care Australia, 2006) and national palliative care competencies.

The education and training was predominantly provided through face-to-face group or individual training. Project officers either delivered the education themselves, or facilitated access to relevant educational opportunities. A number incorporated a train-the-trainer element or similar approach, which enabled the identified palliative care or pain 'link' nurses or 'champions' to continue to deliver the training and embed the changed practices within the organisation in an ongoing manner.

6.2.2 Audiences

Not all projects provided comprehensive data on the evaluations of their educational activities, so it is not possible to estimate the overall reach of the educational component of the sub-program. However, data from those projects that did provide information supports the overall view that there was a significant impact made on the services, clinicians and staff providing palliative care. Some examples of the data reported by projects show the range of educational activities undertaken by the projects: 297 occasions of staff training during the project (NSW-5); 73 sessions (were) delivered, reaching 785 participants (NSW-7); 65 group and individual presentations (NSW-9); 10 RACF staff participated in a special palliative care course and 30 staff attended one of three workshops run by the project on communication and grief issues (NSW-1).

By far the largest single group of providers to receive training and education under the sub-program were staff in RACFs; this is not surprising given that almost half of projects included residents of RACFs in their target group. The method of this training was primarily face-to-face information and education sessions, supported by relevant documentation. Some projects were quite targeted in terms of the audiences for the training which was delivered to registered nurses, enrolled nurses or care staff (e.g. NSW-6); while others had broader audiences which included volunteers as well as community disability services (e.g. NSW-4 and NSW-3).

The majority of training was provided in group settings, ranging from between five to 20 participants, and was delivered as either one-off episodes or a structured series of educational sessions. In some cases participants achieved a certificate of recognition at the completion of the training, such as those who attended the 16-hour education package (four hours per week over a four week period) delivered by NSW-6 and NSW-7. In the main, education was offered at the facility level, or at a common venue within the region. A significant number of project officers also reported that they provided additional one-to-one training and mentoring, particularly where new processes were introduced as part of the project.

Health professionals were also provided with educational opportunities, including staff in primary, acute and specialist services, community nurses and allied health staff. In some cases this was provided in-situ, or to discipline-specific groups, but more often than not education was provided to a range of providers at the same time.

The main professional group to have received individualised attention was general practitioners, primarily through practice visits undertaken by projects which were hosted the relevant Division of General Practice (DGP). This was quite a successful strategy in reaching GPs, as evidenced by one project which reported that feedback from the practice visits showed that GPs were enthusiastic about improving their proficiencies in end of life symptom and medication management as a result (NT-1). However, the majority of projects which were not allied to or hosted by a DGP had difficulty attracting general practitioners to participate in training, despite significant effort on the part of the project officers.

Other health professional groups were more easily targeted, mainly via existing communication and service networks. Typically, the rural and regional projects attracted a broader range of health and service providers to educational sessions, with one reporting it had provided support to general practices, aged care providers, community health and community nurses, as well as allied health professionals and community groups such as the Cancer Assistance Society and the Country Women's Association (NSW-9). Rural projects often convened information and education sessions for the general public, in recognition that the informal service network and broader community often played a vital role in supporting people with palliative care needs in the community.

6.2.3 Subject matter

The topics addressed in the education and training sessions were identified through a range of mechanisms, including feedback from stakeholders (e.g. steering committee members), surveys (e.g. Tool 2.1 of the CHSD Evaluation Toolkit) and through audits of patient/client notes. One project reported that following the outcome of the staff survey (Tool 2.1), an education program was developed covering topics such as advanced care planning; end of life; pain management; symptom management; skin and wound care; loss and grief; communication and anxiety; self care; and interpersonal skills (NSW-5). Other projects reported a similar range of topics identified by staff, for example 'health professionals identified a number of priority education topics, including psychosocial support, advance care planning, "delivering bad news", as well as symptom management and pain control' (NSW-8), and 'priorities for palliative care topics were: physical symptom management; psychosocial issues; grief; and assessment' (QLD-1). Principles of symptom management, referrals to palliative care, and the needs-based model of palliative care were topics covered in a study day for clinicians from RACF and acute wards (SA-5). In addition, they were presented with information about the Program of Experience in the Palliative Approach (PEPA), took part in a case study discussion, and completed computer exercises utilising the CareSearch and MAPCARE resources.

The majority of formal training sessions delivered included evaluation forms for completion by participants at the end, and findings were used to refine and enhance future training delivered. These evaluation findings were also supplemented with surveys, questionnaires and focus groups at the end of the projects to identify future training needs.

The majority of projects developed their own training materials, usually based on existing materials but tailored to the context of the project. All training was aligned to the *Standards for Providing Quality Palliative Care for all Australians* (Palliative Care Australia, 2005b) or the *Guidelines for a Palliative Approach in Residential Care – Enhanced Version* (Palliative Care Australia, 2006). Some had clear ideas of what training was required at the outset, and used the surveys and other methods as a mechanism to ensure the initial thinking met the needs of the particular target groups. Others had a plan at the outset, but were able to respond to new issues which arose as the project progressed, refining their project activities accordingly. An example of this was NSW-4, which developed a Care Planning Guidance Tool – *If and Then Model* and an educational package

to support its implementation in RACFs. However, findings from an audit of residents' notes revealed major deficits in the documentation of pain assessment, staff reporting of pain, recognition of behaviours linked to pain and inadequate staff response to reports of pain. In partnership with NSW-5, a literature review was undertaken, and a training package on pain management of older people with complex needs was developed, comprising a DVD entitled *The Impeccable Assessment of Pain* and Certificate IV training materials. This ability to respond to needs identified was characteristic of a number of projects, and projects were encouraged to do so with the agreement of the Department of Health and Ageing, where it was appropriate and within the overall scope and budget for the project.

The major focus of educational programs for staff of RACFs was end-of-life care, and support of the implementation of tools and pathways developed. A number of projects reported on their activities in this area, for example: 'End-of-life care pathways have been designed to provide best-practice care, and nurses have been educated to use this tool to support decision-making. This model of care has been implemented in all areas of the facility' (QLD- 3). Advance care directives/plans were integral to a number of these approaches, with one project reporting that 'training ... was delivered with an expectation of workplace learning and assessment, and the learning materials had been developed with a major emphasis on advanced care planning discussion techniques and skills to ensure competence and confidence were maximised in the task of talking to people about planning for the future' (NSW-3).

Almost all projects included a focus on improving assessment skills through the production of and/or utilisation of existing resources and tools around palliative stages, care needs and symptom management. These included palliative stages/phases (e.g. NSW-7, NSW-6, VIC-1,VIC-6); clinical prediction of survival (NSW-1); pain (e.g. NSW-3, NSW-4, NSW-5, NSW-6, NSW-7) and symptoms associated with advanced dementia – pain, constipation, weight loss and agitation/confusion (NSW-10), and end-stage heart failure (QLD-5). The project officer for SA-5 reviewed existing education resources and developed a CD resource which directs generalist providers to evidence-based materials that support best practice in palliative care. A palliative care information package was prepared for use in the regional general hospital medical ward. Again, there was limited information reported regarding the actual number of individuals trained, however some projects did provide data: 'Education was also provided on Palliative Care Assessments. Seventeen sessions were provided, reaching 202 participants, to support the use of evidence based tools' (NSW-7); 'Training was provided to 29 experienced participants (seven Directors of Nursing (DON) or Deputy DONs; three nurse educators; and 19 registered nurses)' in decision making frameworks (NSW-10). To support the implementation of end-of-life care pathways in RACF, the Qld-2 project developed a one-hour workshop which introduced staff to the palliative approach and explained how to use the care pathway. This was delivered 17 times to a total of 157 staff. Workshops were held during day, evening and night shifts to maximise accessibility.

Two training packages were developed for use by indigenous staff, carers and communities, however were not implemented during the course of the sub-program. An educational resource for indigenous carers was developed in consultation with community groups and trialled, with positive outcomes. However, decisions by project management regarding funding allocation did not allow for the production and implementation of the final package (WA-2). An educational package targeting staff, individuals, carers and communities on end stage renal disease was also developed, again in close consultation with in Aboriginal communities to ensure a culturally appropriate approach and resources were developed. This educational package is expected to be incorporated into an orientation package for staff working in the new Kimberley Renal Support Service, which was established just prior to the conclusion of the project (WA-1).

6.2.4 Delivery of education

The majority of education was provided directly by the project officers, sometimes with additional support of relevant clinicians or providers. Four projects collaborated closely with those in close

geographic proximity, forming partnerships to develop and deliver the training and education sessions (NSW-4 and NSW-5; NSW-6 and NSW-7).

A number sourced educational resources and presenters external to the project. One project invited a visiting UK clinician to present a series of five education workshops across the region, and to also review the host organisation's education tools (NSW-2). Another noted that feedback from staff suggested that lectures by visiting experts and small group workshops were the preferred learning styles of the project target group (QLD-1). A number of projects facilitated access to training, including working with the local TAFE to include palliative care issues in the training provided for community care staff, identifying Certificate IV competency training for primary care providers, and the promotion of Certificates III and IV in Palliative Care courses offered by the local training organisation (NSW-9, NSW-5, VIC-8).

In addition to the formal education and training sessions offered, a number of projects included the identification of 'champions' or 'link nurses' who were located within the (predominantly) aged care facilities, whose role was to be a resource for the organisation once the initial training had been completed. Two projects jointly delivered training to 33 'champions' in palliative care, and together with those trained under a previous RPCP initiative, resulted in nearly 60 champions believed to be working in different care settings across the region, including RACFs, the local hospital emergency department and medical ward, as well as Aboriginal and generalist community nursing services (NSW-6 and NSW-7). These projects also developed a focus on pain management, training 15 registered nurses and enrolled nurses from aged care, community and hospital settings to act as 'pain campaigners' and promote the use of pain assessment and management tools and resources. Two projects reported that they had presented 'train-the-trainer' education for the link staff to enable them to provide the education to staff in their workplaces beyond the life of their projects (NSW-10 and QLD-6). Link nurses in RACF implementing end-of-life care pathways were supported via bi-monthly meetings, site visits at least weekly by the project officer (enabling opportunistic training and monitoring of evaluation activities), telephone support and a full-day workshop (QLD-2). Similarly, resource nurses or 'nurse champions' were selected from each floor of the aged care facility and given three days' training in palliative care at a metropolitan specialist palliative care service in order that they could provide effective support for colleagues implementing high-quality end-of-life care for residents (QLD-3). Another project used a 'train-the-trainer' model for educating community health staff on the use of home-based infusion pumps for heart failure symptom management (QLD-5).

6.2.5 Outcomes of education

Not all projects provided comprehensive data on the evaluations of their educational activities; where this was available, however, the findings indicated positive outcomes for staff. From the evidence provided, it is clear that a large number of people working in residential aged care, health services and community care have benefited from the education and training provided under the sub-program. Their increased capacity has not only been in terms of skills development, but has also resulted from the increased confidence to make assessments, manage end of life care needs, and participate in discussions with clients and family members around these issues.

The extent to which confidence was enhanced is demonstrated in the findings of one project which reported that enrolled nurses and care staff had an improved confidence in answering questions on the dying process (16 out of 19 post-education, up from only 5 pre-education), reacting to reports of pain from patients (16 up from 6) and reacting and coping with limited patient decision making capacity (15 were confident to perform with minimal or no consultation, compared to 6 pre-education) (NSW-6).

Another project reported that staff training program survey results revealed that the large majority reported improvement in confidence and skill as a result of the education: 23% mild; 46% moderate and 16% very large improvement (NSW-5). The increase in knowledge and confidence in the use of relevant tools and guidelines was also evidenced in the findings of another project

which delivered training to residential aged care staff. It reported that the education programs were well attended by participants, who rated their usefulness as high, and the education also raised awareness of the Guidelines amongst RACFs, some of which previously were not aware of their existence. It went on to say that there was increased use in those facilities that were aware of the Guidelines but had not previously applied them to their care practice (VIC-4).

The quality of the education and training provided by the Care Planning projects was also evidenced in the number which sought to develop, deliver and/or facilitate training which provided specific competencies for participants. One project noted that the project supported two staff completing their Palliative Care Certificate; two staff completing the Certificate IV 'Plan and provide care services using a palliative approach'; and four week-long clinical placements for staff (NSW-5). Another project, which had previously received funding under the Local Palliative Grants Program Round 1 to develop competency based training, concluded that the combined projects had resulted in over 180 staff from within the host organisation undertaking the national palliative care competency training either as part of an entry level trainee ship or as a stand alone module delivered over six weeks with workplace assessment imbedded into the model. A further 35 staff from external facilities undertook the national competency from the community services training package (NSW-3). Fifteen registered nurses working in the acute and community sectors in the South East region took part in a 10-week distance education course in palliative care, while one local GP and two staff of the palliative care service undertook further specialist study in palliative care through Flinders University (SA-5).

There was demonstrable improvement in the capacity of staff to undertake care planning and provide end-of-life care, including evidence-based assessment and symptom management, most commonly in relation to pain management. Results of a resident file audit undertaken before and after the implementation of an end of life care pathway by one project found that analgesia prescribed at 72 hours prior to death was 40% in the pre-test data, compared to 76% in the post-test data. Similarly, PRN (as required) medication for breakthrough pain was recorded at 35% in the pre-test data, compared to 73.3% in the post-test data. The latter audit also found that 36.6% of residents were on an end-of-life care pathway (NSW-6). The project went on to report that these audit findings were supported in feedback provided during focus groups, in which staff agreed that, due to the education, providing palliative care was more structured, there was better recognition of the phases of care and use of assessment tools, improved ability to identify symptoms and provide evidence when someone required pain or symptom management. This was echoed in another project's report, where feedback from staff revealed their perceptions that the quality of end-of-life care provided by their facility had significantly improved as a result of the enhanced capacity of staff due to the education provided to support the pathway following the introduction of end of life care pathway (QLD-2).

Greater confidence and competence in the use of standard assessments tools also resulted in improvements to the way services and professional groups related to each other. A number of projects indicated that there was greater confidence of generic services in dealing with, and referring clients to, palliative care specialist services, and also with RACFs engaging general practitioners in palliative care provision, due to their use of common assessment tools such as Palliative Phases, Karnofsky Scale, Resource Utilization Groups for Activities of Daily Living (RUG-ADL), Palliative Care Problem Severity Scale and the Symptom Assessment Score (e.g. NSW-3, SA-5, NSW-1).

The benefit of the use of link nurses or champions was not well demonstrated in the project reports; the focus of evaluation was primarily on the education provided rather than the strategies used to support it. However, one project did report on the link between consistency of staff and outcomes for residents. It observed that amongst the RACFs involved in the project, the two facilities with the highest percentages of dying residents commenced on the end of life pathway were the only ones to retain the same link nurses throughout the project; these were also the facilities that had the highest number of staff attending education sessions, suggesting higher levels of management support (QLD 2).

6.2.6 New approaches to care planning

The education initiatives described above were essentially designed to support the implementation of new approaches to care planning, coordination and provision. Around two-thirds of the projects resulted in changed systems or processes being introduced and embedded into local practice, including different ways of planning care, assessing and managing identified needs, using evidence in decision-making, and communicating with clients and other providers.

Care coordination
The most common element of all the projects has been the adoption of a multidisciplinary approach to identifying and managing care needs. Strategies developed include formal multidisciplinary team (MDT) meetings, case conferences, case management and care planning pathways. The aim of these approaches is basically to enable care to be provided to people with life-limiting illnesses in a more holistic, planned and coordinated manner. In addition to benefits for clients, the project evaluation reports also show there are clear outcomes for providers in terms of improved communication, relationship building, referral and problem solving, as well as educational benefits for non-specialist health care providers.

Interdisciplinary case conferences or MDT meetings were by far the most common care planning tool utilised by the projects and a number of projects reported significant evaluation findings regarding these care planning processes. The meetings generally included representatives from a range of service and professional disciplines, usually including the general practitioner (either in person or via telephone), residential aged care provider, community nurses, specialist palliative care team and related community care providers. One project reported that it had convened 93 MDT meetings for the care planning of residents across three RACFs, which were attended by 461 participants overall, including 65 general practitioners, 238 nurses and allied health care providers and 158 residents and family members (NSW-6).

A number of projects reported difficulties engaging key stakeholders in the case discussions. One rural project reported that organising a time and venue for meetings was not always practical due to staff shortages and when services covered a wide geographic range (NSW-9). In these circumstances, case conferencing was an iterative process using a series of telephone discussions, fax or email communication to draw up a care plan for clients.

There were also mixed results about the level of participation by general practitioners in case conferences/MDT meetings. The primary reason appeared related to the resource implications for their involvement both in terms of time and money. A number of strategies were adopted by the projects to facilitate greater level of engagement by general practitioners in the care planning processes, including engaging the local Division of General Practice to take a lead role in advocating the benefits of the meetings, scheduling discussions into the GPs' diaries, arranging for their participation to be via telephone and GP issues to be prioritised, and including the relevant Medicare rebate item number to the supporting documentation.

The projects with the most success were those which were run or heavily supported by a Division of General Practice, but even these had to be creative in how they retained the involvement over the longer term. One project developed the role of a GP 'advocate' to chair the meeting, which was drawn from those GPs with an interest in palliative care and had the capacity to influence the broader GP sector (NSW-7). The project reported that the participation by the patient's own GP at case conferences increased steadily, resulting in 215 occasions of involvement by GPs overall. By the end of the project, patients' own GPs were in attendance at 92.5% of MDT meetings, with an average of 74% over the life of the project. Feedback from GPs who participated in the MDT meetings or equivalent processes suggest that the experience was positive, as it enabled them to better identify patient symptoms and problems, and they also valued the interaction with the palliative care service (SA-1).

Benefits were also realised for broader health professionals and service providers participating in these processes. One project reported that a large majority of its participants indicated they felt more informed about the patient (86%), were better able to address their needs (73%) and had improved communication between providers about patients (76%). In addition, the project reported that almost all agreed that planning for their patients' future needs had improved (97%) (NSW-7). Feedback from participants in another project indicated that the focus of the interdisciplinary meetings was appropriate, the tools and common language used with palliative patients were easy to understand and adopt, and they could see the relevance within the broader picture (SA-1).

One of the major benefits for participants of case conferences/MDT meetings was the opportunity for generalists to learn from specialists, and for participants to better understand the contexts in which they each operate. In addition to being opportunities for information exchange, communication and problem solving, case conferences were a means for contributing to improved clinical practice by educating non-specialist health care providers in palliative care and building relationships between specialists and primary care (QLD-6, SA-5). Specialist palliative care services also benefited, as they became aware of the need for a multidisciplinary approach to care, not just nursing consultancy (VIC-4). In a similar vein, projects targeting indigenous communities also found that the multi-disciplinary approach enabled the range of clinicians, providers and families to be aware of not only the clinical and care issues for the client, but also take into account their particular cultural requirements (WA-1). However, one project found that the focus on information exchange sometimes detracted from the time spent planning and coordinating care (SA-1).

The opportunity for care staff in RACFs to benefit from the learning opportunities provided by MDT meetings was limited, however, as participants from RACFs tended to be more senior staff, and not those involved with the day-to-day responsibility of providing immediate care for the resident. One project reported feedback from care staff indicated their interest in participating, however they were constrained by their inability to leave the workplace to attend meetings (NSW-6).

A number of features were identified which were critical to the success of the case conference/MDT meeting approach, including the need to define the purpose, leadership, roles and responsibilities of participants clearly. This is consistent with what the literature tells us are key attributes of partnership arrangements (see Section 7.1.4). These aspects are considered fundamental to ensure that all participants feel they have an equal, but different, capacity to contribute to the discussions. Where this was practiced, projects report that participants did not feel hindered in contributing to the clinical discussion (SA-1, NSW-7). Another element which has been identified as being critical to the success of partnership arrangements is the need for clear and timely communication between partners. This was a feature of all case conference/MDT meetings, and strategies developed to facilitate efficient follow-through of decisions arising from the discussions, including written outcomes to be forwarded to partners within a short time frame (in the case of one project, the aim was within 24 hours), and the inclusion of the appropriate Medicare rebate number (NSW-7).

Care planning
A corollary of the care coordination strategies introduced was the embedding of care planning practices across a range of care settings. This was the focus of nearly all projects. As with the case conferencing and MDT meetings, the outcomes included improved understanding of the need for multidisciplinary approach to care, improved communication between providers, and an appreciation of the different contexts in which care was provided. As discussed previously, the new care planning processes were supported by education and training opportunities, to provide staff with the competence and confidence to implement the plans.

As expected, there was a wide range of disciplines involved in the care planning for clients and carers, with the core group tending to include representatives of relevant primary, acute, specialist and community health and care services. In addition, one project reported that findings of an audit

of case files and home notes revealed involvement of representatives of occupational therapy, physiotherapy, Aged Care Assessment Team, dietician, speech pathology, and a case manager (NSW-9).

Care planning processes provided benefits for staff, enabling them to deliver care in a more planned, holistic and proactive manner, instead of an ad-hoc, reactive approach. One project included case studies which outlined the relevance and usefulness of the new care planning procedures, with feedback from participants indicating that the approaches and resources were relevant, useful and assisted in providing enhanced palliative care to clients (NSW-5). Another noted the improved communication between team members, clinicians and care providers (NSW-8).

Nearly all projects developed resources to assist staff undertake care planning, including assessment and management strategies, documentation of decisions, and facilitation of information sharing between providers. These were usually developed in conjunction with key informants and stakeholders and trialled prior to finalisation to ensure relevance, ease of use, and applicability to the particular context. A number of projects undertook literature reviews to ascertain the evidence regarding best practice to include in the care plans.

Three projects trialled a case management approach to care in rural communities, using the care planning and case conferencing processes described above as some of the core elements of the service delivery model (NSW-2, NSW-8, NSW-9). This model of care took some time to develop, and there were initial difficulties with implementation, due to the perceived duplication of existing services. The projects reported that these issues had resolved over time, as the benefits and outcomes to clients became clear (NSW-8, NSW-2). While the final reports did not provide clear evidence to support the model, the projects claim that the model is a useful adjunct to the suite of services providing palliative care in rural communities, and enhanced communication between clinicians and providers involved in providing care for an individual with palliative needs and their carers (NSW-9).

Patient-held records
As discussed in Section 6.1.1, patient-held records (PHRs), or diaries, were developed as a resource for clients and carers to facilitate improved coordination and communication between clinicians and providers involved in addressing their clinical and care needs. Fundamentally, it is also a shift in power about who controls information about a client; that is, it enables the client to have ownership of information about their own care needs. This approach is consistent with the overall principle about putting the person at the centre of care, as opposed to the historical prominence of the health care provider. As such, it represents a significant shift in emphasis for health providers, and assists them to view the client as an equal partner in the care provision equation.

A number of projects reported benefits for health professionals and care providers as a result of the introduction of the PHR, particularly in terms of facilitating communication (e.g. SA-2, SA-3, NSW-5). The PHRs enabled providers to readily access information about health status, clinical and care needs, details of key contacts (personal and professional), care plans and any documentation that might exist regarding end of life wishes, such as advance care plans.

However, the benefits were offset by a number of findings, which suggested the utility of the diary was not as significant for providers as expected. One project reported the results of an audit of home notes, and found that the engagement by service providers and clinical staff such as community nurses and general practitioners was relatively low, with only 10% of home notes having entries by these groups (NSW-9). Some of the challenges identified included lack of clarity for health professionals about its role and how to use it; missing documentation or documents not up to date; and duplication of effort, particularly for community nurses and palliative care service staff who recorded their interventions in their own reporting processes, and the resultant consequence of taking time away from addressing clients' needs (SA-3, QLD-6).

6.2.7   Improved access to specialist services and resources

The changed activities described above were underpinned by the development of new evidence-based tools and resources, the consistent application of which was designed to result in flexible and individualised care planning. The implementation of the tools was supported by the education and training strategies described above. In addition, access to specialist advice was improved through the provision of triage and referral services, 24 hour telephone support, and the establishment of consultancy arrangements.

Tools and resources
The tools and resources included detailed approaches to care coordination and planning models, referral tools and pathways, service guides, information about death and dying, target group and disease-specific resources, assessment tools and prognostication tools (e.g. Abbey Pain Scale, Palliative Phases, Karnofsky Scale, Resource Utilization Groups for Activities of Daily Living (RUG-ADL), Palliative Care Problem Severity scale and the Symptom Assessment Score (e.g. NSW-3, SA-5, NSW-1).

Some projects were quite clear about the focus and nature of the resources they were intending to produce at the outset of their project (e.g. NSW-10, SA-4). For the majority, however, the detail of the resource was developed following the needs analyses and educational surveys which were part of the early stages of their projects. Another, smaller group of projects went on to develop resources as the needs were identified during the course of implementing their project, for example to improve pain management, and these activities became incorporated into their overall project plan (e.g. NSW-4, NSW-5, NSW-6, NSW-7).

A principle underpinning the majority of resources developed and education provided was the need for reflective practice on the part of providers. One project included this emphasis in the title of its main resource, called the Care Planning Guidance Tool (CPGT) – *If and Then* model. In addition to providing resources on guidelines, advanced care planning and end-of-life care pathways, the document was designed to act as prompt for care planners. For example, each issue is posed as a question, and *if* the answer is yes, *then* the action is completed; *if* the answer is no, *then* the issue is turned into an action item on the care plan (NSW-4).

The impact of these resources on providers was generally considered quite positive, with the main outcomes being increased confidence, competence and engagement with the palliative care service network (e.g. VIC-3, VIC-8, NSW-2, WA-2).

A number of projects reported on the increased confidence of staff resulting from their exposure to the frameworks developed, with one project noting that nurses and care staff who used the frameworks increased confidence in their ability to manage the symptom of concern, and discussing the symptom and its management with family members and general practitioners (NSW-10). The competence of health professionals was improved due to the use of new tools and resources, in particular assessment tools. One project developed a protocol for social workers and doctors regarding the proper use of prognostic tools, and from the evaluation found that hospital staff improved their ability to select those palliative care patients who would do well in nursing homes and also felt much more confident about transferring palliative care patients to nursing homes when they knew they would be closely followed up (NSW-1). Despite the difficulties some projects had engaging GPs in their projects (discussed in Section 5.3.1), those projects that were successful also noted benefits for the broader service network. One project noted that through the inclusion of the palliative care tools and protocols in the patients' case notes, GPs indicated they felt more included in the wider team of care for the patient, and some even participated in joint home visits with the palliative care team for assessment and care planning (SA-5).

Several projects developed care planning processes and resources for specific client groups, such as children (VIC-7), adolescents and young adults (VIC-6), Aboriginal clients with end stage renal

failure (WA-1), people with dementia (NSW-10) and people with advanced heart failure (QLD-5). These projects were particularly beneficial for providers working in these fields, as the evidence based resources and processes developed were often ground-breaking, articulating the issues and needs of these clients, and implications for service provision, in a way that had not been done previously. Feedback on the tools and resources developed indicate that they met the need of providers, with one reporting that 92% percent of participants believed the care planning tools would help them plan care for (the target group) with life limiting conditions and 93% of participants reported they would recommend the care planning tools to colleague to help plan care (for the target group) (VIC-7). A number of kidney education resources were developed for Aboriginal clients and families which outlined the palliative approach, which were also found to be useful learning aids for Aboriginal health workers, nurses, doctors and allied health staff (WA-1).

Not all projects were able to provide data on the impacts and outcomes of their resources; however, the interest generated suggests that they were appropriate, useful and potentially of relevance to broader audiences than initially intended. For example, one project developed a DVD and training package on pain assessment and management which was targeted at staff working in RACFs; a local Division of General Practice requested 100 copies of the package with the intention of distributing it to all RACFs, hospitals and general practitioners across the region (NSW-4).

Access to specialist advice and support
The main strategies developed to enhance the capacity of generalist providers to access specialist advice and support include the provision of triage and referral service, 24 hour telephone support, and facilitation of consultancy services.

A small number of projects provided access to triage and referral services, either through the direct provision of the service by the project officer (NSW-7, NT-1, NSW-2, VIC-2) or through additional funding to support an existing service (NSW-8, NSW-9). The aim of these services was to enable enquiries to be dealt with quickly and referred on to the most appropriate service response, as well as being able to provide information and resources which could assist in care planning. One project reported that it provided 589 episodes of information and/or advice to providers, comprising 148 calls received and 441 made by the project coordinator (NSW-7). The majority of calls received were from residential aged care services (57), GPs (28), community care providers (25), inpatient and allied health services (18 and 17 respectively). The requests received were mainly for triage and referral matters, with almost half the calls resulting in the provision of information and support, and a similar number again requiring referral to the palliative care service, MDT or medical review. Another project to include a dedicated position to undertake triage and referral services reported positive outcomes for relationship between the service and the local Carers Association, and for carers of palliative care clients. Prior to the project's commencement there had been no referrals of palliative care carers to the association; by the time the project finished, the service was the largest independent source of referrals to the association, accounting for 17% of all referrals (NT-1).

Two projects utilised an existing triage and referral service established by the local Carers Resource Centre (CRC) (NSW-8, NSW-9). Staff of the CRC were provided with additional training to meet the needs of the clients and carers with issues relating to palliative care. This strategy enabled the early identification and management of issues, and referral to appropriate services and supports. One project reported that through this mechanism, several carers (4%) were identified as being at risk of complicated grief, and consequently were seen by their general practitioner and referred to a psychologist (NSW-9).

All of these services included availability of access to 24 hour telephone support for both clients as well as service providers. Most included in their suite of resources a contact list of relevant after-hours providers and supports available across the region. However, one project noted that the after-hours service was not utilised by other providers, who preferred to maintain their own established after-hours arrangements (NSW-2).

Facilitating access by generalist services to specialist consultancy services was an important focus for approximately one fifth of all projects (e.g. NT-1, VIC-2, VIC-4, NSW-8, NSW-9, QLD-1, SA-2, SA-5, WA-1). Examples include the provision of a specialist clinical nurse consultancy position which was available to a network of aged care services, funding for short-term after-hours nursing support, and short-term placements of staff within specialist services, and incorporating specialist consultants remotely by telephone in the provision of family meetings.

Outcomes of this strategy which were reported include a raised awareness of a palliative approach to residential aged care amongst staff and an understanding of how to refer for specialist support when needed. One project which provided consultancy support to RACFs saw an increase in referrals from 27% in the first six months of the project to 57.1% in the last six months of the project (VIC-4). A similar model was utilised by another project, which saw a significant rise in the numbers of referrals as the project progressed, and resulting in 50% of all referrals to the service by the project end (VIC-2). The final report noted that only one third of these referrals had a known malignancy, suggesting greater recognition by the RACF staff of providing a palliative approach to care for residents.

Access to specialist consultancy services was especially valued for those providers of target groups such as children, adolescents and young adults, chronic heart failure and indigenous communities, due to the emerging nature of the specialties, and disparate spread of clients. In addition to the resources and protocols developed to assist these providers, a number incorporated specialist involvement in regular multidisciplinary meetings or family meetings. One project noted that this resulted in an increased number of clients attending their clinic for follow-up, and an increase in numbers being referred to the specialist renal clinics throughout the region (WA-1).

Additional resources of volunteers
Approximately one in five projects aimed to enhance the support provided to people with palliative care needs through the development of volunteer programs. The main focus of the role of volunteers was to provide pastoral care for clients and their families, to supplement the activity being provided by the generalist clinical and service providers. These generally included a structured approach to the recruitment, training and ongoing support and supervision of volunteers. The volunteers were used to support clients in a range of settings, with the majority being in residential aged care and the community. From the evaluation data presented in the reports, it can be seen that there were positive outcomes for the volunteers, clients and families, as well as providers. One project reported that staff felt comforted and reassured by the knowledge that care recipients' holistic needs were more likely to be met; families felt able to talk and 'unburden' with the volunteers; care recipients had a personal visitor they could talk to or be with; and volunteers reported that their lives are enriched through personal interactions with the residents they met (NSW-4). Another project noted that the benefits from the volunteers promoting a palliative approach were likely to go beyond the aged care facilities, as they engaged with their wider community networks (NSW-3).

6.2.8 Improved relations between services

The consolidated focus of effort by many of the projects resulted in significant improvements in relations between relevant professional groups and service providers involved in supporting people with palliative care needs. As one project summarised in its report, robust relationships were nurtured between stake holders, enhancing capacity with numerous education and training opportunities provided and multi dimensional resources disseminated (NT-1). This was confirmed during the exit interviews undertaken by the NET, with around a third of projects reporting that improved relationships were one of the major gains of the program.

Formal processes to improve relations
A number of additional specific strategies were developed to cement the relationships, including protocols and processes to facilitate referrals and improve transitions between care settings, as

well as formal mechanisms such as partnership agreements and Memoranda of Understanding (MOU).

Referral processes and protocols were developed by the majority of projects following close consultation with the relevant stakeholders. The majority resulted in positive outcomes for clients and service providers alike, with a number of projects citing examples of improved access to clinical and service supports as a result. A small number of projects, however, experienced difficulties in facilitating referrals (NSW-2, NSW-8, NSW-9). These were generally projects which had trouble articulating their point of difference from established services, and referrals only improved once the role and boundaries of the project were clarified, benefits for clients became evident, or referral sources changed to those with established links to the project officer. In most cases these projects were well into their second year before referrals improved, with consistent referral patterns achieved by the end of the project. Evaluation findings from one of these projects indicated that by the conclusion of the project the broader service network representatives had a high level of confidence in utilising and recommending the service to others (NSW-2).

Almost half the projects used a formal agreement to engage related stakeholders in the operations of their projects, often as required in their funding agreements. These took the form of partnership agreements, as well as formal MOU which articulated the roles, responsibilities and expectations of the different parties. In many cases, these also underpinned the governance arrangements for projects, with MOU signatories forming the project's steering committee. A number of projects reported that the strong relationship between the partners was critical to the success of the project, in terms of ensuring appropriateness of strategies and resources developed, facilitating the uptake of new processes and providing strong moral support to the project officer (e.g. NSW-1, NT-1, SA-2, SA-5). This was not the experience of all projects, however, with a number reporting problematic relationships with these stakeholders. Issues ranged from the benign, such as the failure to attend committee meetings or provide feedback on strategies or resources developed (e.g. NSW-3, NSW-5), subtle opposition and resistance, such as the withdrawal of key specialist support (NSW-7), to overt opposition such as the establishment of parallel processes which duplicated and undermined the efforts of the project (e.g. NSW-8, NSW-9).

Informal processes to improve relations
A major theme arising from all of the reports is the improved communication between service providers which has arisen from the projects. This has primarily resulted from the approaches and tools developed to improve coordination and care planning and through participation in steering committees and education and training opportunities. As a consequence, a number of projects reported that the profile of palliative care amongst generalist health, community and carer support services was raised (NT-1, VIC-4, NSW-8). This was particularly the case for RACF staff and GPs, who were heavily targeted by the projects, resulting in a greater understanding of palliative care issues and engagement with specialist services (NT-1, NSW-7). One project reported that communication between general practitioners and families of residents improved, showing greater evidence of family and general practitioner awareness that the resident was dying (NSW-6). The range of providers involved in the support for people with palliative needs was also extended due to more holistic assessment processes; examples include pastoral care, social work, equipment and transport services (e.g. SA-3, NSW-8, NSW-2, QLD-2).

However, as noted above, a small number of projects experienced pockets of resistance by certain professional groups (NSW-2, NSW-8, NSW-9), where it appeared the project duplicated existing services. One reported that even though the program had been running for two years, community nurses who participated in the evaluation focus groups could not identify, without prompting, the main components of the program (NSW-9).

6.2.9   Improved competence, confidence and self-awareness

As indicated previously, a key outcome of the activities of the care planning projects was an improved competence and confidence of providers to assess, plan and deliver palliative care. This was evidenced in the evaluation findings of a large number of projects (e.g. QLD-1, QLD-3, QLD-

4, SA-5, NSW-1, NSW-2, NSW-3, NSW-4, NSW-5, NSW-6, NSW-7, VIC-1, VIC-2, VIC-4, WA-2). This was achieved not only through the provision of resources and education, but also through the processes introduced, such as reflective practice. While not formally evaluated, a number of projects observed an increased level of self-awareness within themselves, as well as in the staff participating in the projects, particularly those working in RACFs (NSW-3, NSW-4, NSW-5, NSW-6).

This was typically revealed when dealing with end of life, grief and loss issues. In response, one project reported that optional grief and loss training was offered to its staff, with a total of 58 members attending over four sessions (QLD-4). The training was evaluated and feedback from surveys indicated that participants' confidence and competence in the language and issues surrounding grief and loss had increased.

6.3   Impacts and outcomes on the health care system

The main outcomes for organisations or the broader palliative care service system have been the integration and enhancement of services, including new ways of care coordination, planning and delivery into daily practice, as well as establishing new services or models of care. In addition, the sector more broadly has benefited from the resources developed, many of which have been made available to services and professional groups beyond the scope of the project. A key theme to have emerged from the projects is the importance of partnerships in ensuring holistic, planned and coordinated care. This is demonstrated in the culture shift – both within agencies/services, and between them, in the way they relate to each other. A number also have demonstrated an increased capacity of the sector to undertake research and apply evidence based practice to everyday care delivery.

6.3.1   Integration of new processes and models of care

As noted in the discussion regarding impacts and outcomes for providers (Level 2), there was a significant focus on the development of new models of care planning, coordination and delivery. A number of these models became embedded into the existing service systems and processes at both the organisational and the broader service network levels.

The main element to be developed and incorporated into practice is the use of multidisciplinary case conferencing and case coordination models of care. Approximately two thirds of projects introduced this approach, with a significant percent indicating that it has become integrated into the way they do business (e.g. NSW-7, NSW-6, SA-1, SA-5, QLD-6, NT-1). The parties involved in these processes are varied, but usually include representatives of the palliative care specialist service, general practitioner, social worker or case coordinator/manager, hospital or aged care service chaplain, and relevant community care service representatives. An underlying principle is that clients and their families/carers are also invited to participate, but the process is not dependent on their attendance.

Where there is debate, however, is over the service or professional group that should lead the process. One project indicated that the GP, represented by the relevant GP Division, should take the lead in case conferencing and coordination (NSW-7); another recommended the palliative care services should drive the process, employ a dedicated position which could identify when case conferences are required, who should attend, engage relevant service and professional representatives, lead the case conference and also formulate and implement outcomes (SA-1); and finally, a number of aged care facilities indicated that they had incorporated this focus into their care planning processes, as staff now had the skills, tools and confidence due to the project activities, as well as organisational policies in place to support this activity (NSW-3, NSW-4, NSW-6). For services aimed at specific target groups, the approach may be different again. One such project indicated that as a result of the project, workplace practices had changed and now included more discussions around goals of care and palliative care issues generally, increased coordination and case conferencing, and the service had moved from a consultative model of care, to one of shared care with treating teams (VIC-6).

Another feature of enhanced service provision has been the integration of models of care into services that did not previously target people with palliative care needs. As a result, these services have been able to provide staff with additional skills and networks to continue to be able to be responsive to the needs of palliative care clients and their carers. Conversely, it also raised awareness within the broader service network of the role of the host service and the nature of supports it provided. These projects reported that clients were able to be provided with additional support as a result of the project facilitating access to the host organisation's existing services and/or brokerage funds (NSW-2, NSW-8, NSW-9).

A number of projects were part of organisations which underwent restructures during the term of the sub-program. Some of the impacts were only evident at the local level, as organisations changed auspices or focus (e.g. NSW-8), but a number involved the merging or incorporation of the project into a larger organisation with the potential for a much greater impact than had initially been expected (e.g. WA-1, NSW-6). In one case the protocols, tools and resources were automatically included as the key processes to underpin the new service (WA-2), while the other had received favourable indications from senior management regarding the project outcomes, including a request that the project officer participate in the organisation-wide palliative care special interest group (NSW-6).

The majority of projects included new processes for referral and communication between service providers which have been incorporated into every day practice. As an example, one project reported that it had introduced new referral protocols, documentation and feedback mechanisms, to ensure other providers were included in the initial assessment and subsequent reassessment processes, as well as a protocol which ensured that at the time of their referral, all clients were registered with the specialist regional palliative care service (NSW-2).

Mechanisms such as patient-held records, home notes, patient diaries and visit register which were introduced by projects have resulted in improved communication for the client, as well as between clients, clinicians and providers involved in their care. These were reported to be particularly important for people living in cross-border areas, if they are not known to local providers or if they receive their primary care from GPs across the border (NSW-5). The extent of the reach of these documents is not possible to calculate, as projects provided them to service providers and clinicians for distribution, and not all provided accurate data on the actual number utilised in their evaluation reports. That said, however, a number of projects reported printing these items in the hundreds, with the clear expectation that they would continue to be used as a communication and care planning tool beyond the life of the project (e.g. SA-2, SA-3, QLD-6, NSW-5).

A number of projects introduced changes that focused on improving access to information and support out of hours. The benefits of these triage and referral services at the system or network level include having a central point of contact for relevant service information and referrals, expediting referral to the most appropriate clinician or service, and freeing up clinicians and service providers to focus on their core roles rather than being diverted by requests for information. Consequently, a number of projects indicated that this facility will be sustained into the future, integrating key elements into the host organisation's functions (e.g. NSW-7, NSW-8, NSW-2, VIC-2).

While the information provided through the triage services is primarily of a generalist nature about service provision, one project identified the need for timely access to information about clients for nurses providing support after hours (VIC-2). This project worked closely with the local nursing service, which was responsible for triaging calls and providing emergency support after hours, and enabled staff to have read-only access to their data base to ensure that information on any client can be accessed immediately, and used to assist with the issue at hand. Following its success, the host organisation extended this read-only access to the data base to three other geographic areas. This same organisation was also able to negotiate a Memorandum of Understanding with

the pharmacy of a major cancer centre, to ensure timelier and cheaper access to medications for its clients.

6.3.2 Establishment of new services

One of the major outcomes of the sub-program has been the demonstration by projects of the need for additional services. This has been a direct result of research and evidence gathered during the projects, as well as a heightened awareness of the issues amongst senior management in a number of organisations. Examples of new positions created include a counsellor to provide bereavement care for families (QLD-3), an aged care nurse case manager (VIC-2), a palliative care service delivery officer (QLD-1) and a referral coordinator (VIC-2). In addition, a number of new services have been established, or are planned, as a direct consequence of the project activities, including a hospice consultancy service targeting aged care facilities (VIC-4), consultative palliative care service (QLD-1) and a new renal support service targeting indigenous communities (WA-1).

6.3.3 Development of resources

All projects developed resources of one sort or another, ranging from pamphlets about their project and information on palliative care, to comprehensive care planning resource kits, care management frameworks, DVDs and competency training kits. In developing these, the majority of projects were aware of the need to ensure that the information could be generalisable and accessible to a wider audience than that of their immediate focus. Consequently, many used project funding for the production of a larger number of resources than required for the timeframe and focus of the project so they could continue to be made available into the future (e.g. NSW-4, NSW-5).

A number of projects have focused on making their project accessible to the sector more broadly through placing resources on the internet, as well as participating in targeted educational opportunities. One of the projects has commenced working with the TAFE network in the region, and is expected to have finalised products placed on its website in the near future, making them readily accessible to a range of care providers and students in the immediate area, as well as more broadly (NSW-6). Another had its care planning tools and framework the subject of an Aged Care Channel program, which it estimates has the potential to be viewed by approximately five thousand residential aged care staff across Australia (NSW-3). Major industry conferences have also been targeted to promulgate project outcomes, and these are often reinforced through the inclusion of web-links to relevant materials and sites.

Several projects developed educational materials to address national competencies, making them more readily generalisable to other service contexts and geographical locations (e.g. NSW-3, NSW-4, NSW-5). The capacity of the sector to deliver education into the future was also enhanced by a number of organisations preparing to become Registered Training Organisations, which will support the ongoing implementation of the educational materials, and the philosophy of care which is embedded within these. Existing educational opportunities such as PEPA were also accessed by a small number of projects, resulting in greater awareness at the local level of these national initiatives. In one case, a project reported that the benefits were also realised for the specialist service, which became more aware of the issues confronting those involved in service delivery in a rural context.

Five projects developed resources designed for specific target groups not addressed by the broader care planning projects. One project developed information regarding the management of chronic heart disease, some of which was incorporated into educational resources produced by the relevant national peak body (QLD-5). Another developed specialist resources to support the implementation of care planning tools and guidelines for children with palliative needs. The project was overseen by a national partnership of children's hospitals, and is currently being evaluated through a clinical trial, the outcome of which is expected to become endorsed as a national guideline for all children's hospitals (VIC-7). A third project targeted adolescents and young

adults, and the data collected from the project was able to provide a better description and understanding of this group of the palliative care population, from the time of transition to a palliative goal of care through to end of life. It is anticipated that an outcome of this will be the development of an integrated model of specialist palliative care for this population group (VIC-6). Two projects specifically endeavoured to produce resources for Aboriginal clients and communities. One of these was able to produce a series of educational resources which underpinned a palliative approach to the provision of end stage renal disease, which has become incorporated into the policies and procedures of the new renal support service which was established just prior to the projects end (WA-1). The other project developed an educational package for carers and a script for an educational DVD, both of which remain in draft form until additional funding can be sourced for their implementation (WA-2).

6.3.4   Impact on hospitals

A significant finding of a number of projects has been a reduction in the numbers of people being transferred to hospital for end of life care. This appears to be due to a range of activities, including the development of resources to assist smooth transition between care settings, improved communication tools and mechanisms, access to specialist support as well as the introduction of end of life care planning and the education, support and resources to underpin this. One project estimated a 75% reduction in the number of its aged care residents being transferred to the local hospital for end of life care issues (NSW-4). This was echoed by another project which reported that the number of residents being transferred to hospital and dying had reduced over the course of the project, from 8 in 2006, to 1 in 2008 (NSW-3). A third project reported similar findings, with a reduction from 24.3% of all referrals at the start of the project to 12.5% in the last six months in the number of referrals by local hospital to the specialist palliative care nurse consultant, which were a direct result of a reduction in the number of inappropriate admissions by aged care residents to the hospital (VIC-4).

One project demonstrated that with appropriate support, the opposite can also occur; that is, more appropriate admissions to RACFs from acute hospitals. This project aimed to improve the transitions of patients from an acute facility to residential aged care, providing education and resources to staff in both settings as well as psychosocial support for the client and carer. The project reported that these clients had improved survival times in the RACF with 50% living longer than three months after transfer, compared to 33% previously (NSW-1).

6.3.5   Access to financial resources

Access to additional funding was a key incentive used by a number of projects to encourage the adoption of new processes and systems to improve palliative care. A number of projects focused on facilitating access by GPs to the Medicare items such as Enhanced Primary Care for their contribution to the care plan, GP Management Plans and Team Care Arrangements (e.g. NT-1, NSW-7, NSW-6). This included the project officer or case coordinator ensuring the relevant Medicare claim numbers were included on the documentation relating to case conference or MDT outcomes, and undertaking practice visits for academic detailing. As noted previously, however, the ability to engage GPs was problematic for a number of projects. There was an expectation by some that the ability to claim reimbursement for time through Enhanced Primary Care items would be an incentive for GPs to participate in activities such as case conferences and care planning, however a number reported poor uptake of EPC items (VIC-6, NSW-8), and this route for reimbursement appeared to be used only when the MDT coordinator or project officer filled in the necessary codes and/or paperwork.

A number of projects targeting RACFs indicated that they expected the introduction of the new Aged Care Funding Instrument (ACFI) in 2008 to enhance the uptake of care planning processes. The ACFI includes a 'complex care' category, which includes palliative care, and requires evidence of appropriate assessment and care planning in order for facilities to claim for this additional funding. However, there was no evidence provided in the reports that indicated whether this had in fact occurred, and what impact, if any, it had made on financial resources for the RACF.

6.3.6   A change in attitude toward palliative care

A recurring theme amongst the projects is the change in the appreciation by organisations of palliative care issues. A number expressed this in terms of a 'culture change', and the overwhelming message was a greater appreciation by generalist services of their capacity to provide care for people with palliative care needs. This change in attitude occurred in a range of settings, including acute, residential, community and primary care. The evidence for this culture change was a combination of data regarding the support for and implementation of new processes, attitudes judged through stakeholder feedback and surveys, and perceptions of the project officers.

A small number of projects reported a greater appreciation by acute services of the need to provide support for RACFs providing palliative care. One project noted meaningful discussion about the palliative care needs of the community at the executive and board level of the local hospital, and a greater appreciation of the need for the hospital to provide ongoing support to RACF staff to provide a palliative approach (VIC-4). Similarly, another project reported that there was an increased responsiveness on the part of specialist palliative care service community nurses to the ongoing care of residents in local RACFs, especially in the terminal phase (NSW-1).

The improved skills and confidence of RACF staff, and resources and processes to support them, appeared to be key factors in assisting a change in attitude at both the individual staff member, as well as the larger organisation. One project noted that referrals to the local palliative care service were more appropriate than previously and contained more information about phases, diagnosis, and problem severity (SA-5). Another noted how the project activities had assisted in building the organisation's reputation for having a clinical focus, in addition to aged care (NSW-2). The greater engagement of GPs with aged care facilities was provided as evidence of both a skills development and attitudinal shift on their part, as well as an indication of their improved confidence of the local RACFs to provide a palliative approach, as a result of project activities (NSW-3, VIC-4). One project also reported on findings from interviews with GPs, which showed they had become more involved in the palliative care of their dying patients (NT-1).

The increase in organisational and palliative care knowledge has neatly been described by one project as being a result of the interface of executive, quality, education, primary and specialist care provision and community (VIC-8); it reported that 80% of survey respondents agreed that there had been an increased profile of palliative care as a result of project activities.

There are clear benefits for aged care organisations when there is strong management support of a palliative approach to care. One project reported that the aged care facilities involved in the project did not experience staffing problems and agency nursing staff did not have to be recruited in the time since the project commenced (NSW-3). In another, the two facilities which had the highest number of staff attending education sessions also were the ones which retained the same link nurses through the project, and also had the highest percentages of dying residents commenced on an end-of-life care pathway (QLD-2). Where there was not strong management support, this resulted in barriers to the engagement with and implementation of new initiatives. A number of projects commented on the expectation that staff were required to attend education sessions within their own time, potentially limiting the number who could attend, and some facilities did not include time for handover at the change of shift, which limited the opportunity for staff to communicate about residents' changing status (NSW-6, NSW-3).

When organisations were faced with additional stress or change, it was also found to deflect interest and support for the introduction of new initiatives. Several facilities underwent restructures, including incorporation into a larger entity (NSW-6), new management (NSW-8) and rebuilding (NSW-3) which impacted on the project officers' ability to engage with staff, and also required them to focus on rebuilding internal relationships. Another inhibitor was the impending accreditation process, with facilities less likely to introduce changes such as new frameworks if accreditation was due in the near future (NSW-10).

6.3.7   Improved partnerships

A key theme which emerged in the reports and exit interviews with projects was the importance of the relationships between services which have developed as a result of project activities. This was identified as one of the most fundamental components in care planning. Partnerships were critical to a number of processes introduced, including case conferencing and care planning, as well as in recognition of the complex range of care needs to be addressed. Most projects included the development of resources to facilitate improved communication between partners, such as referral protocols and patient-held records, and also participated in regional service network meetings (e.g. NSW-2, VIC-1, NSW-9). As one project noted, the development of strong links and networks has facilitated better inter-agency conversations, consultation and collaboration (NSW-4). In addition to sharing information, these relationships provided formal and informal opportunities for education. This was particularly evident in projects that involved case conferencing or multi-disciplinary team meetings, which were often a means for non-specialist health and care providers to receive education in palliative care, as well as build relationships between specialists and primary care (QLD-6, SA-5). Further discussion regarding partnerships can be found in Section 7.1.4.

Paradoxically, building relationships also provided one of the most significant challenges for project officers. There were mixed messages from the projects about the preparedness of general practitioners (GPs) and area health services to engage in care planning. A number of projects proactively developed strategies to encourage their participation in care planning; however not all were successful (e.g. NSW-7, NSW-3).

6.3.8   Building the evidence base

In addition to the skills and processes to improve palliative care which were acquired by participants in these projects, a number also pointed out the improved capacity for their organisation in terms of research activities and access to evidence-based practice. For some, this meant that the skills they had gained in undertaking needs analyses, literature reviews, submission writing, project management and evaluation activities, which will continue to be used within the organisation when addressing other issues, and in determining future priorities or strategies (e.g. WA-2, VIC-4, NSW-5). In addition, some had indicated their greater engagement with industry initiatives such as the Palliative Care Outcomes Collaboration (PCOC), with one project subsequently developing a palliative care assessment form for the hospital. It reported that a chart audit revealed that the average of pain scores documented almost doubled, from 39% to 66% as a result (NSW-7).

Benefits were not only limited to individual organisations, but to the sector more broadly, with a number of new research and program initiatives arising following the evidence based approach of the projects. One project officer has received additional research funding to continue the work undertaken during the sub-program (NSW-1). Another project has received funding under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program to implement the care pathway developed as part of this sub-program (QLD-2)

Importantly, a number of specific target groups will continue to benefit from the application of the skills, processes and resources produced under the sub-program, and the evidence underpinning them. For example, one project found that adolescents and young adults tend to disengage from their services and will not always contact health professionals when problems arise, suggesting that a proactive, preventative model of service delivery was necessary to prevent crisis interventions (VIC-6).

There has also been an extension to the scope of providers involved in palliative care, with an increased awareness of the particular attributes that social workers can bring to palliative care. Two projects were actively involved with the NSW Social Work Palliative Care Special Interest Group, and one of these is proposing ongoing study to develop key performance indicators (KPIs) for psychosocial interventions, and theoretical underpinnings for social work practice in palliative

care (NSW-8, NSW-1). These projects also engaged with local universities, including one which employed students from the local university to assist with research for the project, potentially opening up opportunities for future nursing and social work placements in palliative care.

7 Sustainability, partnerships, capacity building and generalisability

Health programs in Australia and elsewhere often fund a set of local projects for a limited period, typically three to five years, intended to improve services and outcomes for a specific group of clients. One of the questions often asked about the grants model is whether such projects – set up as demonstrations or with 'seed funding' – can survive after the end of that funding (Scheirer, 2005, p. 320).

Consideration of the longer term outcomes of projects was part of the application process for the Care Planning Sub-Program. Organisations making submissions were required to plan how the project's outcomes would be sustained, for example through appropriately trained staff, dedicated resources, and/or provision of funding for any ongoing service delivery initiated by the project. From the start, projects were asked to consider elements that could be sustained and to develop and implement strategies to enable this to occur. Thus, successful applicants were meant to:

> *demonstrate that the proposed project outcomes are sustainable and can be continued after the grant funding is expended (DoHA, 2005, p. 6)*

Research into the sustainability of projects after program funding ends is at an early stage of development (Scheirer, 2005). To provide a framework for considering sustainability issues in the Care Planning Sub-Program, the national evaluation drew on a study of the sustainability of organisational reforms in the UK National Health Service (Maher et al., 2006). This study began with a literature review and used its findings, along with action research methods, to identify a set of key factors associated with increased likelihood that reforms or innovations would be sustained. There were three broad groups of factors: characteristics of the project itself; issues around how the implementation of the project would affect staff; and organisational factors including resources and the project's 'fit' with the organisation's goals (Maher et al., 2006). These were incorporated into a tool, which both provides scores on the likelihood of sustainability and stimulates discussion around strategies.

The NET adapted the NHS Sustainability Model (Maher et al., 2006) for use in palliative care by making minor changes to some of the language, and used it to introduce discussion about sustainability issues during the initial site visits to projects. It was administered to each project again at or around the time of the exit interview. Additional sections, based on tools developed and used at CHSD for previous evaluation projects, were included in the tool to encourage projects to consider related issues around partnership building, capacity building and generalisability (definitions are provided below).

All 33 Care Planning projects provided initial (time 1) data and 31 provided final (time 2) data. Projects were asked to report on the strategies and activities identified in this tool as part of their six-monthly evaluation progress report to the NET.

Initial and final data from the Sustainability and Spread Tool are presented below, first for sustainability and partnership building, then for capacity building and generalisability. These sections focus on the strategies used and the activities generated by projects to address these issues. Apparent changes are noted, although no inferential statistics were performed so these are indicative only. Qualitative data on strategies used by projects are then summarised.

Each of these sections is followed by a discussion of outcomes; that is, the extent to which the strategies and activities were successful.

7.1 Sustainability and partnerships

Initial and final data from the Sustainability and Spread Tool for sustainability and partnerships are presented in Table 9.

Table 9 ***Sustainability and partnership building data: initial (clear rows) and final (shaded rows)***

Statement		Strongly agree	Agree	Disagree	Strongly disagree	Don't know	Not applicable	Total
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Section I: Characteristics of the project likely to enhance its sustainability								
1	The project will improve the efficiency of palliative care services	11 (33)	19 (58)	2 (6)	0	1 (3)	0	33 (100)
		15 (48)	11 (35)	1 (3)	0	2 (6)	0	31 (100)
2	Staff will notice a positive difference in their working lives as a result of the project	9 (27)	22 (67)		0	2 (6)	0	33 (100)
		15 (48)	11 (35)	1 (3)	0	3 (10)	0	30 (97)
3	Benefits of the project are immediately obvious	5 (15)	14 (42)	7 (21)	1 (3)	5 (15)	1 (3)	33 (100)
		9 (29)	14 (45)	2 (6)	0	0	1 (3)	30 (97)
4	Stakeholders are aware of the benefits of the project	6 (18)	21 (64)	2 (6)	0	2 (6)	2 (6)	33 (100)
		9 (29)	20 (64)	0	0	1 (3)	0	30 (97)
5	The new processes introduced by the project do not rely on a single individual or group, technology or funding source to continue	7 (21)	15 (46)	8 (24)	0	1 (3)	1 (3)	32 (97)
		9 (29)	14 (45)	7 (23)	0	0	0	30 (97)
6	There is a system in place to monitor progress and initiate action as a result of feedback	15 (46)	17 (52)	1 (3)	0	0	0	33 (100)
		9 (29)	12 (39)	4 (13)	1 (3)	1 (3)	2 (6)	29 (94)
Section II: Issues affecting staff who are involved in implementing changes introduced by the project								
7	Staff have been involved from the beginning of the project, and their ideas influenced the change process	11 (33)	16 (49)	2 (6)	0	2 (6)	2 (6)	33 (100)
		19 (61)	10 (32)	1 (3)	0	0	0	30 (97)
8	Staff have been adequately trained to implement and sustain the new processes introduced by the project	7 (21)	14 (42)	4 (12)	0	0	8 (24)	33 (100)
		9 (29)	16 (52)	2 (6)	0	1 (3)	2 (6)	30 (97)
9	Staff believe the new processes introduced by the project are a better way of doing	4 (12)	15 (46)	1 (3)	0	8 (24)	5 (15)	33 (100)

Statement		Strongly agree n (%)	Agree n (%)	Disagree n (%)	Strongly disagree n (%)	Don't know n (%)	Not applicable n (%)	Total n (%)
	things	10 (32)	16 (52)	0	0	3 (10)	1 (3)	30 (97)
10	There is someone in authority or senior management, other than the project manager, who is an advocate for the project with staff	16 (49)	14 (42)	2 (6)	1 (3)	0	0	33 (100)
		19 (61)	10 (32)	1 (3)	0	0	0	30 (97)
11	Clinical leaders have been involved in the project and will promote it to staff	13 (39)	15 (46)	3 (9)	1 (3)	0	0	32 (97)
		14 (45)	13 (42)	2 (6)	0	0	0	30 (97)
12	Systems are in place to ensure staff can share information with, and seek advice from, managers and clinical leaders	7 (21)	19 (58)	1 (3)	0	2 (6)	4 (12)	33 (100)
		12 (39)	12 (39)	2 (6)	0	1 (3)	3 (10)	30 (97)
Section III: Organisational factors which affect how long projects last								
13	The host organisation has a history of successfully sustaining improvement	15 (46)	11 (33)	0	0	5 (15)	0	31 (94)
		13 (42)	12 (39)	2 (6)	0	3 (10)	0	30 (97)
14	The goals of the project are consistent with the host organisation's strategic aims	19 (58)	11 (11)	0	0	3 (9)	0	33 (100)
		18 (58)	11 (35)	0	1 (3)	0	0	30 (97)
15	Staffing levels are adequate to enable the new processes introduced by the project to be sustained	5 (15)	12 (36)	4 (12)	3 (9)	7 (21)	2 (6)	33 (100)
		7 (23)	8 (26)	6 (19)	2 (6)	3 (10)	2 (6)	28 (91)
16	Facilities and equipment are available to support the project	11 (33)	20 (61)	2 (6)	0	0	0	33 (100)
		10 (32)	15 (48)	4 (13)	0	0	1 (3)	30 (97)
17	Policies and procedures have been developed to support the project	7 (21)	15 (46)	7 (21)	0	0	4 (12)	33 (100)
		10 (32)	14 (45)	5 (16)	0	1 (3)	0	30 (97)
18	Systems are in place to ensure the project team can communicate with stakeholders	18 (55)	15 (46)	0	0	0	0	33 (100)
		15 (48)	11 (35)	1 (3)	0	0	2 (6)	29 (94)
Section IV: Relationships with partner agencies								
19	The project has improved communication between participating agencies	10 (30)	16 (49)	1 (3)	0	5 (15)	1 (3)	33 (100)

Statement		Strongly agree	Agree	Disagree	Strongly disagree	Don't know	Not applicable	Total
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
		19 (61)	8 (26)	0	0	1 (3)	1 (3)	30 (97)
20	The project has positively changed relationships between participating agencies	8 (24)	15 (46)	1 (3)	0	6 (18)	2 (6)	32 (97)
		16 (52)	11 (35)	0	0	2 (6)	1 (3)	30 (97)
21	The project has resulted in a more streamlined and coordinated service for palliative care clients	9 (27)	8 (24)	4 (12)	0	5 (15)	6 (18)	32 (97)
		11 (35)	9 (29)	1 (3)	0	8 (26)	0	29 (94)
22	The costs of the changes implemented by this project are greater than the benefits	0	2 (6)	11 (33)	10 (30)	9 (27)	1 (3)	33 (100)
		0	1 (3)	9 (29)	18 (58)	1 (3)	0	29 (94)
23	Protocols and tools developed during this project will be adopted for routine use after it is over	15 (46)	14 (42)	0	0	4 (12)	0	33 (100)
		16 (52)	11 (35)	0	0	3 (10)	0	30 (97)
24	The project has demonstrated that relationships between agencies at the local level can be changed by the use of formal policies and protocols	2 (6)	13 (39)	3 (9)	0	11 (33)	3 (9)	32 (97)
		11 (35)	7 (23)	4 (13)	0	3 (10)	5 (16)	30 (97)
25	Projects such as this one help to strengthen relationships between agencies	19 (58)	14 (42)	0	0	0	0	33 (100)
		19 (61)	9 (29)	0	0	1 (3)	1 (3)	30 (97)
26	Projects such as this one provide important local lessons in how to do things better	18 (55)	11 (33)	1 (3)	0	2 (6)	0	32 (97)
		20 (64)	9 (29)	0	0	1 (3)	0	30 (97)

7.1.1 Sustainability strategies

Initially, project officers were reasonably confident that the project would improve the efficiency of palliative care services (Q1) and provide benefits to clinical staff (Q2). Their confidence regarding these two indicators had increased by the end of the Care Planning Sub-Program.

Project officers were less confident that the project had immediate and obvious benefits (Q3), both initially and at the end of the sub-program, although there was some improvement over time with more endorsing the 'Strongly Agree' option. At both measurement points, most project officers felt that stakeholders could see the value of the project (Q4).

Change management issues were addressed in most projects by having systems for seeking feedback from staff (Q5) and ensuring a two-way flow of information from staff to managers and clinical leaders (and vice versa) regarding the project (Q12). These two indicators did not change

substantially over time. Another change management strategy, involving staff in the change process (Q7), was much more strongly endorsed at the end of the sub-program, presumably because at that stage more projects had actively incorporated ideas from staff into the new protocols, procedures and documents that were developed and implemented.

In contrast, by the end of the sub-program fewer project officers were confident about the systems they had in place to monitor progress and collect and act upon feedback (Q6), suggesting some doubt about whether these systems could be sustained. All project officers had put in place systems to communicate with stakeholders (Q18).

At both time points, a substantial minority (just under a quarter) of project officers felt that sustaining the new processes relied to some extent on the project funding and/or their own time and energy (Q5). There was also some doubt about whether clinical staffing levels (particularly in nursing) were adequate (Q15) and this opinion did not change substantially. Initially, a few projects could not say whether the host organisation had a history of innovation (Q13) or whether the project was consistent with its strategic aims (Q14), probably reflecting the fact that they were newly appointed to their roles.

When they first completed the tool, there was considerable uncertainty among project officers about whether clinical staff would see the advantages of the new processes (Q9). By the end of the sub-program, their confidence was greatly increased, with 84% of respondents agreeing that staff believed the new processes were a better way of operating. There was also greater agreement that staff had been adequately trained to implement and sustain the new processes (Q8), and fewer project officers said this was 'not applicable' to their situations.

At both time points, there appeared to be strong support from management (Q10) and clinical leaders (Q11) for most projects. Initially, seven projects were without policies and procedures to support the new processes (Q17); by the end of the sub-program, five were still not supported in this way. The proportion who agreed that adequate facilities and equipment were available fell slightly over time (Q16).

7.1.2 Partnership strategies

Both initial and final assessments of relationships with partner agencies were largely positive. Initially, three in ten project officers strongly agreed that their projects had improved communication with partner agencies (Q19) and almost a quarter strongly agreed that relationships had been changed for the better (Q20), although a substantial minority were unsure. In their final assessment, project officers were more confident, with strong agreement by 61% and 52% respectively to these two questions. Most agreed, at both time points, that in principle these kinds of projects help strengthen such partnerships (Q25).

At first, only 6% strongly agreed the project had demonstrated the usefulness of formal policies in linking local agencies (Q24); by the end, 35% strongly agreed with this statement.

Almost two thirds of the project officers concluded that their work had resulted in a more streamlined and coordinated service for palliative clients (Q21), which was one of the main goals of the Care Planning Sub-Program. The vast majority (87%) remained confident that protocols and tools (e.g. referral processes, care pathways) developed during the project would continue to be used (Q23).

Initially there was a fairly high level of uncertainty about whether benefits of the projects outweigh costs – a third of project officers were unsure. This changed in their final assessment after they had collected evaluation data and summed up the impacts of their projects; only one was still uncertain, and one felt that the costs outweighed benefits.

7.1.3 Sustainability outcomes

Previous studies have used three types of sustainability measures, or 'operational definitions' of sustainability, which were described in a review by Shediac-Rizakallah and Bone (1998, cited in Scheirer, 2005):

1. Sustaining benefits for clients
2. Continuing the project activities within the funded organisation
3. Maintaining community attention on the problem addressed by the project

We will use these as a framework for considering the sustainability outcomes from the Care Planning Sub-Program.

Scheirer (2005) reviewed 19 studies of the sustainability of health-related programs in the United States and Canada and found that few studies directly measured outcomes for clients. This is consistent with our findings from the Care Planning Sub-Program: most projects did not attempt to collect outcomes data from clients or carers due to practical and ethical difficulties, and those that did often had problems with recruitment and follow-up simply due to the nature of the client group. Although a variety of client and carer outcomes were reported by projects, these were mostly inferred from the presence of new service delivery models or improvements to existing services, rather than directly measured (see Section 6.1). The scarcity of data on client or carer outcomes means even less information is available on the sustainability of these outcomes in the Care Planning Sub-Program.

Given that the client group has life-limiting illness, the most sustainable outcomes for individuals are likely to be for the primary carers who were specifically targeted by some of the projects. For example, the 96 carers who took part in carer support groups and a bereavement model developed by the QLD-4 project reported that they now understood grief was a process and they no longer thought they were 'going mad'. Their improved understanding and access to support may well result in enhanced well-being and reduced likelihood of psychological distress in the long term, but this cannot be confirmed with the existing data.

In relation to the second of the three 'operational definitions' of sustainability, almost all of the studies reviewed by Scheirer (2005) examined whether program activities were continued within participating organisations. Again, this finding is echoed within the Care Planning Sub-Program, as maintenance of project activities was the major focus of sustainability efforts.

Scheirer (2005) found that five factors consistently appeared to influence the extent of sustainability:

1. A program can be modified over time
2. A champion is present
3. A program 'fits' with its organisation's mission and procedures
4. Benefits to staff members and/or clients are readily perceived
5. Stakeholders in other organisations provide support

Of these factors, the ones most often used by Care Planning projects were the identification and nurturing of champions, ensuring that project activities could be incorporated into routine practice and policy in participating organisations, and emphasising benefits to providers in terms of improved skills and enhanced confidence. Stakeholder support was another key strategy and is discussed below, when we consider partnerships.

Champions
A number of projects selected key staff for additional training and support in order that they could take on some of the responsibility for implementing and sustaining new processes. Many of these were nurses working in RACFs. For example, implementation of QLD-2 project was supported by

link nurses, who met regularly and were provided with ongoing education and monitoring. QLD-3 also provided resource nurses in aged care with extra training to prepare them for their role in supporting colleagues. However, despite the planning for sustainability, it was difficult for the project officer to maintain the enthusiasm of the resource nurses and their willingness to take on the extra responsibility of the role.

Similarly, the NSW-5 project identified 'Change Champions' at each site to continue driving the change process. However, ongoing leadership from senior staff, such as clinical nurse specialists, consultants and managers is required to ensure that newly developed resources and practices are embedded into everyday use.

Champions also had a role outside RACFs, for example in NSW-9 where they were predominantly primary health care nurses associated with the Division of General Practice across 13 small rural communities. Their job was to facilitate client access to general practitioners, undertake assessments and clinical care, participate in MDTs, remain as a link for families to primary health care and be involved in coordinating community education.

End-of-life planning, through Advanced Care Directives, will continue as a result of the NT-1 project. The palliative care service has a 0.6 FTE clinical nurse consultant working with that initiative.

Skilled facilitators are required to sustain the carers and bereavement courses initiated by QLD-4. This role will be absorbed into the job description for the host organisation's current Clinical Nurse. Grief and loss training will continue to be offered to staff at Spiritus Bayside. There is strong encouragement from the central office for this to be adopted at all branches within Queensland.

The evaluation and dissemination of the heart failure palliative care protocol (QLD-5) will be carried out as part of the role of the Statewide Heart Failure Coordinator (who was the project manager) in liaison with local hospital heart failure teams. This arrangement has the support of two senior clinicians, one in heart failure and the other in palliative care, who plan to continue developing the document and incorporating its use into the care their units provide.

In order to sustain the links established between stakeholders, and support new models of service delivery, some projects led to the creation of new staff positions or the extension of existing positions. The PallNet network set up by QLD-1 recommended the appointment of a palliative care service delivery officer for the Fraser Coast region, a position that has been given ongoing funding by Queensland Health. By the end of the NSW-7 project, agreement had been reached by the project partners (Mid North Coast Division of General Practice, Coffs Harbour Nursing Service, Baringa Private Hospital and North Coast Area Health Service) to collectively fund a Palliative Care MDT Coordinator, one day a week, for 12 months. The VIC-4 project established the need for an ongoing role of specialist palliative care nurse consultant. At the project's completion, the Peninsula Hospice Service agreed to undertake this role as part of their ongoing business. The Aged Care Nurse Case Manager and the designated referrals coordinator position will help sustain the work of the VIC-2 project.

Where champions were conspicuously lacking, sustainability is more doubtful. For example, NSW-3 was very much driven by, and dependent on, the project manager, as the steering committee folded. It is not clear who will take responsibility for maintaining the website created by the project and where money will come from to update and print resources annually.

Fit with mission and procedures
One of the most important strategies was incorporating the new procedures, tools and resources developed by projects into the host organisation's (and partner organisations') policies and routine practice.

For example, the model of service delivery created by SA-2 includes Memoranda of Understanding between the palliative care service and the Royal Adelaide Hospital, primary care providers and residential aged care providers respectively which define their roles and responsibilities in the new regional model. Each MOU has a review date. Dates have been set for an annual review of the regional palliative care resource guide. This is in contrast to many projects which produced resources such as brochures and websites with no clear plan for updating or distributing them following the program's end. Similarly, the PaedPallCarePlan developed by VIC-7 will be hosted by the Royal Children's Hospital website without ongoing costs. Monitoring and updating of the website will be supported by a team of web experts who have been involved in the design and creation of the site and are familiar with its purpose and content.

The NT-1 project was mainly systems based with no direct contact with clients or carers. A set of policies and procedures were developed with the specialist palliative care service during the project, mandating GP involvement with the palliative care process: Admission to the palliative care service; Hospice admission; Care coordination; Care plans; Case meetings; Client office file. Ballarat Hospice Care Inc. has fully integrated the Listen Up! (VIC-1) project into its policies and procedures and Bacchus Marsh Palliative Care Service is currently using the Listen Up! procedure to aid communication with GPs in 'after hours' scenarios.

In some cases the project activities will be sustained because they provide financial benefits. The residential aged care end-of-life care pathway developed by QLD-2 meets all requirements to allow facilities to gain complex health care funding for their residents under the Aged Care Funding Instrument (ACFI), which was introduced nationally in March 2008. The documentation allows for easy validation that the requirements have been met, namely a directive issued by a medical officer, palliative care specialised nurse or senior registered nurse; pain assessment; a care plan; and evidence of ongoing care. The ACFI therefore provides a funding mechanism which will encourage uptake of the RAC EoLCP. The NSW-3 project also utilised the ACFI funding to provide added incentive for the organisation to continue to implement the palliative approach.

Numerous projects developed resources such as referral documents and education packages which contribute to sustainability. The SA-3 project included a support package which was not used during the project's lifetime but may prove useful for sustaining the project. This document sets out in detail the process of referring patients who may benefit from the communication package and includes a script for the community nurse and copies of evaluation questionnaires for clients and carers. SA-5 produced a set of standardised documents for referral to the palliative care service which have been adopted into routine clinical practice for many providers. External stakeholders have access to the protocols and forms via a CD resource and information package. A tool developed by NSW-4 has been integrated into routine clinical practice in a RACF. Although some difficulties remain – for example, blocking by some strong personalities with vested interests – the project's strong evaluation results and support from CEO increase its chances of sustainability.

The WA-1 project developed resources and systems to support a palliative approach, which will be integrated into all aspects of the new Kimberley Renal Support Service which commenced prior to the completion of the project. The aim of the service is to provide education and support to regional health staff around the prevention, screening, care and management for those with chronic kidney disease and community dialysis. At the time of reporting, the new service had incorporated the multidisciplinary case conferencing for clients developed by the project, and commenced case conferencing meetings and education sessions on alternate months with the visiting palliative care consultant from Perth.

Another activity that looks likely to be maintained by several projects is multidisciplinary team meetings. SA-5 has management support to continue holding inter-disciplinary team meetings, which provide a forum for client discussion, education and care planning. The costs associated with the meetings are a matter for negotiation. NSW-6 multidisciplinary team meetings will continue, with the project's toolkit to inform proceedings. Discussions regarding advance care

planning (ACP) are now initiated at the time of admission of a new resident, and the assessment documents developed, education program and end of life pathways have also been integrated into local practice. Also in the NSW-7 project, multidisciplinary team meetings are now embedded into local practice, with the core group of participants including the palliative care CNC and social worker, CHHC chaplain, link nurses as available, the MDT coordinator and a GP advocate. For the QLD-2 project, case conferences will continue, with administrative support now provided by the palliative care service (instead of the project officer). Also, case conferences will be built into existing multidisciplinary team meetings but there will only be time to address the more complex cases.

A few projects have specifically identified the need for resources for a staff member to take responsibility for continuing to promote and facilitate project activities. The trial of case conferences and care plans run by SA-1 concluded that the palliative care service is in the best position to identify the trigger for care coordination (i.e. reduction in patient's functional status), for example at weekly meetings, and should therefore initiate the process. To sustain care coordination there needs to be someone within the palliative care service who drives the process. Ideally there would also be someone (e.g. the practice manager) who ensures GPs attend case conferences and are remunerated. This should be formalised as part of their role (e.g. a dot point in their job description) and training provided.

The level of service delivery initiated by VIC-6 has not been continued, due to lack of staffing resources. The project reports that additional staff positions are required to sustain the improvement achieved by this project. Specifically, additional palliative care nursing staff would sustain care coordination, care plans, case conferences and community partnership. Stakeholders who were consulted regarding sustainability also recommended a half-time registrar position and increased palliative care medical specialist staff to assist in the development of state-wide partnerships and support adolescents and young adults dying in rural and regional areas. These positions could also be offered on a rotational basis to increase the skills of the team as a whole.

Perceived benefits to staff and clients

Many projects were able to demonstrate that their activities benefited staff by increasing skills, improving confidence and, in some cases, enhancing job satisfaction. For example, as part of its implementation of end-of-life care pathways in RACF, the QLD-2 project ran a change management workshop for key clinical and management staff; and provided education sessions and ongoing support for RACF staff. All the tools created for the QLD-6 project were designed in consultation with staff, to be compatible with existing work practices.

Sustainability can be difficult to achieve when the initial funding or timeframe runs out before implementation has been completed (Scheirer, 2005). An example of this occurred with NSW-1, which set out to provide psychosocial and spiritual support to patients transferred from a specialist palliative care unit to RACFs. It was initially intended that pastoral care workers from the hospital could undertake this role. However, due to staffing shortages, this outcome was not fully realised during the project, and there proved greater reliance on the volunteers from Calvary Hospital. Nevertheless, by the end of the project some partner RACFs had systems in place to provide spiritual support, and Calvary pastoral care services now had the capacity to continue to support transferred residents.

Similarly, several projects planned to facilitate GPs' use of the Extended Primary Care items in the Medical Benefits Schedule in order to engage them in case conferences and/or multidisciplinary care plans, but this was not always successful. In some cases the amount of paperwork was a deterrent; in others poor levels of participation in the evaluation made it impossible to judge whether this was a good strategy for engaging GPs.

Stakeholder support

Costs of the courses delivered to current and bereaved carers by QLD-4 were kept to a minimum through the use of free or low-cost venues and publicity. The presenters provided their services for free and have made a commitment to continue to do so.

The DGP for the Yorke Peninsula region supported the SA-3 project by promoting the patient diaries and encouraging GPs to distribute them. On Mornington Peninsula, a palliative care special interest group for GPs is to continue with financial support from the regional DGP.

The Palliative Care Planning Package with its three components, developed by NSW-5, have limited production runs, and will need to be updated, re-printed and re-packaged at some time in the future. However, the engagement of the local services in the development and production of elements of the package, such as the local Men's Shed and cotton manufacturer, suggests that local commitment is likely to be readily harnessed if a driver is provided.

The Victorian Paediatric Palliative Care Program (VPPCP) will continue to support and monitor the use of guidelines and tools produced by VIC-7, while the Children's Hospital at Westmead, the Sydney Children's Hospital, the Royal Children's Hospital in Brisbane and the Child, Youth and Women's Health Service in Adelaide will adopt similar supportive and monitoring roles within their states. The collective input of these organisations will then be used by the Paediatric Palliative Care Reference Group in ongoing evaluation and revision. The project reference group also functions as the Australian and New Zealand Paediatric Palliative Care Reference Group, and so will continue after the project is completed.

Future funding

At least 10 projects had strategies in place for obtaining further grant or ongoing funds to maintain project activities. Two projects were planning to use Home and Community Care funding (QLD-4, NSW-2) to support carers and clients in the community. The project team for QLD-2 has scheduled meetings with Queensland Health to explore implementation opportunities. Aged Care Queensland has expressed interest in providing resources to the project's host organisation to develop an implementation plan for using the pathways in RACF across the State. To support its continuing research on the use of case conferences and care plans, SA-1 project team is planning a follow-on NHMRC grant application for the 2010 project grant round to address questions raised by this study.

Several projects have sought further grants from DoHA in subsequent funding rounds. For example, there is a proposal to review and evaluate the MAPCARE (SA-4) resource and roll it out nationally. The host organisation for NSW-8 successfully applied for funds under Round 4 of the LPCGP (transition to home and equipment). The new project is using the lessons of its predecessor to inform interventions and support provided to both patients and carers.

The NSW-5 project has obtained agreement from DoHA that the DVD and associated training package can be sold at a price commensurate with the ongoing reproduction and distribution costs.

The NSW-9 project has acknowledged that its palliative care packages cannot be sustained without ongoing funding. Elements such as carer respite, carer support, some equipment hire and access to a 24-hour telephone number can continue where there are Commonwealth Carer Respite Services available. The project reported that where palliative care packages are implemented into regional settings, additional case management resources are considered essential. The project has secured additional funding through AGPN grants to extend its activities for two years.

The host organisation for NT-1 was successful in obtaining funding for the Rural Palliative Care Project across the Northern Territory. In this new project, lessons learnt in the Top End Palliative

Care Planning Project will be generalised and also more directly relevant as the new project will also be systems-based.

A major outcome of the WA-2 project has been the ability of the Indigenous Womens Cancer Support Group (IWCSG) to secure additional funding for a two-year period.

Several projects reported that their activities would be relatively easy to maintain as little input is needed. Projects such as SA-2, QLD-4, and NSW-6 were not costly to implement, while NT-1 mainly utilised resources and opportunities and infrastructure already in existence, saving the costs of establishing new resources.

Other

Several other types of sustainability strategies, which do not fit into the framework identified by Scheirer (2005), were reported by Care Planning projects. These included an imprest system enabling timely access to end-of-life medications for residents of RACFs (QLD-2).

Education components of the NSW-6 will be made available more generally by their development into a web-based learning package and available on the Mid North Coast NSW Institute of TAFE website 'HEALNet'. The NSW-8 project has been involved in discussions with social work and health sciences departments at local universities, regarding specific training and learning outcomes in palliative care as a separate area of study, in order to encourage more social workers and other allied health care workers to gain competency in aspects of palliative care.

Further piloting of the frameworks developed by NSW-10 would improve their reliability and acceptability, especially for less skilled care staff.

A project designed for sustainability: case study

The VIC-8 project was very focused on ensuring that aspects of the project would continue and serves as an example of how sustainability strategies can be integrated into project activities.

One key strategy was the project's Sustainability Strategies Group which produced an options paper. The other was the development of sustainability criteria for activities to be undertaken as part of the project. The criteria included assessing whether the proposed activity would be sustainable, integrated, build capacity, encourage partnership development and be transferable to other sites. The focus of sustainability was on integration into the processes and structures of the organisation; building relationships as a precursor to partnership development; developing capacity through a range of formal and informal interactions; and building in generalisability so that project results can be utilised widely.

Many other sustainability strategies were implemented in this project:

- Working with existing organisational programs and staff such as the Quality Manager, so that the project fits in with the Accreditation and quality improvement program
- Developing a palliative care policy for the organisation
- Reforming a palliative care working party where the project was a member, rather than the leader
- Using or modifying existing organisational tools and resources such as the case audit tool and the Quality Improvement Planning and Reporting tool
- Reviewing the project activities and goals with the revised Hume Region Palliative Care Consortia Plan to ensure consistency with the regional directions.

The overarching principle was to facilitate system-level change, working in collaboration with existing services and systems. The planning model/framework was based on the Palliative Care Standards and Palliative Care Australia guides, and is now embedded in the organisation as the palliative care policy. This policy aims to inform and guide future palliative care planning, service development and public health / community initiatives to ensure more accessible and equitable

service delivery for people in the local area. The project nurse continues in her permanent nursing role in the hospital and is able to continue influencing project outcomes.

The other key sustainability measure identified by Scheirer (2005) was the continued existence of community coalitions as structures for coordinating activity and maintaining focus on the problem addressed by the program. This corresponds to the third of the three 'operational definitions' listed above (Shediac-Rizakallah and Bone, 1998, cited in Scheirer, 2005). In the national evaluation framework, this type of sustainability is defined as partnership building and is discussed separately below, as it contributes not just to the maintenance of project activities but also to capacity building and generalisability.

7.1.4   Partnership outcomes

It is increasingly recognised that addressing complex issues in society will require leaders to work across organisational and professional boundaries, initiating and coordinating concerted efforts among a variety of stakeholders. In this 'public value' paradigm, the relationships built are as important as the results obtained (O'Flynn, 2007).

Establishing links and networks among stakeholders was one of the key tasks for the Care Planning projects. The application guidelines for the sub-program stated:

> *The objective of this funding round is to ensure that care systems are responsive to the increasing and decreasing intensity of needs of palliative patients. Such responsiveness will, as a matter of course, involve different levels of care, from different service providers, at different times (DoHA, 2005, p. 6).*

In order to meet this objective, applicants were strongly encouraged to build collaborations between organisations in undertaking their projects. One of the assessment criteria was that the applicant had *'the capacity to work across sectors to develop strong working relationships with a range of service providers'* (DoHA, 2005, p. 5).

Collaboration (or partnership building) has been defined as the process whereby stakeholders from public, private and community sectors work together voluntarily towards a common goal:

> *All members contribute in some way to the collaborative effort and all benefit to some extent. The intention is that together they achieve more than any of them can accomplish alone (Warburton et al., 2008, p. 471).*

It takes time for newly established partnerships to become fully productive, which makes the process of evaluating partnerships somewhat complex (Pope and Lewis, 2008). Interviews with 120 people involved in ten community development partnerships in Victoria investigated the structure of networks that had been developed and the value placed on them by participants in the partnerships. Analysis of these networks highlighted five characteristics of effective partnerships, namely: a good broker/facilitator to build relationships; the right decision makers at the table with a commitment to contribute; a clear purpose; good process; and ongoing monitoring (Pope and Lewis, 2008).

The importance of these factors was confirmed by a recent review of the literature on partnership building in ageing policy, in which Warburton and colleagues (2008) identified six factors that contribute to the success of collaboration. These are:

1. context (a history or culture of collaboration; favourable socio-political climate; supportive financial climate)
2. characteristics of partners (diversity of membership; grass-roots involvement; skills such as flexibility, negotiation and ability to work across professional boundaries; mutual inter-dependence and equal power)
3. procedures (frequent, open and culturally-sensitive communication; joint decision making through deliberation)

4. structures (formalised and clearly defined, but not bureaucratic; a learning environment; coordination and monitoring role of convenor or leader)
5. purpose (concrete attainable goals, different from yet consistent with those of the participating organisations; strategic importance; innovation)
6. resources (funding; a skilled convenor; willingness of members to exercise leadership skills; local knowledge and specialist expertise)

Data on partnerships developed during the Care Planning Sub-Program were drawn from a number of sources. Project officers discussed partnership development strategies during the initial site visit interview with a member of the NET, and were asked to report on the implementation and success of their strategies as part of the six-monthly evaluation progress reports. This topic was again reviewed during the exit interviews. In addition, the projects' final reports for DoHA and for the national evaluation provided information on the success or otherwise of the partnerships established, the difficulties encountered, and the benefits that flowed from effective partnerships. These findings are presented below, and compared with the success factors identified in previous research (Warburton et al., 2008).

By the end of the sub-program, Care Planning project officers had established links with a wide range of stakeholders. The most common project partners were:

- Residential Aged Care Facilities (RACFs)

- Hospital staff, including medical specialists, discharge planners, ward nurses and staff of outpatient clinics

- General practitioners, either singly or through Divisions of General Practice

- Existing local palliative care networks

- Specialist palliative care providers

- Community and allied health services including Aged Care Assessment Teams (ACAT), Home and Community Care (HACC) providers and Aboriginal Health

Other targets for partnership building activities included area health services, peak bodies, state government departments, Centrelink, training providers, university-based researchers and a local 'Men's Shed' project.

During the projects' first site visits, a few common approaches were reported. At this early stage, many project officers were in the process of establishing advisory, steering or reference groups, generally with broad representation from key stakeholders, and often with formal terms of reference. Some projects, such as SA-4, arose from an existing network of stakeholders who had identified a need for the project. This, as suggested by the first success factor (context) above, was advantageous to the efficient completion of this short project and to its continued sustainability, as the group continues to meet and has applied for further funding to evaluate the MAPCARE resource produced by the project.

The other key early strategy was the development of, and agreement on, Memoranda of Understanding with partner organisations. These two approaches provided a firm foundation for building partnerships and sustainability for many of the projects.

It is clear from project officers' accounts of the process of establishing steering committees that they paid considerable attention to the task of identifying the key stakeholders – those who would be most committed, skilled and influential – and ensuring diversity of membership including representation from consumers. This is consistent with the second success factor (characteristics of partners; Warburton et al., 2008). The written Terms of Reference or MOU provided a shared and clearly defined purpose, range of activities and expectations of members, meeting the fifth

success criterion of shared, attainable goals and a focus on the strategic importance of the project activities to participating organisations (Warburton et al., 2008).

A major theme to emerge from the exit interviews with project officers and managers was the paradoxical nature of relationship-building activities. On one hand, these were acknowledged as crucial to the success of most projects; on the other, the input required to establish and sustain these partnerships represented a considerable proportion of project officers' workloads and, for some, the benefits were not obvious or immediate.

For example, it took considerable time and effort from project officers to help project steering committees or advisory groups continue to function productively. These partnerships were nurtured through activities such as having a structured approach to meetings, sending emails to maintain contact with those who could not attend, arranging numerous one-to-one meetings, and inviting and responding to feedback on draft materials. Although time-consuming, these activities can be seen as constituting the necessary procedures (success factor three) and structures (success factor four) for the effective operation of these newly established partnerships (Warburton et al., 2008).

Having done this ground work, numerous project officers reported close collaboration with stakeholder organisations on project activities such as providing education and participating in multidisciplinary team meetings or case conferences. These activities established the partnership as a beneficial 'learning environment' for all participants, one of the identified success factors for partnership building (Warburton et al., 2008). For example, one project officer explained in the exit interview that:

> *The multidisciplinary team meetings have facilitated a system of palliative care rather than a palliative care service. The whole team is engaged, that is, the hospital, the aged care facility and the GP. This recognises that palliative care is operating in the domain of primary care.*

A few projects, however, were unable to establish a functioning steering committee or advisory group, forcing the project officer to seek support elsewhere (e.g. within the host organisation, or from individual, external mentors) or to work in relative isolation. In most cases a lack of resources was responsible. Some project officers observed that members of advisory groups were simply too busy or unwilling to take on the leadership roles required to drive the project. Such difficulties are described in more detail (see Section 5.3.1). A lack of resources (success factor six) would be expected to compromise the effectiveness of the collaboration, according to Warburton and colleagues (2008). In a few cases, the personality of the project officer and unwillingness to accept guidance or feedback from others meant that steering committee members were not able to participate fully in decision making on key project activities. This situation represents a failure in success factors two and three (Warburton et al., 2008).

The scope of partnership building activities broadened considerably during the course of the sub-program. Apart from their steering committees, one key strategy reported by project officers was to establish local palliative care networks, or to link in with existing networks. For example, NSW-3 gained the strong support of the Hunter Aged and Disability Palliative Care Network, which became the project's de facto advisory committee. In the absence of an existing network, QLD-1 brought together a diverse group of stakeholders in the Hervey Bay and Maryborough region, with a reference group and a snappy title: PallNet. For VIC-5, the project advisory group evolved into an implementation group, with three working groups providing input. In Geraldton, the project officer for WA-2 established productive links with the Indigenous Women Carers Support Group, which has the backing of peak groups such as Breast Cancer Foundation of WA, Cancer Council of WA and the Combined Universities Centre for Rural Health. The project manager for NSW-2 was invited to join the regional Palliative Providers' Network, while the project officer for NT-1 joined the steering committee for CanNET, a collaborative project (about cancer treatment) with the NT Government.

Partnerships with consumer groups and individual consumer representatives on steering committees were important to several projects. For example, in VIC-3 the consumer representative was very enthusiastic and maintained involvement with the project over the three years, adding a different perspective to the project governance. SA-2 had a very active past carers' group that continued to meet after its formal role in the project ended, contributing to the sustainability of the project activities.

A number of projects worked in the aged care area and links with RACFs were crucial to their success. SA-2 was one of several projects that established formal partnerships with RACFs through the signing of Memoranda of Understanding. The project officer and working party members from NSW-10 regularly attended meetings at which the Directors of Nursing from local facilities get together, so that they could discuss the project with them face-to-face and as a group. The project officer from QLD-2 sought advice from the expert RACF nurse practitioner who provides specialist palliative care services to the facilities that took part in the project.

Another important stakeholder group was GPs and their Divisions. The project officer for NSW-4 took part in the local DGP Aged Care Panel. In southern Adelaide, the CEO of the local DGP was invited to attend investigator meetings of the SA-1 project and was provided with reports and updates on its progress. The project officer also liaised with a member of Southern DGP who helped organise GP focus groups for the project evaluation. Interested GPs helped develop a template for preparing care plans for palliative patients. Similarly, a group of GP representatives reviewed QLD-5 project materials. Other partnership building strategies reported by projects included formal presentations to DGP, use of DGP resources to disseminate project information and letters to local GPs introducing the project. One project (SA-5) instituted weekly interdisciplinary meetings at a large, local GP clinic. Another (SA-3) had little success with engaging GPs themselves but found that practice managers and practice nurses were very helpful in implementing project activities.

The NT-1 project officer worked closely with both the Top End Division of General Practice and the local specialist palliative care service in Darwin, and found that working a few days a week at each site helped develop trust and build relationships with both organisations. The DGP, which hosted the project, also worked in partnership with the NT Government on the CanNET cancer management project.

Although not originally part of the project plan, a partnership with the Riverina Cancer Care Coordinator brought unexpected benefits to the NSW-9 project. The coordinator took on the role of case manager for some clients of the project, where appropriate, and was also instrumental in connecting the project with a senior social worker at Centrelink, and facilitating carer payments through completion of Centrelink forms.

The QLD-4 project was based within a community care organisation, but referrals to the project's carer support groups and bereavement model were sought from other, similar organisations more often seen as competitors than collaborators. In order to increase referrals from these organisations, representatives were invited to attend the project steering committee. Referrals from local hospitals were boosted by inviting personnel to take part in the program as guest speakers, thus raising awareness of the courses.

Several project officers (including those for TAS-1, SA-4 and VIC-7) were able to build productive relationships with information technology experts in order to design websites, making the resources they had developed available to a wider audience.

Finally, a number of very productive partnerships were established among Care Planning projects. Some were operating in the near vicinity of each other and it made sense to pool resources and coordinate activities (e.g. NSW-4 and NSW-5 worked together, as did NSW-8 and NSW-9). In other cases, one project had particular expertise that was valuable to others. For example, one of

the QLD-6 project sponsors had knowledge of how to engage GPs in case conferencing and offered support to several other projects, including SA-1 and NT-1.

During the exit interviews, the importance of partnerships emerged as a fundamental component of care planning, although it also provided some of the most significant challenges for project officers. When asked, 'What did your project do best?' the most common response (from 15 participants) related to the development of partnerships between the host organisation and other stakeholders. Project staff discussed the importance of ongoing investment in relationships, which involved respecting and building on existing relationships as well as seeking out, in collaborative ways, new relationships that could contribute to the project's success. Effective collaborations were seen as critical to the ongoing sustainability of projects.

Another closely related theme that emerged in response to this exit interview question was the importance of having a consultative approach when working with stakeholders. Nine project staff mentioned this as something their project did well, for example:

> *Information relating to the project was widely disseminated to other key stakeholders for feedback. In this way developing the model was a very collaborative and inclusive process.*

It is clear from the exit interviews and the other available data that the success factors highlighted by Warburton and colleagues (2008) were present in the efforts by Care Planning project staff to establish effective collaborations and partnerships. Nevertheless, there were reservations from some projects about the preparedness of some stakeholders – particularly GPs and area health services – to engage in care planning, and the results of their strategies to engage these stakeholders were mixed. These findings have profound implications for the future of any care planning initiatives given that GPs and area health services are the two key service types responsible for medical care delivery to people who require palliative care.

The partnership building activities reported by projects likely contributed to capacity building and, ultimately, to sustainability. For instance, the project officer for QLD-1 mentored PallNet members with a strong interest in palliative care, who could lead the network once the project comes to an end. The partnerships established to support project activities are also, however, an end in themselves. From the perspective of the 'public value' model (O'Flynn, 2007), the partnerships built by Care Planning projects can be viewed as one of the major achievements of the sub-program.

7.2 *Capacity building and generalisability*

Initial and final data from the Sustainability and Spread Tool for capacity building and generalisability are presented in Table 10.

Table 10 Capacity building and generalisability: initial assessment (clear rows) and final assessment (shaded rows)

Statement		Strongly agree	Agree	Disagree	Strongly disagree	Don't know	Not applicable	Total
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Section V: Factors within the organisation's setting that relate to capacity building								
27	This project has been able to establish agreed policies or procedures with other organisations regarding the provision of palliative care services	6 (18)	10 (30)	5 (15)	0	5 (15)	6 (18)	32 (97)
		9 (29)	13 (42)	1 (3)	1 (3)	2 (6)	4 (13)	30 (97)

	Statement	Strongly agree	Agree	Disagree	Strongly disagree	Don't know	Not applicable	Total
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
28	This project has generated and supported local skills to direct, provide, lead or otherwise contribute to the provision of palliative care services	12 (36)	12 (36)	1 (3)	0	5 (15)	2 (6)	32 (97)
		17 (55)	13 (42)	0	0	0	0	30 (97)
29	More organisational resources have been directed to the area of palliative care services in this community as a result of this project	3 (9)	9 (27)	7 (21)	1 (3)	7 (21)	5 (15)	32 (97)
		9 (29)	7 (23)	5 (16)	1 (3)	5 (16)	3 (10)	30 (97)
30	The project has involved formal and/or informal training of people whose skills and interests will be retained in the project or its immediate environment	9 (27)	18 (55)	0	0	1 (3)	4 (12)	32 (97)
		15 (48)	9 (29)	4 (13)	0	0	2 (6)	30 (97)
31	The project was designed to enable people not directly involved in the project to develop capacity (skills and/or knowledge) to provide palliative care	19 (58)	9 (27)	0	0	1 (3)	4 (12)	33 (100)
		15 (48)	12 (39)	1 (3)	0	0	1 (3)	29 (94)
Section VI: The generalisability of the project								
32	The project has been designed specifically to meet our own local needs	15 (46)	9 (27)	6 (18)	2 (6)	0	0	32 (97)
		14 (45)	7 (23)	7 (23)	1 (3)	0	0	29 (94)
33	Other regions/services/organisations will learn useful lessons/information from the project	16 (49)	17 (52)	0	0	0	0	33 (100)
		23 (74)	7 (23)	0	0	0	0	30 (97)
34	It is reasonable to expect that our outcomes could be replicated elsewhere	20 (61)	13 (39)	0	0	0	0	33 (100)
		21 (68)	9 (29)	0	0	0	0	30 (97)
35	The success of the project depends on how flexibly it can be implemented according to local circumstances	11 (33)	14 (42)	4 (12)	1 (3)	1 (3)	1 (3)	32 (97)
		11 35)	14 (45)	3 (10)	0	2 (6)	0	30 (97)
36	We already have a strategy in place to ensure that our experience and findings are shared with other people who want to develop and improve palliative care services	14 (42)	14 (42)	3 (9)	0	1 (3)	1 (3)	33 (100)
		18 (58)	10 (32)	2 (6)	0	0	0	30 (97)
37	By the time the project ends, we will have a strategy in place to ensure that our experience and findings are shared with other people who want to develop and improve palliative care services	18 (55)	12 (36)	0	0	0	2 (6)	32 (97)
		18 (58)	8 (26)	1 (3)	0	1 (3)	2 (6)	30 (97)

Statement		Strongly agree	Agree	Disagree	Strongly disagree	Don't know	Not applicable	Total
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
38	Projects such as this one provide important lessons for other regions in how to do things better	17 (52)	14 (42)	0	0	0	1 (3)	32 (97)
		18 (58)	11 (35)	0	0	1 (3)	0	30 (97)

7.2.1 Capacity building strategies

In their initial assessment, almost half the project officers reported that they had already established policies and procedures with other organisations regarding service provision, and this increased to 71% by the final assessment (Q27). This strategy is consistent with the Care Planning Sub-Program goal of ensuring smooth transitions for patients between care settings.

There was a strong emphasis on providing training to care providers as a strategy for supporting the implementation of the project. The vast majority of project officers agreed that the project would involve (or already had involved) education of care providers (Q28) and people directly involved in the project (Q30). In both cases there was a trend towards more project officers strongly agreeing with these statements by the end of the sub-program. Most project officers also agreed (at both time points) that people outside each project's immediate environment also developed capacity in palliative care due to project activities (Q31).

The only area of uncertainty about capacity building was whether the projects had resulted in greater resource allocation to palliative care; initially only 12 project officers agreed that this was the case, increasing to 16 by the final assessment (Q29).

7.2.2 Generalisability strategies

At both time points, about three-quarters of project officers stated that their projects had been designed to meet local needs (Q32) while the remainder saw a broader agenda for their projects. Nevertheless, they all agreed that other organisations or regions could learn useful lessons from the projects (Q33), with almost three-quarters strongly agreeing to this statement by the end of the sub-program. Similarly, all agreed that outcomes of their projects could be replicated elsewhere (Q34). Most felt that their projects would demonstrate how to 'do things better' (Q38), and this opinion did not change over time.

The vast majority of project officers had already devised a dissemination strategy when the initial assessment was made (Q36) or were planning to do so by the end of the project (Q37).

7.2.3 Capacity building outcomes

Capacity building is a key component of the evaluation framework and answers the question, 'what has been learnt?'

Capacity building has been defined as 'the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply health gains many times over' (NSW Health, 2009). Another definition of capacity building includes the concept of 'value adding' to the outcomes offered by any particular program (Hawe et al., 2000, p. 42).

From the exit interviews, the majority of the projects felt that that the project activities had built capacity and 'value-added' within palliative care service delivery as well as at the organisational

level. Projects were able to identify, in the exit interviews, a number of individual and organisational gains from their involvement in the Care Planning Sub-Program, which included:

- Development of palliative care skills for staff
- Development and/or enhancement of partnerships between organisations
- Increased awareness of palliative care
- Development of resources
- Improvement of organisation's profile regarding palliative care
- Improvement of patient outcomes
- Improvement of organisation's capacity to carry out research

These gains were also confirmed in the project final reports, with evidence of skills, resources, and partnerships being embedded into existing practice and policies. These gains show that the projects, collectively through the sub-program, have built capacity in the health and care sectors. An example of how education can enhance capacity is provided in the following:

> *Education and training opportunities addressed the skill gaps in end-of-life care and promoted a palliative approach within the primary RACF workforce. Positive caring outcomes resulting from use of the RAC End-of-Life Care Pathway in conjunction with the on-going education, co-ordinated by the Link Nurse, were progressive and increased over the period of the project. This suggests that the model of networking a Link Nurse, supported by appropriate documents and linked to a specialist palliative care service, provides ongoing increases in the palliative care capacity of generalist staff working in RACFs.*

Capacity has also been built within the project officers themselves, many of whom were experienced clinicians prior to their involvement in the sub-program, with little or no formal project management experience. Additional skills and benefits acquired as a result of their participation include project management, stakeholder management, evaluation techniques and data analysis, budget management and grant writing, research methods and report writing.

Importantly, there has been an increased competence, confidence and self-awareness amongst the project officers as well as health and care staff as a result of their involvement in the sub-program activities. These are in addition to the capacity building outcomes achieved through education, changed care practices, access to specialist services and resources, as well as improved relations between service providers which resulted from project activities, and which are discussed in detail in Sections 6.2 and 6.3 of this report.

7.2.4 Generalisability outcomes

The concept of generalisability refers to whether lessons learned from a project could be useful to others, and is one of the six key issues addressed by the national evaluation framework. The following section outlines those aspects of the projects that can be generalised across services and sectors, plus present some of the lessons learnt by the projects. This is based on what the projects have reported in their exit interviews, progress reports and / or project final reports.

One of the goals of the Care Planning Sub-Program was to extend the impacts and outcomes of individual projects to related services and sectors. The application guidelines stated:

> *The sub-program funding was made available for projects to develop resources and models of care which are able to be applied more widely, and with the potential to be applied extensively (DoHA, 2005, p. 4).*

Successful applicants were required to ensure their project, or elements thereof, could be generalised and applied to other services. Many of the projects were, however, exercises in change management and community development, which by definition require tailoring to local needs, constraints and accepted ways of working. This meant they needed to find a balance between producing resources and models with specific local benefits and ensuring potential wider

applications. Three common strategies were employed to ensure that the models and resources developed by Care Planning projects were transferable to other settings:

1. tying project activities to objective standards of best practice
2. designing project activities around an evidence base
3. working closely with stakeholders who could advise on creating built-in generalisability.

The sub-program application guidelines strongly encouraged potential projects to consult *A Guide to Palliative Care Service Development: A population based approach* (Palliative Care Australia, 2005a). Projects used these guidelines in planning, development and implementation of their project activities. Another document that proved useful for projects was the PCA 'standards' (Palliative Care Australia, 2005b). A number of projects undertook a gap analysis based on the PCA standards, such as NT-1, SA-2, NSW-5 and NSW-6. For example, SA-2 began with an analysis of gaps in service delivery: stakeholders were asked to compare existing service provision with what should be available according to the PCA national standards, which were summarised in a questionnaire and also presented at a workshop.

Projects that encompassed Residential Aged Care Facilities were required to ensure that local resource / tools were developed in line with the *Guidelines for a Palliative Approach in Residential Aged Care – enhanced version* (2006). Similarly, local resources / tools developed relating to Aboriginal and Torres Strait Islander Peoples being cared for in RACFs were to be developed in line with the Practice Principle contained in the *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples Resource Kit* (2004).

The second approach to ensuring generalisability involved consulting the academic and practice literature for examples of existing models and resources that could be adapted for local use. All projects were required to utilise CareSearch in the development of any local resources and to ensure the lodgement of all local resources / tools developed with CareSearch. To assist with this requirement a CareSearch representative presented at the second national workshop.

A key initial activity for a number of projects was conducting a literature review. These were conducted to establish an evidence base for the project, to reduce duplication by building on existing models or resources, and to guide the development and implementation of project activities. A significant number of projects spent time reviewing the literature, including existing tools and resources, and the findings were incorporated in their projects. As well, 12 'stand alone' literature reviews were completed, and the titles or topics are listed in Table 11.

Table 11   Project literature review topic / title

Project	Literature review title or topic
NSW-10	Each of the four frameworks- dementia: pain, constipation, weight loss & agitation - included supporting information
NT-1	Care planning & case conferencing; Involving GPs in the palliative process; Carers needs
QLD-1	Effective models of care and expected outcomes for palliative care clients, carers and providers.
QLD-2	End-of-life pathways
QLD-3	Evidence for best practice in end-of-life care planning
QLD-4	'Palliative carers', their emergence and support needs'
	Approaches to working with family carers of people with a life-limiting illness.
QLD-6	Discharge procedures for palliative patients and the information needs of patients, carers and community-based health care providers
VIC-2	Being Smarter: A partnership model of palliative care
	Patterns and models of community based palliative care, both in Australia and internationally.

Project	Literature review title or topic
VIC-3	What happens after dark? An exploration of models of palliative care service provision for people dying at home
	Different models of after hours services in rural and urban Victoria to identify gaps in service delivery.
VIC-5	Decision making tool for GPs; education strategy to assist GPs; and carer resource.
VIC-7	Focus on models of care, guidelines, frameworks or protocols in paediatric palliative care
WA-1	Focus on issues, resources and policies or procedures in the development of an end stage renal disease palliative approach

Some of the literature reviews are quite specific in their project content area (NSW-10, VIC-3 and VIC-7), but most were more general and are therefore of greater potential use as resources for later projects. For example, there were a number of projects working on end-of-life care pathways, or working with carers.

Some of the projects specifically developed partnerships with stakeholders who could advise and assist them to develop models, resources and tools that could be applied outside the scope of the local projects. This included working with peak bodies such as Palliative Care Australia (state and national offices), consulting with experts (clinical and evaluation) and collaborating with industry leaders (in aged and palliative care). There were several projects that developed linkages with state heath representatives, and one project commented that:

> *Good communications along the way with other service providers and the DHS has been the key to the project's generalisability. The model has good state-wide applicability.*

In the exit interview the projects were asked to consider how generalisable the outcomes of their project were to other settings. Nearly all projects that answered the question stated elements of the model or tools developed by the project could be generalisable to another setting.

> *The protocol's capacity to be generalisable has been a big focus of its design. The project has forged links … to ensure that there is good communication between key stakeholders. This will also ensure that the protocol is not reinvented by a different organisation. There are plans to embed the protocols across the state. There is also demand and interest for the protocol at a national level.*

Specific aspects of the projects that are being or have the potential to be replicated elsewhere include models of care, which have been described in detail earlier in this report (see Section 6.3.1). Although these were developed for specific locations or client groups, many include generic elements that have wider application. For example, a care planning model for paediatrics developed was showcased at a recent conference and feedback suggested it could be replicated in other health care disciplines, such as disability, or even in aged care.

All the projects developed resources and/or tools that can be generalised to other services and sectors. Some of the resources and tools support the models of care or project activities, and many have not been evaluated.

In the exit interview, participants were asked to consider what their organisation learned from its involvement in the Care Planning Sub-Program. All 33 projects gave examples of organisational learning such as:

- Difficulty in engaging general practitioners
- Importance of collaboration and partnerships
- Understanding and working with the aged care sector
- Resistance to training from some health service staff
- Importance of using 'champions' (such as link nurses, clinical champions)
- Importance of using change management strategies
- Requirement for project officers to have project management training

Future projects and programs could apply lessons such as the importance of collaboration and partnerships, of using 'champions' and of using change management strategies in the planning and implementation stages.

Other lessons from the sub-program could serve as a warning and/or a flag for certain activities such as the engagement of GPs in project activities including case conferences or education sessions. Some projects did have success in engaging GPs, as expressed by one project:

> *It is important to have good administrative support for GPs to facilitate their attendance at the multidisciplinary team meetings. Working with GPs at these meetings is an incremental process of building their confidence over time. This process has been enhanced by the presence of an enthusiastic GP advocate.*

The prerequisites required to undertake a project should also be carefully considered, such as the requirement for project officers to have skills in project management.

About a quarter of the projects worked with RACFs and for some, this was a new experience. In doing so, they were able to understand the challenges and constraints of the aged care sector and so address these to enable the implementation their activities.

The sub-program has generated many models of care, resources and tools, and other project elements that are free of charge and accessible for others to use. However, there will still be additional resources required for introducing new procedures or tools, implementing education programs, or applying models or care. For example, one project indicated that the generalisability of the model of care developed depended very much upon the availability of human resources and a robust information management system to generate key documentation. Another project commented:

> *Whole concept could be transferred to any aged care facility as a quality improvement activity. Need to identify a person to take on the role, could use the tools developed for this project, education package has been trialled with nurses here, would need to write own paperwork (adapt for own facility). Audit tool has potential for use in evaluation.*

Some of the tools and resources may need modification to enable them to be used in different States and Territories. One project noted that their advanced care planning fact sheet would need altering to be in-line with legislation at a state level. Whereas another project indicated that their medication imprest system would only be relevant in the state that it was developed due to the jurisdictional issues surrounding medications.

The proposal is that information on the models of care, resources and tools, and other project elements are available from CareSearch. From a program perspective, it would be extremely useful to know if other services accessed and/or implemented any of the information. Perhaps CareSearch could measure the 'spread of the sub-program' by monitoring access to their website. It would be important to obtain feedback from those who applied the models or resources, that is, 'how did they go'? Some projects have attempted to gain feedback by including an evaluation or review process when sharing their resources and tools.

Generalisability was a key component, and requirement, of the sub-program. Projects produced many models, resources and tools and other project elements that are potentially generalisable. One caveat is that few projects conducted rigorous evaluations and so evidence of effectiveness varies considerably from project to project. Those in the future who look through the Care Planning Sub-Program to inform evidence-based policy and practice need to consider carefully the nature and strength of the evidence for the resources and models produced.

Future programs might consider the challenge of taking this one step further to measure what was actually generalised and transferred across the different settings and sectors.

8 Dissemination

One of the evaluation framework requirements was for projects to disseminate their lessons learnt both within and beyond the sub-program.

Therefore, to monitor dissemination, projects were asked to complete dissemination logs and submit with their six-monthly progress reports. Data were received from all 33 projects, however not all projects submitted data for the entirety of their project. Although collection of dissemination data was a contractual requirement for projects, the degree of the non-compliance may be in part due to a misunderstanding of this requirement.

Approximately half of the project officers indicated in the exit interviews that they had no dissemination plan at the outset of their project. The remaining half of the projects indicated they had some plans for dissemination at the outset. Most commonly, original plans of dissemination strategies included presentations at conferences, newsletters, staff education, and publishing in journals.

As projects progressed it is evident that plans were established in all projects (or were further developed from their original conception). Five projects noted their realisation of the importance of dissemination as their projects progressed. Ten projects seem to have had plans that were vague or minimal which later evolved to include more improved and expanded activities. This development and enhancement of dissemination plans was assisted by the influence of the NET, and their continued emphasis on the importance of dissemination in discussions and correspondence with project officers.

The dissemination log distinguished activities by two purposes, as follows:

1. Information may be shared with project stakeholders, such as steering committee members, management and staff of participating services, and groups or individuals in the local community. This type of dissemination supports the capacity building and sustainability aspects of the project.

2. Information may be shared with the wider palliative care community, including clinicians, academics, managers, planners and policy makers. This type of dissemination supports the generalisability of the project.

Project officers were asked to classify their dissemination activities by purpose (see Table 12). A number did not do so, excluding a total of 599 activities from this analysis. Data provided by one project accounted for the majority of these unclassified activities (as can be seen in the range across projects).

Between them, the projects that supplied these data carried out a total of 1398 dissemination activities during the course of the sub-program in order to support the capacity building and sustainability aspects of the project. This included, for example, presentations to staff at participating organisations. An additional 824 dissemination activities were designed to support the generalisability of the project, for example, through publicity and consultations involving the wider palliative care community. A further 64 activities were classified as having a dual purpose.

Table 12   Dissemination activities undertaken by purpose – September 2006 to May 2009

Purpose of dissemination activity	Total activities	Percent of activities	Range across projects
1. Information may be shared with project stakeholders, such as steering committee members, management and staff of participating services, and groups or individuals in the local community. This type of dissemination supports the capacity building and sustainability aspects of the project.	1398	48.2	0 – 164
2. Information may be shared with the wider palliative care community, including clinicians, academics, managers, planners and policy makers. This type of dissemination supports the generalisability of the project.	824	28.6	0 – 107
Purpose 1 and 2 combined	64	2.3	0 – 15
Blank	599	20.8	0 – 335
Grand Total	**2885**	**100.0**	**N/A**

Table 13 presents the kinds of activities undertaken by projects during the entirety of the sub-program (covering both purposes). The most commonly reported types of dissemination activities involved presentations and talks to staff, either within a single agency (reported by all 33 projects) or to mixed groups of staff from several local organisations (reported by 32 projects). Together, presentations to staff accounted for more than half of all dissemination activities reported during the sub-program. This type of activity supports the capacity building and sustainability of the projects (i.e. Purpose 1).

Targeted communication via email lists was used by 26 projects. Eight project officers reported that their organisations' websites hosted pages dedicated to their respective projects, five had project newsletters and nine were using purpose-designed brochures and/or posters to promote the project. Twelve project officers had articles published in a professional or industry magazine, while eleven had submitted information to a local magazine or newsletter.

Three projects had a paper published in an academic journal by the completion of their projects, with a number of others indicating they had submitted papers and were awaiting acceptance from the respective journals. There has been considerable exposure of the program at local (72), state (44) and national conferences (50) through posters or presentations by project officers. Presentations have also been given at international conferences by four projects. Furthermore, a number of presentations have been prepared and will be delivered in the near future, for instance at the Palliative Care Australia 'International Conference on Cultural Connections for Quality Care at the End of Life', in September 2009.

Around one in five dissemination activities were classified as 'other'. These activities included letters, phone calls, liaison with peak bodies and government agencies, consumer focus groups and annual reporting to steering committees.

Variation between the numbers of dissemination activities reported by projects was evident. It is possible that these differences were at least partially due to different interpretations of the requirements for completing the log. Also, the types of dissemination activities carried out would have been influenced by the type of project itself and the funding the particular project received. For instance, not all could attend conferences, not only due to budget constraints, but also some project officers lacked the skills or confidence to present. Data showing the range across projects (of numbers of activities) are indicative of these variations. To illustrate, seven projects did not classify any of their activities as 'Other', whereas one project gave 244 of their activities this classification (Table 13).

These data are supported by the comments made during the exit interviews. Project officers commented on what they felt were the dissemination activities that worked best for their projects. In order of incidence, from highest to lowest, were: media activities including newspaper articles and radio; conferences; newsletters i.e. staff or parish newsletters; face-to-face meetings, where project findings were discussed, usually one-to-one; websites; community meetings and presentations within the community; journal articles; tools developed within project i.e. GP referral pad, DVD; staff training; consultations with GPs; and 1:3:25 report.

Table 13   Types of dissemination activities undertaken – September 2006 to May 2009

Dissemination activity	Total activities	Percent of activities	Range across projects
Brochures, leaflets or posters in health and community settings	41	1.42	0 – 6
Email communication to groups/lists	205	7.11	0 – 69
Information provided on a website	37	1.28	0 – 6
Other (please describe briefly)	537	18.61	0 – 244
Peer-reviewed journal article	8	0.28	0 – 6
Presentation or poster at a local conference	72	2.50	0 – 15
Presentation or poster at a national conference	50	1.73	0 – 5
Presentation or poster at a State/Territory conference	44	1.53	0 – 9
Presentation or talk to staff at one service or agency in the local area (e.g. talk at a staff meeting, during a hospital grand round)	975	33.80	2 – 144
Project newsletter	14	0.49	0 – 3
Radio	18	0.62	0 – 7
Story in the local newspaper	51	1.77	0 – 24
Story or article in a local magazine or newsletter (e.g. GP news, hospital newsletter, community agency newsletter)	96	3.33	0 – 21
Story or article in a professional or industry magazine or newsletter	48	1.66	0 – 6
Talk to staff from more than one service or agency in the local area (e.g. talk at an interagency meeting)	535	18.54	0 – 74
Television	5	0.17	0 – 3
Grand Total	**2736***	**94.84***	**N/A**

* 149 activities were given either multiple codes or were not coded, and therefore could not be included in the analysis. (i.e. 2885 – 149)

Project officers were also asked to estimate the number of people who heard or read about the project via the dissemination activity, and to indicate whether anyone who heard about the project had followed up by seeking more information. Table 14 presents this information for all dissemination methods. It should be noted that these numbers are estimates only and should be treated with some caution.

Data on follow-up may provide more useful information, as it is more of a reflection of the people that showed genuine interest in projects, to the extent that they sought additional information after initially hearing about the project.

Table 14   Persons reached and level of follow-up for selected dissemination activities

Description	Reach		Follow-up	
	Total activities	Persons reached	Total activities	Follow-ups
Brochures, leaflets or posters in health and community settings	35	112978	22	120
Email communication to groups/lists	194	459512	128	834
Information provided on a website	25	3082	17	73
Other (please describe briefly)	526	54791	419	1111
Peer-reviewed journal article	5	5	1	4
Presentation or poster at a local conference	66	3233	56	265
Presentation or poster at a national conference	43	5685	37	244
Presentation or poster at a State/Territory conference	42	2334	36	181
Presentation or talk to staff at one service or agency in the local area (e.g. talk at a staff meeting, during a hospital grand round)	941	7598	470	1232
Project newsletter	13	2335	8	41
Radio	10	795000	8	20
Story in the local newspaper	44	3367452	24	169
Story or article in a local magazine or newsletter (e.g. GP news, hospital newsletter, community agency newsletter)	89	590750	45	260
Story or article in a professional or industry magazine or newsletter	33	54825	23	86
Talk to staff from more than one service or agency in the local area (e.g. talk at an interagency meeting)	529	6627	320	1193
Television	3	27	3	6
#N/A	27	2813	7	8
(blank)	113	693	74	85
Grand Total	**2738**	**5469740**	**1698**	**5932**

Dissemination via commercial news media (i.e. newspapers and radio) had the greatest reach, and the numbers here are presumably based on published audited figures for circulation or audience size.

Oddly, dissemination through television and peer reviewed journal articles was reported to have a particularly small reach. In relation to the low estimates of people reached by media such as television and peer-reviewed journal articles, it could be assumed that project officers lacked confidence to guess numbers and instead opted to leave blank.

Distribution of brochures, leaflets and posters in health centres is a slightly more targeted strategy, and although the reach was not as great, this activity produced a high proportion of follow-up contacts.

Presentations to staff from one or more local agencies generated by far the most follow-up, suggesting this is an effective (albeit time-consuming) way to reach people who are genuinely interested. Communicating with stakeholders via email lists and articles in local newsletters or magazines also resulted in a considerable amount of follow-up communication.

Conference presentations appear to be a successful strategy for reaching the wider palliative care community. Projects reported a total of 151 papers or posters at local, state or national conferences, and between them these efforts generated interest from 690 individuals who later sought further information about the projects.

Forty-five activities were coded as follow-up being 'ongoing'. Activities that were recorded as having 'ongoing' follow-up were most commonly classified as 'Other' with no description given.

Presentations or talks to staff at one service or agency in the local area were the second most common. One presentation at a national conference was also recorded as receiving ongoing follow-up.

The projects worked hard to disseminate information about their projects activities and findings throughout the sub-program. Dissemination activities were implemented both to support the development and implementation of the projects, as well as sharing the findings with the broader health and aged sector.

9 Unintended consequences

9.1 Project level unintended consequences

In their final reports to DoHA, projects were asked to describe any unintended consequences of project activities that they had noticed. The following section summarises these reported impacts of the sub-program.

Most of the unanticipated impacts of projects were positive. These included:

- Additional grants to expand or continue project work
- Additional resources not originally planned
- Career development for project staff
- State-funded positions supporting palliative care service delivery
- Stakeholders more extensively engaged and contributing more than expected
- Opportunities to build partnerships that were not originally planned
- Additional services for clients and carers
- Improved access to palliative medications
- Additional training for staff, not originally planned

Two main types of negative impacts were reported:

- Some clients or carers became distressed
- Deficiencies in staff training were highlighted, leading some staff to experience stress and difficulty dealing with issues (particularly with bereavement)

Enhancements to projects – funding and resources
By far the most commonly reported type of unintended consequence was the generation of 'spin-off' projects or additional grants to expand or continue the work of care planning projects. Examples include the project officer for QLD-5 receiving a grant from the Queensland Nursing Council for a project to interview 10 people living with advanced heart failure and conduct thematic analysis. The SA-5 project was included in two new DoHA-funded national programs and selection of the Mount Gambier and Districts Health Service to trial a multidisciplinary team pilot project through CanNet.

Several projects produced additional resources that were not originally planned, including a training package for RACF titled 'The Impeccable Assessment of Pain' (NSW-4 and NSW-5) which was developed into competency training package and DVD. The TAS-1 project developed a medication formulary with potential for national use. The resources produced by NSW-3 were promoted more broadly than anticipated, through its participation in the Aged Care Channel's video link education program and to develop an educational DVD around family experiences at end of life across the residential aged care and acute sector.

One project was recognised with an award. Feros Care's 'Northern Rivers Primary Palliative Response Project' (NSW-2) was named the winner of the Project of the Year at the Not-for-Profit Regional Network Annual Awards (announced 14 October and awarded 14 November 2008).

Career development opportunities
Projects also led to career development opportunities for a number of project officers. The project officer for NSW-6 was invited to participate in a special interest group on palliative care in residential aged care, while the project officer for SA-5 was asked to contribute to a feasibility study investigating the need for a hospice in the region. The NSW-1 project officer received a grant from the Cancer Institute NSW for an international study trip during 2008, and also successfully applied for a psycho-oncology clinical fellowship from the same organisation to

continue the research undertaken as part of the project. Several project officers enrolled in PhD degrees or other further education courses.

State government involvement
Several projects resulted in new positions funded by state governments, or highlighted the importance of existing roles within public hospitals or area health services. During the course of QLD-1, a local, independent palliative care service ceased operations and remaining funds were returned to Queensland Health for reallocation. The officer within Queensland Health responsible for the allocation of NGO palliative care funds approached the project manager to consider innovative ways in which these funds could be utilised on the Fraser Coast. The PallNet Core Group established by the project was asked to consider the needs of the local communities of the Fraser Coast and the optimal ways to improve the provision of end of life care in this region. They identified the need for the role of a Palliative Care Service Development Officer, which was subsequently funded.

The NSW-1 project highlighted the need for the hospital's community team to include a medical palliative care specialist or registrar. This level of expertise was inconsistently available during the project period, but was clearly needed to ensure optimum care for patients who are transferred from Calvary to aged care facilities. In particular, GPs liked to discuss complex symptom and medication issues with a specialist palliative care doctor.

The role of an aged care nurse case manager was established by the VIC-2 project, while the VIC-4 project developed a new model of care coordinated by a clinical nurse consultant. When the person appointed to the role went on maternity leave the role was 'subcontracted' to the area health service, providing an opportunity to 'pilot' the new model.

Stakeholders and partnerships
In some cases, stakeholder engagement went further than expected, bringing unanticipated benefits to the project. The SA-2 project set up two consultation groups in addition to the steering committee. The GP advisor group communicated by email and this forum was very successful in gaining GPs' comments and feedback on the proposed resources and service model. The consumer advisory group of former carers was also a successful strategy for supporting the project. Neither of these were originally planned but evolved during the course of the project. Another project (SA-5) established a collaboration with the police to develop protocols for informing families who to contact after an expected death at home.

The NSW-7 project took advantage of the fact that several projects had been funded concurrently in the same area. This project collaborated with the Spiritual Care Project (Mid North Coast Division of General Practice, LPCGP Round 2) and Catholic Healthcare (Care Planning Project) to deliver education to providers, enabling a multi-faceted approach to developing local palliative care across the range of organisations and care settings. Another partnership was established with Home Hospice to roll out their program of Volunteer Home Mentors and to offer training programs for volunteer mentors in rural communities.

Partnerships were also developed as a consequence of changes in local stakeholder arrangements. Following a reduction in capacity of the local palliative care the WA-1 project was able to forge links with a palliative care consultant from Charles Gardiner Hospital (Perth) who agreed to attend meetings every second month. This assisted in getting stronger engagement and networking between the palliative service in Perth and the local renal services.

Equipment and technology
Change in the availability of services or equipment were other unanticipated outcomes of Care Planning projects. The NSW-8 project established a collaborative relationship with the NSW Cancer Council policy branch which meant that results of the project - especially in regard to equipment availability and provision for palliative care patients and their carers - formed part of the NSW Cancer Council's submission to the PADP enquiry. Changes were not always positive,

however: the NSW-7 project reported that discussion around risk and liability in formalising the process and requirements for loan of Graseby Syringe Drivers as part of the project's Smooth Transition Working Group resulted in the palliative care service suspending loan of available devices to organisations external to the North Coast Area Health Service, which they had informally provided for many years. They cited the reason as limited capacity to continue at present, with an undertaking to review in the future.

Access to technology strengthened the partnership between VIC-2 and Royal District Nursing Service (RDNS) Customer Service Centre which triages after-hours calls from clients and their carers in the community. Agreement was reached to give RDNS customer service centre staff read-only access to MCMPC's PalCare system, ensuring that information regarding any client can be accessed immediately, and used to assist with the issue at hand.

Improved services
The success and positive feedback from conducting case conferences for adolescent and young adult cancer patients through the VIC-6 project has built enthusiasm in the host organisation for making case conferences routine care for all complex patients, not only this particular age group. NSW-1 reported that the volunteers from Calvary Hospital who supported clients transferred to RACFs played a very significant role and contributed significantly to the success and sustainability of the project.

Medications
At least two projects had a side benefit of improved access to palliative medications. The imprest system introduced in RACF by QLD-2 has implications for all residents, not just palliative patients. An MOU between Melbourne Citymission Palliative Care and Peter MacCallum Cancer Centre pharmacy was established by VIC-2 to enhance timely and cheaper access to medications for clients. There had been an issue with nurse practitioners prescribing as some local pharmacists were unaware that a nurse practitioner is able to write prescriptions. Also, lack of access to the Pharmaceutical Benefits Scheme for nurse practitioners means prescriptions are regarded as private and therefore costly. The MOU and discussions with local pharmacists helped resolve these issues.

Impacts on staff and carers
Project activities also resulted in greater interest in palliative care by primary health and care staff including a GP who enrolled in a Graduate Certificate course in palliative care, thus becoming the first GP with these specialist qualifications in the region (SA-5). The NSW-3 project reported that the RACF involved in the project did not experience any staffing problems and agency nursing staff did not have had to be recruited in the time since the project commenced. This was attributed to the education provided; resulting in the capacity and capability of care staff was increased. The NSW-6 project also found that interest from support staff, such as cleaners, catering, clerical and maintenance personnel, was much greater than expected. Education regarding end-of-life issues was well received and evaluated positively.

Sometimes, project activities around carers and clients highlighted deficiencies in staff skills in dealing with difficult conversations, and led to improved training opportunities. For example, the bereavement model set up by QLD-4 brought attention to a need for training in bereavement issues for community care staff visiting clients and carers. As a result, grief and loss training was made available and during the project was attended by 58 nursing and care staff. The organisation has proposed extending this training to all Spiritus staff across Queensland on a regular basis.

A similar situation arose with the VIC-4 project. The most common staffing issue identified by the project related to cultural needs, specifically, when it was culturally appropriate that a resident not be told of a diagnosis, or a request for information about treatment plans be discussed with family members only and not the resident. Staff found these issues confronting and sometimes had difficulty reconciling the families' requests with their own beliefs. The clinical nurse co-ordinator

was not always skilled to deal with these issues. Similarly, the project officer for SA-3 found that some clients and carers, when introduced to the patient diary and other materials bearing the title, 'palliative care', became very distressed as they were not ready to talk about this stage of the illness. This resulted in some difficult conversations and the project officer felt she would have benefited from appropriate training.

Two other projects also reported client or carer distress resulting from project activities. During the final session of the course for bereaved carers participants were encouraged to express their grief and the session became highly emotional. For some, this was unexpected as they thought the final session would be a fairly light-hearted wrapping up of the course, and instead it was quite confronting. This was identified during the external evaluation. Their concerns were addressed by inviting them to an additional session, and by modifying the course content for future sessions. One resource developed proved difficult for some patients to deal with, as described by the project officer:

> *There has been the anger from some of the patients when using the resources; they now suddenly understand how bad their kidney disease is and how close they are to needing dialysis. We were unprepared for this reaction as our intense focus was on the resources and just getting them to understand.*

Additional, unexpected benefits for clients and carers were also reported. For example, the NSW-9 project was able to serve twice the anticipated number of clients and carers, due to the ability of the contracted agencies to absorb some brokerage through their existing programs. This also built sustainability into the project as clients and carers could be supported beyond the life of the project, if they met Commonwealth Carer Respite Centre eligibility criteria. Evaluation of the patient-held record developed by QLD-6 found that it had unexpected benefits for carers.

9.2 Program level unintended consequences

There were four main unintended consequences, both negative and positive, as a result of the Care Planning Sub-Program.

Prominence of residential aged care
By the end of the sub-program over half the projects had conducted activities with RACFs, with half of these not originally planned. This confirms that palliative care is core business for aged care. Further, it shows not only an untapped need, but also a missed opportunity for the sub-program. With so many projects ending up working in this area, there could have been a more coordinated approach, with similar activities such as end-of-life care pathways being rolled out across the sector. As the sub-program progressed, it became clear that projects targeting RACFs could see benefits in increased networking, problem-solving and sharing resources. There is recognition by DoHA of the need to enhance skills within the sector more broadly, and three palliative care projects have been funded, working across a number of RACFs, in the Encouraging Best Practice in Residential Aged Care (EBPRAC) program. However, there is potential duplication between these two programs and clear opportunities for sharing of lessons learnt from the sub-program with the EBPRAC projects.

Negotiating Commonwealth/State boundaries
A number of projects experienced tensions resulting from difficulties negotiating Commonwealth/State areas of responsibility. This is an ongoing dilemma for 'grants' type funding, which was overcome by some projects through their partnerships arrangements, but not by all. This was particularly apparent with State health services being conducted in Commonwealth funded RACFs.

Facilitating linkages
The sub-program, through the work of the NET, was able to develop and enhance linkages with other programs e.g. Palliative Care Outcomes Collaboration (PCOC) and National Standards Assessment Program (NSAP). This was a two-way street, with projects contributing to the work of

programs (PCOC, NSAP) as well as projects then using these programs in their project implementation (e.g. PEPA). The sub-program was able to link projects and their partners into other government programs.

Program flexibility
The sub-program had the flexibility to enable projects to develop and implement activities not originally documented in their project plans. The enthusiasm and the commitment of the project officers and their projects to undertaking new opportunities and to making ongoing improvements have been highlighted by the unintended consequences described. At the program level, unintended consequences are key areas to consider for future programs.

10   Discussion

The Care Planning Sub-Program has achieved a significant amount in the last three years. With an overall budget of $7.5 million, 33 projects have been funded across the nation targeting a range of audiences in a variety of contexts, developing models of care, frameworks, processes and resources, and building relationships, capacity and confidence of the health and care services sector as a result. The additional funding provided to the National Evaluation Team to undertake program support as well as evaluation activities, certainly assisted the program being more than the sum of its parts.

10.1   Building communities of practice in palliative care planning

10.1.1 Community of practice defined

The approach of the sub-program has been to build a 'community of practice' (CoP) in regards to improving care planning for people with palliative care needs. The Improvement and Development Agency of the UK government describes a CoP as providing 'an environment (virtual and face-to-face) that connects people and encourages the development and sharing of new ideas and strategies. This environment supports faster problem solving, cuts down on duplication of effort, and provides potentially unlimited access to expertise' (Improvement and Development Agency, 2008).

In their systematic review of the literature, Li et al. (2009) commented that learning takes place in social relationships, rather than through the simple acquisition of knowledge, and identified four key characteristics of a CoP:
- social interaction (formal and informal, in person or through technology);
- knowledge sharing;
- knowledge creation (e.g. new ways of doing things, solving problems); and,
- identity building (i.e. the process of acquiring a professional identity or being identified as an expert in the field) (Li et al., 2009).

10.1.2 Care planning community of practice

From the evidence provided in the evaluation reports of the individual projects, and the data from national evaluation activities, it would appear that there has evolved communities of practice in care planning, at several levels. At the local level, this has been a fundamental component of the strategies and models of care developed, many of which have required the participation of a number of key stakeholders to communicate with each other, share knowledge, problem solve, plan and coordinate care for individual clients and their carers. Examples include the MDT meetings and case conferences, as well as the development of patient-held records and care planning pathways. These were supported by systems and processes, some of which were formal and others less structured. All aimed to engage diverse health and care providers to develop solutions and strategies which meet the particular needs of the client, within their particular context, and were characteristic of the first three elements of a CoP articulated by Li et al, above.

Formal processes adopted by some projects included the development of Memoranda of Understanding (MOU), while others sought agreement to terms of reference for participation in steering committees or advisory groups. Consequently, for some, this resulted in the establishment of a clear identity within the local service context, with participants being the key advisory or coordination mechanism for palliative care issues at the local level, or within the sector more broadly (addressing the fourth characteristic regarding building identity).

The feedback from projects at their exit interviews was that the building of relationships and establishment of partnerships has been the major achievement of the sub-program. This was echoed in numerous evaluation reports by the projects, which documented outcomes of

stakeholder feedback, surveys and focus groups. It is also evidenced in the number of local contexts which since adopted the processes, protocols and tools established by the projects, and integrated them into existing practice or sourced funding to establish new services in which they can be incorporated.

The sub-program also had a focus on establishing a broader community of practice, at the state level as well as nationally. This was primarily achieved through the inclusion of a facilitation and project support component, in addition to an overall program evaluation function, of the National Evaluation Team (NET). The concept of a facilitator has been identified as one of the key aspects of the formation of a CoP (Li et al., 2009), and the NET's role and activities in this area were clearly articulated in the Communications Framework, which was developed to support the overall Evaluation Framework for the sub-program. The proactive approach to facilitation and support of the NET was based on previous experience which demonstrated that projects appeared better able to build capacity and achieve sustainable outcomes when provided with opportunities to share resources and work together to generate solutions to common issues. The activities included significant contact with individual projects through site visits, telephone and email, to assist with project planning and evaluation activities, as well as general support and problem solving. In addition, resources were sourced and distributed to projects, and the use of common evaluation tools and strategies was encouraged, including providing information on those used by the Palliative Care Outcomes Collaboration (PCOC), to attempt to obtain an aggregate of findings across the sub-program. Projects were encouraged to work together and share their resources, tools and experience through the establishment of an email list-server, forum and information bulletins. The 'virtual' environments established were supplemented with face to face opportunities for communication, through the facilitation of three national workshops over the course of the program, and identification of the need for, and support of, the state forums. The focus of these activities was to assist projects get to know each other, so they would feel more confident to network outside of the workshop, and also to encourage sharing of resources, strategies and problem-solving between the projects. Additional resources in term of expertise and information about broader sector initiatives were also provided, through the participation of Palliative Care Australia, CareSearch, and PCOC.

Through our site visits, observations at the national workshops and past experience working on programs such as this, the NET recognised the need for greater collaboration and networking at the State level and advocated that this be facilitated by the Department. Consequently, additional funding was provided to coordinate networks and forums in five states. Although not part of our contracted obligations, the NET participated in the planning and running of these meetings at the invitation of projects, as we believed it was important to embed these networks to encourage sharing of resources and skills amongst the members, as well as enhancing the prospect of the networks and relationships being maintained in the longer term once the projects finished.

These program level activities were regarded as highly positive and constructive, and proved particularly valuable for the large number of project officers who were experienced clinicians, but who had little or no prior project management experience. From the feedback received through their exit interviews, as well as from evaluations of the workshops and forums, we can conclude that the role of the NET in facilitating these processes was an important contribution to communities of practice at the local, state and national levels.

In a similar vein, the NET assisted in the development of relationships between projects with similar strategies (e.g. case conferencing) and target groups (e.g. residential aged care). Opportunities for networking were provided at the annual workshops, special interest email (aged care) and state-specific (NSW projects) list servers were established by the NET. In addition, relevant information and tools were disseminated to the projects (e.g. literature reviews, journal articles) as well as to broader audiences, such as at sector-specific conferences. Feedback from the projects indicates that they have valued these opportunities, and there is evidence of projects sharing ideas and concepts as the sub-program developed.

A number of partnerships that were established between the projects remain in place following the end of the sub-program, and this is evidenced by the co-presentation at workshops and conferences, and joint applications for further funding to state and national grants programs to continue the work and networks established under the sub-program.

The ability for the communities of practice to continue beyond the life of the sub-program may be inhibited with the lack of a dedicated facilitation role which was played by the NET. It is hoped that the peak bodies and industry leaders, who were strategically included in the workshops and as targets for the communication activities, will be in a position to undertake this facilitation role at the state and national levels in the future.

10.2 Lessons learned about effective care planning

A number of themes emerged as being important considerations in the enhancement of care planning for palliative care. These include the significance of putting the client at the centre of care, how this requires the development of partnerships and relationships between care providers, what sorts of models of service delivery work best, and what are some of the implications for staff, organisations and the system in implementing these models more generally.

10.2.1 The client at the centre

The underlying principle behind the care planning sub-program is that clients need to be at the centre of care when palliative needs are being addressed. Fundamentally, this represents a shift in the way care has historically been provided, in that it moves the locus of control and focus onto the individual, rather than that of the service provider or clinician. This is consistent with the philosophy of the palliative care service delivery model developed by PCA (Palliative Care Australia, 2005a):

> *… the model is driven by the level and intensity of patient, primary carer and family needs as well as their strengths and limitations, rather than by organisational and service structure or objectives, or by traditional patterns of service delivery…*

The recent report of the National Health and Hospitals Reform Commission (2009) echoes this sentiment in its statement:

> *We need to* **redesign health services around people…** *(NHHRC, 2009, p. 6)*

The Care Planning Sub-Program has identified a number of models of care, strategies, resources and processes which facilitate this objective. Projects were designed to ensure the client and their carer had:

- their wishes taken into account in decision-making about care planning – e.g. end-of-life care planning, advance care plans, carer support groups;
- access to information - e.g. brochures, education;
- multidisciplinary care planning so all needs are addressed in a planned and coordinated way - e.g. MDT meetings, case conferencing;
- evidence-based assessment tools applied to ensure care is tailored to their individual needs – e.g. care pathways, assessment education and training;
- access to specialist support when required;
- resources to facilitate communication with and between providers -e.g. patient held records,
- enhanced community support, and,
- reduced burden of care – e.g. care coordination, case management

Paradoxically, while these were the key outcomes sought for clients, very few were actually directly consulted in the development of initiatives, or were direct recipients of project activities. Instead, the majority of projects sought to enhance the capacity of those providing care to place the client at the centre, through education and a focus on individualised assessment, care planning and coordination.

10.2.2 Importance of partnerships

Fundamental to the processes developed to achieve client-centre care is the need for services to work cooperatively around the particular needs of the individual and their carer and context. The importance of partnerships in providing palliative care is widely recognised; indeed, it is one of the three goals of the National Palliative Care Strategy, and as noted above, was built into the funding agreements of projects. Many project officers experienced first hand the considerable effort that was required to construct and maintain working relationships between what is often a disparate array of services, many of which have resource constraints, competing agendas and priorities, as well as negotiate professional boundaries. Various strategies were adopted, with differing degrees of success; these are articulated in detail in Section 7.1.4 of this report. The success of the partnerships underpinned the success or otherwise of the models of care or new processes and frameworks which were developed, and also provided indications regarding the sustainability of the project outcomes.

Projects which appeared to have the most success in developing and maintaining partnerships were those which met the attributes described by Warburton et al. (2008), i.e. favourable context; variety of characteristics of partners; clear communication and procedures; structured roles and processes; clear purposes; and sufficient resources. A small number of projects had great difficulty establishing partnerships at the local level because one or more of these characteristics was lacking. These include projects where there was not a clearly identified need for the new model, or it appeared to duplicate an existing service; contexts where there was a poor history of collaboration between services; decision-making was not seen as collaborative; an inability to negotiate or work across professional boundaries; and, leadership limitations of the project officer and/or host agency, in terms of skills and/or resources.

The large majority of projects were successful in establishing and enhancing partnerships between local services. A smaller number still were able to develop partnerships with each other, due to close geographic proximity and similar target groups. Benefits of these arrangements included greater coordination of activities, enhanced capacity building through joint education initiatives, strengthening of local networks, joint resource development and enhanced visibility of project outcomes through shared conference presentations. In addition, one partnership found the arrangement extremely beneficial as it combated the professional isolation which was typical of project officers in rural areas.

10.2.3 Partnerships which place the client at the centre

The most common models of care which were implemented to facilitate partnerships to provide client-centred care were multidisciplinary case conferencing (also know as multidisciplinary team meetings) and care coordination, planning and management. Almost all projects had some element of inter-disciplinary engagement as part of its strategies, some of which were formalised through establishment of MDT meetings, others which were less structured such as the incorporation of family conferences which included representatives of a range of disciplines participating.

Multidisciplinary case conferences
Around half the projects included the multidisciplinary or team meetings (MDT meetings) or case conferencing in their activities. For some, this was the primary focus of their project (e.g. NSW-7), for others, it was incorporated within a broader approach to care planning or end of life care pathways. The elements for success appear to be consistent with what the literature tells us about partnerships – i.e. a good broker/facilitator, decision makers at the table, clear purpose, good processes and ongoing monitoring (Pope and Lewis, 2008). There seems to be good evidence emerging from the projects about the success of these processes, primarily in terms of the impacts on the providers involved. These include a greater understanding of the needs of clients, improved relationships between providers and, particularly for generalist providers, improved understanding of palliative care issues. However, limited data were available on the impacts on clients themselves, primarily reflecting the difficulty of recruiting palliative patients to projects such

as this, and the ethical considerations around the use of what may be perceived as intrusive procedures required for evaluation purposes. Perceptions of providers were predominantly used as a proxy for client feedback, and these suggested that there were significant benefits for clients in the provision of more holistic and individualised, appropriately targeted care, and a reduction in the burden of care for carers.

Care planning for end of life
Approximately a third of all projects addressed end-of-life care planning, including the development of pathways, skills, resources and advance care directives. These were primarily projects working in residential aged care. One of the main messages arising from the projects is an increased awareness by the sector that palliative care is core business for aged care facilities. This is now reflected in the funding arrangements, with the ACFI now including a complex care category which includes palliative care. Fundamental to these processes is the development of a care pathway, appropriate assessment, management and ongoing monitoring of care needs, particularly around pain relief.

Care pathways essentially provide a structured approach to providing individualised care for people who are dying. As Power explains, 'their growing popularity reflects the emergence of new modes of governance in the context of a shift away from trust in professional expertise to confidence in systems and auditable rules and procedures' (Power, 1997, cited in Allen, 2009, p. 354). This focus on the individual, rather than the provider, is demonstrated through the use of evidence-based assessment tools to monitor and manage client needs and the inclusion of end of life decision making tools, such as advance care plans/directives (ACDs). The approach includes the participation of relevant disciplines in developing the care plan, as well as addressing spiritual and pastoral care matters. Clients and their carer/families are pivotal to this process and projects based in RACFs had a higher rate of client participation and/or representation in their case conference or care planning discussions than those undertaken in other contexts.

One of the major benefits of improved end-of-life care has been the ability of the client to remain in their home/aged care facility to die. A number of projects demonstrated reduced transfers to hospital for end-of-life symptom management, as well as improved use of pain assessment tools and appropriate medications. This suggests significant benefits for clients, as well as for providers and the health and aged care systems more generally. A number of projects reported increased feelings of confidence by staff in discussing end-of-life issues and providing end-of-life care; facilities also had reduced staff turnover, suggesting an impact on staff morale as well. A reduction in transfers to hospital and hospital stays is also likely to result in cost savings for the health system, although no project included calculations of cost savings in their evaluation reports.

Competence and confidence of staff
Improvements in care planning and delivery has only been achieved through significant amount of education and training provided by projects, underpinned by the development of appropriate resources, protocols and processes. While the overall reach of educational activities is not clear from the project evaluation reports, we do know that this was a major part of their activities. The education and training was provided in both formal and informal processes, including structured education programs, competency-based training packages, in-service sessions and access to existing industry opportunities, as well as through mentoring, supervision and action learning through participation in MDT meetings and multidisciplinary forums.

The education and training was predominantly designed to enhance the implementation of new models of care or processes, such as multidisciplinary considerations, care planning approaches, assessment tools, and end of life care. The main target groups appeared to be staff of RACF and health services, and participants were provided with in-house learning opportunities or a location near by, and placements with specialist services. The outcome has been a significant improvement in the capacity, competence, and confidence in staff providing care, which has been evidenced in the survey, focus group and audit results presented in the project reports. It can be deduced from these findings, that these educational efforts have resulted in improvements for

clients and their carers, and this is supported by those projects which did include consumer feedback in their evaluation strategies.

The importance of a skilled and confident workforce cannot be underestimated, particularly in high care residential aged care where the needs of residents are increasingly complex and end-of-life issues are a daily occurrence. The facilitation of care planning is a complex process, and staff are 'not passive processors of different interests, but active mediators who displayed considerable skill in negotiating a space in which different frames of action could coexist by finding creative solutions in which they could be brought together while at the same time kept separate to contain the potential to pollute' (Allen, 2009). This suggests that a focus on supporting staff involved in care planning, through the provision of appropriate resources, training and systems, is critical to ensure sound outcomes for clients and residents around whose needs care is planned.

Targeting specific population groups
The sub-program provided the opportunity for a number of projects to focus on specific population groups, such as residents of aged care facilities, people with dementia, indigenous populations, children, adolescents and young adults, and people with chronic heart failure. There was a critical mass of projects targeting RACFs, and these were encouraged to network with each other, sharing experience, knowledge, resources and, potentially, evaluation tools. Sector-wide issues were canvassed at national workshops, as well as through the development of an email list-server and projects were encouraged to participate in sector-specific initiatives such as conferences. While a significant number of resources, tools and processes have been developed for residential aged care staff, it was not possible to draw any conclusions about the overall impact on the sector from the evaluation findings, due to the variation in tools used, and data presented in the project final reports. As noted previously, it is clear that this sector is likely to require ongoing coordinated support, given the increasing recognition that the majority of residents will require end of life care.

The specific needs of indigenous populations with end-stage renal disease were also addressed, resulting in the development of resources, strategies and processes that have been embedded into a new service across the region. Less successful were those resources developed for aboriginal carers, which remain in draft form due to decisions by project managers to focus on development of project initiatives, and not on the implementation.

Funding was also provided to develop care planning resources for children, adolescents, young adults and people with dementia and chronic heart disease. Together with the Aboriginal renal project, these have undertaken ground-breaking work to identify the evidence around best practice, engage with the broad range of client groups and stakeholders, and developing strategies and resources that meet their various needs. The focus of these projects has primarily been developmental, and most will require ongoing support to further test and better articulate models of care that will meet the complex needs and service arrangements required for these population groups.

10.2.4 Facilitating partnerships – organisational and system issues

As noted above, the development of partnerships has been critical to the delivery of care for palliative clients and their carers. A number of formal processes were used by the projects to facilitate these relationships, including Memoranda of Understanding, service agreements, and Terms of Reference of steering committee meetings. Most projects used one or another of these formal strategies to engage stakeholders, while some also used informal processes such as communication tools and protocols, referral mechanisms, and financial incentives.

Formal agreements
The use of MOU or service agreements has become increasingly popular as a means to ensure the cooperation and participation of relevant partners around an agreed goal. This was an explicit requirement in a number of funding agreements for care planning projects. The premise is that signatures represent a negotiated relationship which binds the parties, and in the majority of cases this occurred. There were a number of projects, however, for which this process was not

successful, and which caused considerable delays in achieving the agreed project outcomes. Theoretically, these agreements are contractual arrangements, however, there is no actual means of enforcing them apart from the moral incumbency it places on the stakeholder; and this does not always have an impact. The reasons for this dissonance were usually around the differing agendas of stakeholders which were not clearly agreed at the outset, and the perceived power dynamic in the local service network. As Allen reminds us, 'care pathway development brings to the surface many of the tensions they are designed to resolve (Pinder et al., 2006, cited in Allen, 2009) and like other formal tools, the order embedded in the end product contains much of the messiness it set out to erase' (Berg,1998, cited in Allen, 2009, p. 360). The key message here is that reliance of formal mechanisms to establish partnership between services may be misplaced; these relationships need to be negotiated according to the local context.

Engaging GPs
Primary care providers are regarded as critical partners in the provision of palliative care, this is explicitly addressed in the *Guide to Palliative Care Service Development* cited above. This is echoed in the recent report by the National Health and Hospitals Reform Commission (2009), which strongly argued that '**strengthened primary health care services** in the community should be the 'first contact' for providing care for most health needs of Australian people' and recommended there should be 'a focus on **integrating multidisciplinary primary health care services'.** It goes on to recommend that 'we need to build the capacity and competence of primary health care services to provide generalist **palliative care support** for their terminally ill patients, supported by additional investment in specialist palliative care services to allow better access to care for people at home' (NHHRC, 2009, [Commission's emphasis in bold])**.**

A number of projects developed strategies to enhance the ability of general practitioners to provide palliative care. Some of these were undertaken by Divisions of General Practice, while others recognised the need for their engagement in the care planning process, and sought ways to include them in the models of care and processes being implemented. On the whole, this proved more difficult than expected. The major impediments to GP involvement appeared to be around resource constraints, and a number of projects introduced specific strategies to address these. Examples include the inclusion of the GP by telephone in case conferences , which were booked into their diaries, with GP issues prioritised for discussion; and the inclusion of a GP 'advocate' to chair MDT meetings, who also had the capacity to influence colleagues in the region. A number had envisaged that the attraction of a Medicare rebate would be an incentive for GPs to participate, however, this alone was not sufficient; projects which undertook to prepare the necessary paperwork, including providing the correct rebate number, were generally more successful in engaging GPs in their processes. This raises significant implications for a service delivery model that places such a strong emphasis on the role of the general practitioner. Without additional support to organise, communicate with stakeholders, facilitate meetings (including relevant paperwork and report writing) it is unlikely that GPs will be able to take on this pivotal role.

Engaging RACFs
Similarly, it was expected that the introduction of ACFI, with its additional category of funding for complex care (e.g. palliative care) would encourage RACFs to adopt more evidence-based approach to care planning. At the time of reporting, however, no project had indicated the extent to which this had been a factor for decision-making, and what impact, if any, it had made on overall resources for care. However, a number of positive outcomes did arise for those RACFs which were involved in care planning project activities. In addition to the capacity, competence and confidence discussed earlier, a number of organisations had integrated educational materials and new processes developed into their policies, and were actively engaged in seeking to continue these impacts beyond the life, and geographic context, of the project. The sustainability and spread of project findings is likely to be more easily achieved when the host organisation is part of a larger network, and where systems are in place to facilitate sharing of lessons learned, e.g. through a special interest group, organisational conference or website. Benefits for RACFs also included the increased capacity of staff to undertake research and implement evidence-based best practice, improved morale and reduced staff turnover, greater clarity for staff in terms of end-of-life

care through the uptake of advance care plans, and the reduced number of hospital transfers for people with end-of-life care needs.

A number of recent initiatives indicate the greater recognition of the importance of RACFs in being resourced and supported to provide palliative care. Three projects have received funding under the Encouraging Best Practice in Residential Aged Care (EBPRAC) Program to improve clinical practice in providing palliative care, however, these projects are time-limited and localised, and at the time of reporting there are no clear indications how their outcomes will be integrated into practice across the sector more broadly. The National Health and Hospitals Reform Commission included a number of recommendations aimed to improve the capacity of RACFs to provide end-of-life care, including strengthened access to specialist palliative care services for residents (Recommendation 55) and funding to implement advance care planning (Recommendation 56). We can only concur with these recommendations, to ensure that this sector is appropriately resourced in terms of skills development and opportunities to apply evidence-based practice, as well as financially through the relevant funding mechanisms, to be able to respond to the wishes and needs of residents requiring end-of-life care.

Access to resources
In addition to the financial and educational resources already discussed, there will continue to be the need for information to be made readily available, particularly to generalist service providers after hours. A number of projects trialled a triage and referral service, which included this aspect, however the reports did not provide clear evidence regarding the success or appropriateness of this model. Access to data bases and information about clients by relevant after-hours services, such as community nurses and emergency departments, may prove to be a more appropriate model in some contexts, and with the improvement in technology and communications, is likely to become more accessible in the future.

A small number of projects developed strategies to harness the assistance of volunteers, particularly in the provision of pastoral care support. These were found to have very positive outcomes for clients, carers and staff, as well as the volunteers themselves. A clear message from the projects, however, was the need for appropriate recruitment, education, supervision and ongoing support for volunteers.

10.2.5 Improving care planning – program management and evaluation

In addition to care planning, a focus of the sub-program was to encourage best practice both in project management and self evaluation. This was implicit in the appointment of the NET which had as its role both project support as well as program evaluation. Over the course of the sub-program the NET was able to identify a number of themes which seemed to impact on the success or otherwise of projects, particularly around governance arrangements, project officer skills and resources, and management support.

The sub-program was characterised by a significant proportion of the project officers employed being experienced clinicians who had taken on the project in addition to, or on secondment from, their primary employment. The majority had little project planning, stakeholder management and evaluation experience. This was particularly evident during the initial site visits and national workshop, where a number had not seen or understood the significance of their funding agreement, which outlined what they had been contracted to achieve. Consequently, considerable effort was expended on providing assistance and guidance on project planning and evaluation techniques (especially in the first half of the sub-program), data analysis and report writing (the latter half) and facilitating networks to encourage shared learning (through-out the project). In addition, a number of projects required significant moral support, particularly where there were difficult stakeholder relationships to manage, unclear or unsupportive governance arrangements. The exit interviews revealed that for a number, the early part of the project had been quite overwhelming, but by the end they felt they had much greater competence and confidence in

project management. This represents a positive outcome in building capacity amongst clinicians to undertaken research and project management.

This suggests there could be greater clarity at the outset regarding expectations for project management, stakeholder negotiation, evaluation techniques and reporting requirements, and where support is required to achieve this, it is explicitly built into project and program budgets.

10.2.6 National leadership in care planning

The Australian Government has provided national leadership in palliative care through its funding and support of the National Palliative Care Strategy, in conjunction with States and Territories. The NET is aware that a review of the Strategy is planned for the near future, and there are opportunities to continue to provide leadership in this area. In addition, as noted above, the National Health and Hospitals Reform Commission recently reported to the Australian Government and includes a number of specific recommendations to improve end-of-life care (recommendations 54-57), as well as a range of related recommendations which are also likely to have a positive impact on end-of-life care for clients, carers and providers alike: access to information (recommendation 12), carer support (14), primary health care (16,17, 20, 21), and aged care (45, 46, 50, 51, 52).

Critical to the development of future initiatives will be the engagement of all levels of government to ensure health services and systems work in partnership to provide client-centred care for people with palliative needs. In addition, it is clear from the projects that the scope of sectors needs to be extended beyond health, and include aged care, community care as well as carer support programs.

11   Conclusion

The Care Planning Sub-Program has delivered on the development of a community of practice for care planning, at a number of levels. Thirty three projects have built capacity in a range of care settings, producing educational materials, resources, processes and protocols as well as partnership arrangements which will continue to have an impact beyond the life of the sub-program. In the large majority of cases, projects have utilised best-practice approaches, aligning activities with the Palliative Care Standards, incorporating evidence-based approaches and developing competency-based educational resources. Many of the projects articulate a model of care which is consistent with contemporary national directions, including a focus on building capacity of generalist services, facilitating partnerships and access to specialist support, and promoting end-of-life care that aligns with clients' wishes.

There were a number of obstacles identified during the sub-program, primarily around skill sets and capacity of staff, project management and evaluation, stakeholder management and governance arrangements, which impeded the ability of some projects to achieve their objectives to the extent they had wished. The inclusion of a program support role within the remit of the national evaluation was a critical factor in enabling these barriers to be overcome, or alternative strategies to be identified. The NET was able to facilitate the development of networks within the sub-program, and between individual projects and the broader palliative care sector, with a number of these relationships continuing after their involvement with the sub-program ended. Therefore, we can confidently say that the whole of the sub-program has been very much more than the sum of its 33 individual parts.

That said, there is a clear need for a continued national leadership and support to ensure the achievements of the sub-program are not lost, including opportunities to maximise exposure of the project outcomes and assisting in the translation of the evidence into policies and programs of health and related care services. Critically, there is a need to ensure that the voices of clients and their carers are better incorporated into these processes.

12 Recommendations

The experiences of the national evaluation team and that of the individual projects have identified a number of opportunities for improvement in the management of programs, as well as the care planning, and these are discussed below.

12.1 *Recommendations for best practice in project management and evaluation*

In the following section we outline recommendations to encourage best practice both in project management and self evaluation. This is based on what the projects have reported in their exit interviews, their project final reports and includes comments from the NET discussed throughout this report.

Most of the program management and evaluation practice established and implemented throughout the sub-program was effective. The following are recommendations for improvements at the project and program level.

12.1.1 Project level recommendations

Application process: The submission timeframes are set outside the Christmas / New Year period to enable projects to develop a consultative and thorough document.

Application and/or contract requirements: For future programs the application and/or contract could be enhanced by including some other components as listed following.

- Dissemination: A requirement to disseminate is included in the application guidelines or project contract. This could include each project completing a 'dissemination or communication plan', either as a stand alone document or perhaps as an activity in the project plan, and then keeping the dissemination log and report progress on the dissemination activities. This would ensure that all projects are aware of this requirement so that they can plan and budget for dissemination activities.

- Risk management: Some DoHA programs, such as EBPRAC, include a section in the application form to list risks and management strategies. For the successful projects, a risk management plan is then required with the initial set of deliverables and then this is reported in the progress reports. This process helps projects to consider potential problems and have strategies at the ready to implement.

- Final report: A final reporting template was included as a deliverable for all projects in this sub-program. Rather than a table format, perhaps the requirement is changed to ensure that a more comprehensive summary of the project is documented. This would assist with dissemination and generalisability of the projects. This needs to be clearly stated in the application guidelines or project contract to allow the projects to ensure that they plan for this deliverable in terms of time but also skills to be able to complete the final report to a certain standard (such as for CareSearch). Perhaps for future programs a clear document could be provided to guide projects by, for example, stating the potential time frames for final report writing (for instance, allow six weeks for final report writing), with a completed example report and/or the template modified to include standard responses to particular questions as a guide.

- Evaluation plan and activities: Evaluation section is included in the application form and guidelines outlining the requirement for each project to conduct a project level evaluation, and requesting a budget line for evaluation activities in the application. Application guidelines are written to explain what evaluation is required to assist projects in this process. Project evaluation is considered as an integral component of the project process, not an added extra.

Project selection: There are three suggestions for consideration in the project selection process.

▪ Geographical boundaries: Careful review of geographical boundaries to be aware of, and if appropriate, reduce the number of projects with overlapping regions.
The exception may be when there are projects that are geographically isolated.

▪ Panel membership: Select a broader representation of related DoHA and State / Territory programs, and a detailed examination of the purposes and methods of proposed projects to ensure these complement, rather than duplicate, previous projects and resources.

▪ Evaluation: The organisation's capacity to deliver not just a worthwhile project but also a high quality evaluation is considered in the selection process.

Project planning: The project plans needed to be written in enough detail so that they can be reviewed to ensure that the tasks planned are realistic and achievable in the time frames, with the resources provided.

Project officers (recruitment and retention): Projects are provided with guidelines to ensure the support of project officers, such as an orientation process, adequate office space and equipment, and ongoing support and/or mentorship. This may include information (or a manual) on the skills and possible resources required to manage a project (such as MOU templates), and lists options such as contracting in evaluation expertise and/or report writing assistance, and lists possible training programs (e.g. program management).

Organisational support / partnerships: Applications should include a demonstrated history of providing organisational support for initiatives, and evidence of their capacity to develop and maintain partnerships.

Project evaluation planning and implementation: An evaluation plan is included either as part of or attached to the project plan as a mandatory deliverable. Rather than adding evaluation tasks to a project plan at a later date, it would be preferable to build evaluation into the process from the start. This would mean including evaluation plans, strategies and tools in the final project plans. Rather than simply documenting whether project activities have been completed (i.e. process evaluation), the plan should include details of the kinds of impacts and outcomes expected and how these will be measured. Completion of project plans including evaluation activities and tools could be part of the developmental phase. It could be that the national evaluator reviews and supplies comments on the evaluation plans for DoHA to 'sign off', prior to project commencement.

Project evaluation tools: Certain evaluation tools could be mandated for projects to use. Although the projects are diverse, there are coherent themes within the program, and the consistent use of some tools would have allowed some aggregation of data across the program and facilitated comparisons among projects.

Project ethics process: A requirement of projects to obtain ethics approval could be included in the application guidelines and in the project contracts.

Project evaluation training: Information and education on evaluation requirements and methodologies is provided by the national evaluator. This could be at the first workshop or at state workshops, depending of the needs.

Information and education on writing up evaluation results for final reports is provided by the national evaluator. This could be at the second or third workshops or state workshops.

Project resources i.e. timing and funding: Projects incorporate recruitment and project establishment costs in terms of time and money, as well as report writing requirements, in their applications for funding and project planning.

Project activities:
- Literature reviews: Depending on the program focus, a generic literature review could be undertaken as a first step, which could be used by all the projects.

Project reporting: One template is developed and distributed early on in the project that includes the program (i.e. contract) and the evaluation reporting requirements.

Project sustainability, generalisability and dissemination: The sub-program application focused on sustainability, generalisability and dissemination but this was not monitored or reviewed by DoHA except through the national evaluation report. This report is based on what the projects said would happen. If this is a priority it might be useful to conduct a follow-up, such as an on-line survey (Scheirer et al., 2008), where they obtained details on what have been sustained and disseminated (after the funding has ended). If the project's final reports and /or resources and tools are posted to Care Search, it may be useful to monitor if they are accessed and if possible track if they are used in other settings / services / sectors.

12.1.2 Program level recommendations

Linkages across the Palliative Care Programs: Future programs should include a requirement to link individual program across the Palliative Care program (PCOC, PEPA, NSAP, RPCP, etc) plus across the Commonwealth (EBPRAC) and across each jurisdiction (e.g. NSW Health Representatives at State Forums).

Program activities: There are a number of program activities that would be recommended for future programs.

- Site visits: Site visits are continued in other programs. One site visit to all projects in the start up period. This needs to be flexible due to potential (and inevitable) recruitment delays. Plus the additional visits for the second and third years to allow follow-up visits for projects with issues such as new project officer, or data collection or report writing. First time project officers may also need a second visit, depending on their local support systems.

- Regular telephone contact: The phone calls which followed each six-monthly progress reports would be a useful communication and support process for other programs.

- Workshops: The annual workshops achieved a number of aims and would also be recommended for future programs.

- State forums: The State Forums were a new initiative for the sub-program and would be recommended for future programs with the change that all projects are included in a forum. Consideration needs to be given to the commonality of the projects, and well as their geographical location. If state based, then the inclusion of state / territory representatives would be recommended. Formal leadership, with more detailed implementation guidelines may improve the forums.

Communication within the program: DoHA provides information about other programs and their contribution to the national strategy to ensure all funded projects and their evaluators are aware of other current and recent developments.

Strategic management of the program: A significant number of projects have indicated their sense of isolation in a professional and geographic sense. This suggests that there are opportunities for a more strategic approach to project selection and overall project management, by ensuring that projects are linked into existing service and policy contexts. For example, there appears to be a strategic approach to project selection and needs identification, as well as program management (i.e. co-ordination) in Victoria, with strong involvement of the Department of Human Services and the lead role taken by Palliative Care Victoria (PCV). Such an approach is

also likely to have benefits in terms of generalisability, and capacity building, as well as enhancing prospects of sustainability.

Program dissemination: There may be opportunities for DoHA, as funders and administrators of the Care Planning Sub-Program, to take a more active role in engaging key stakeholders and informants around the objectives, opportunities and processes – as well as outcomes - of the sub-program. This would facilitate a receptive context to the work being undertaken at the local level by individual projects, and enhance the potential for project outcomes to be sustained beyond the life of the sub-program.

Care Planning Evaluation reports: The final reports should be made available to the sector, as these reports provide important lessons in terms of project management, evaluation, dissemination, and sustainability, as well as facilitating a more receptive context to the application of project outcomes.

National evaluation role: If the national evaluator was contracted earlier, then they could be part of the project selection process – such as a technical advisor for evaluation and other relevant components. They would also be able to develop or obtain common evaluation tools that could be used across all the projects.

12.2   *Recommendations for best practice in palliative care planning*

In the following section we outline recommendations to encourage best practice in care planning. This is based on what the projects have reported in their exit interviews, their project final reports and includes comments from the NET discussed throughout this report.

12.2.1 Focus on clients

Client involvement in decision-making
Projects need to provide greater opportunity for client, family and carer involvement in the strategies, processes and resources they are developing, to ensure these are responsive to their needs and facilitating a sense of partnership in the provider/client relationship. This includes having meetings which are accessible in terms of timing and location and improved communication processes, especially in relation to decisions regarding care planning.

Carer considerations
Further work needs to be done on articulating carers' needs and developing appropriate responses to reduce their burden of care, improve access to information and support. The current network of carer support services should be enhanced to better cater for carers of people with palliative needs.

12.2.2 Models of care that place client at centre

End-of-life care
Greater emphasis needs to be placed on providing mechanisms so that clients, families and carers are able to make informed decisions about their end-of-life care, including through the promotion of advance care directives and plans. Providers need to be skilled in engaging in discussions about options, assessing and managing end of life care needs, and organisations need to provide the contexts and policies to support clients' wishes regarding end of life care. This is consistent with recommendation 56 of the NHHRC report regarding advance care planning.

Control over information and improved communication
Clients should be provided with information about their clinical and care needs in a way that is accessible and does not require duplication of effort. Ideally, this would be in the form of an electronic health and care record that would be owned and controlled by the client, and accessible by those partners involved in the provision of clinical, care and support. This is consistent with recommendation 13 of the NHHRC report regarding electronic health records.

Multi-disciplinary approach to care planning
Care planning needs to be conducted in a multi-disciplinary context, in recognition of the range of clinical and care needs that clients may have. The attributes of the case conferencing need to include a good broker/facilitator to build relationships; the right decision makers at the table with a commitment to contribute; a clear purpose; good process; and ongoing monitoring. Resources need to be allocated to facilitate case conferencing. There is no clear evidence about which professional group should take on the role of facilitator; this will be best determined and negotiated according to the local context. Consistent with Recommendation 1, processes need to be accessible to clients, families and carers. This is consistent with recommendation 18 of the NHHRC report regarding multidisciplinary services and care coordination for people with chronic and complex conditions.

Education to improve capacity, competence and confidence
A consistent and coordinated approach to palliative care education needs to be provided across all service types, building on the numerous resources developed during the sub-program. Education should be aligned to the palliative care standards, and encourage the use of evidence based tools and processes. There is an opportunity for national leadership targeting distinct professional groups, working in partnership with state and territory health authorities. This is consistent with numerous recommendations in the NHHRC report, particularly those relating to a national education and training initiatives for clinicians (e.g. 100, 101 etc) and end of life care (57).

12.2.3 Targeting specific population groups

Groups addressed within the sub-program
There is an opportunity to build on the ground-breaking work targeting specific population groups, such as Aboriginal, rural and remote communities, children, adolescents and young adults, and chronic heart failure. The models, tools and resources developed should be further developed (if necessary) and promoted within the relevant sectors. Funding should also be provided to ascertain whether there are elements of the models which could be used across different chronic illness groups.

Groups not addressed within the sub-program
People from culturally and linguistically diverse (CALD) groups were not specifically targeted by any of the care planning projects. Consideration should be given to ascertaining the appropriateness and relevance of the models, tools and resources developed for these diverse groups, and what additional factors need to be taken into account to ensure culturally appropriate end-of-life care is provided.

12.2.4 Importance of partnerships

Fundamental to the provision of quality care planning and end-of-life care is a partnership between clinicians, care providers and clients, their families and carers. The relationships at the provider level may be enhanced by formal service agreements, but this is not guaranteed. Successful partnerships have to be negotiated and differing roles recognized as having equal value, and these need to be underpinned by agreed goals, processes (e.g. referral mechanisms) and sound communication strategies.

12.2.5 Primary health care

General practitioners have a vital role in providing clinical care for the majority of people who need palliative care; however their ability to work in partnership with other stakeholders is hindered by resource and time constraints. The Medicare items are not sufficient incentives to encourage GP engagement in coordinated care planning. Additional resources are required to facilitate their engagement at the local level as well as facilitate access to specialist support and advice, especially in rural areas. This is consistent with recommendations in the NHHRC report e.g. 21

regarding Primary Health Care Organisations; 54 regarding Primary Health Care Centres; and, 66 regarding referral and advice networks for rural GPs.

12.2.6 Residential aged care facilities

Education
It is clear that palliative care is core business for residential aged care services, and these services are likely to increase as the population ages and people with chronic disease and complex care needs live longer. Staff need to be skilled in using evidence-based tools and have the confidence to have discussions with clients and families regarding end-of-life decisions, and the competence to provide end-of-life care that is in accord with residents' wishes. Significant work is already underway regarding improving evidence-based clinical practice through the EBPRAC program, Aged Care Accreditation Agency Better Practice initiatives, and other programs. A coherent national framework aimed at providing competency-based education, which facilitates access to further tertiary education if desired, is needed to ensure a consistent approach to and quality of end-of-life care in RACFs. This is consistent with recommendations 51 of the NHHRC report regarding staff training in advance care directives.

Organisational support
Policies and procedures need to be embedded to facilitate the provision of end of life care which is in accord with residents' wishes. This includes the use of Advance Care Plans, access to specialist resources, facilitating communication between staff (e.g. through handover time), and access to education and training (e.g. incorporating into work time and practices), as well as providing a suitable context for residents which allows the engagement of family members during the end of life period. This is consistent with recommendations of the NHHRC report e.g. 57 regarding advance care directives; 52 and 55 regarding access to specialist support and resources; and, 53 regarding electronic health records.

Appropriate resources for care coordination
As noted above, case conferencing and care coordination requires additional support and leadership, which needs to be adequately resourced. It is recommended that funding be made available for RACF staff to undertake the assessment and care coordination and planning processes, similar to that available to GPs. This is consistent with recommendation 52 of the NHHRC report regarding access to specialist support.

12.2.7 Information

Clients, families and carers need to have access to information about their health status, in order to anticipate and plan for future care needs. A consistent and coordinated approach to the provision of information needs to be provided across all service types, building on the numerous resources developed during the sub-program. This is consistent with recommendations 9, 13 and 14 of the NHHR report regarding improving access to information.

12.2.8 Supporting volunteers

There is significant value in having a volunteer network support the role of formal care providers, particularly in RACFs. A structured approach is required to the recruitment, education, supervision and ongoing support of volunteers. A consistent and coordinated approach to the development of volunteer networks should be developed, building on the resources and processes established during the sub-program.

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