



# Providing Palliative Care in Rural Australia: results of a national program evaluation

*Providing Palliative Care in Rural Australia: Results of a National Program Evaluation*

Centre for Health Service Development



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## Common abbreviations used in this report

ADGN	Australian General Practice Network (previously the Australian Division of General Practice)
CCP	Caring Communities Program
CHSD	Centre for Health Service Development
CME	Continuing Medical Education
CNC	Clinical Nurse Consultant
CPD	Continuing professional development
DGP	Division of General Practice
DoHA	Department of Health and Ageing
DON	Director of Nursing
EPC	Enhanced Primary Care
GAPS	Griffith Area Palliative Care Service
GP	General Practitioner
HREC	Human Research Ethics Committee
IT	Information Technology
MPS	multipurpose service
MSOAP	Medical Specialist Outreach Assistance Program
NET	National Evaluation Team
PCS	Palliative Care Service
PCT	Palliative Care Team
PEPA	Program of Experience in the Palliative Approach
RACF	Residential Aged Care Facility
RN	Registered Nurse/s
RPC	Rural Palliative Care
RPCP	Rural Palliative Care Program
RUG-ADL	Resource Utilisation Groups Activities of Daily Living scale

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## **Part One – Background and Methodology**

# 1 Introduction

Palliative care services in Australia are provided across a range of inpatient, outpatient and community settings by a mix of specialist and generalist providers from the public and private sectors. The range of services and models of care are strongly influenced by geographical dispersion. The ability of patients and their carers to move freely between settings and providers, which is generally assumed to be essential for quality and continuity of care, is variable with patients in urban areas generally having more choices.<sup>1</sup>

There is little evidence to guide the provision of palliative care in rural areas and the research that has been done has tended to focus on identifying problems rather than providing evidence to support effective interventions.<sup>2</sup> The work to promote multidisciplinary palliative care in rural and regional areas has included such strategies as:

- enhancing skills available in rural communities with outreach programs and use of telemedicine
- promoting community awareness of and engagement with palliative care
- promoting the role of general practitioners (GPs)
- development of a community hospice
- regular case conferences
- establishment of a palliative care team
- payments to GPs to attend team meetings with other health professionals
- use of an electronic health record for palliative care patients

The Rural Palliative Care Program (RPCP) was built around a core model that included many of these elements (Table 1). The foundation for the model was laid by work in Griffith, NSW, for what came to be known as the GAPS model (Griffith Area Palliative Care Service). Further details of this work have been published (Hatton et al), as have the results of the evaluation of that work (Eagar et al). It was anticipated that most RPCP projects would implement most elements.

**Table 1 Core elements of the rural palliative care model**

<b>Governance and management</b>	<b>Direct Care Delivery</b>
Governance – Clinical, Scientific and Organisational	Common referral criteria
Existing funding and payment arrangements, including EPC	Shared service protocols
Agency partnerships and collaboration	Access line
Role delineation and networking	Patient held medical record
	Multidisciplinary care planning
<b>Management and use of patient information</b>	<b>Professional participation and development</b>
Shared clinical information system	Multidisciplinary participation – medical, nursing, allied, pastoral, volunteer
	Professional education and development

After undergoing a competitive selection process (see Section 3.1), eight Divisions of General Practice (DGP) were funded to run a Rural Palliative Care Project and, in doing so, to test how the GAPS model worked in different regions:

<sup>1</sup> Eagar K, Owen A, Masso M, Quinsey K. *The Griffith Area Palliative Care Service (GAPS): an evaluation of an Australian rural palliative care model. Progress in Palliative Care 2006*; 14(3): 112-119.

<sup>2</sup> Evans R, Stone D & Elwyn G. (2003) *Organizing palliative care for rural populations: a systematic review of the evidence. Family Practice 20*(3): 304-10.

- Adelaide Hills South Australia
- Eastern Goldfields (Kalgoorlie) Western Australia
- Eurobodalla (Moruya) NSW
- Mid North Coast (Coffs Harbour) NSW
- North West Tasmania (Burnie)
- Pilbara Western Australia
- South East Queensland (Kingaroy)
- West Victoria (Ararat)

The projects began in late 2003 and ran for three years. Each project took place in a different context, started from a different point in terms of pre-existing capacity, and implemented slightly different components of the model elements, thus providing fertile territory to inform the further development of knowledge about how best to provide palliative care in rural areas.

This report is one of a series that presents the evaluation findings of the Rural Palliative Care Program at both the overall program level and at the project level. Consistent with the evaluation framework (see next section), it is set out in six parts:

Part One – Background and methodology (page 1)

Part Two – Program level evaluation (page 11)

Part Three – Impact and outcomes for consumers (page 22)

Part Four – Impact and outcomes for providers (page 57)

Part Five – System level impact and outcomes (page 72)

Part Six – Discussion and conclusions (page 82).

Other reports in the series are:

- Lessons from the National Evaluation of the Rural Palliative Care Program: a synthesis of the findings and recommended next steps
- Rural Palliative Care Program: Adelaide Hills Evaluation Report
- Rural Palliative Care Program: Eastern Goldfields Evaluation Report
- Rural Palliative Care Program: Eurobodalla Evaluation Report
- Rural Palliative Care Program: Mid North Coast Evaluation Report
- Rural Palliative Care Program: North West Tasmania Evaluation Report
- Rural Palliative Care Program: Pilbara Evaluation Report
- Rural Palliative Care Program: South East Queensland Evaluation Report
- Rural Palliative Care Program: West Victoria Evaluation Report.

## 2 Approach to the evaluation

### 2.1 Method

The role of the National Evaluation Team (NET) was to evaluate the program as a whole and to evaluate each of the projects within the program. As shown in Figure 1, the evaluation was framed around three levels (consumers, providers and system).

**Figure 1 Evaluation framework**

What did you do?	How did it go?	Can you keep going?	What has been learnt?	Are your lessons useful for someone else?	Who did you tell?
Level 1 Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)					
<ul style="list-style-type: none"> <li>Direct Care Delivery</li> </ul>	<ul style="list-style-type: none"> <li>Patient impact</li> <li>Carer impact</li> </ul>	<ul style="list-style-type: none"> <li>Sustainability assessment</li> </ul>	<ul style="list-style-type: none"> <li>Capacity Building assessment</li> </ul>	<ul style="list-style-type: none"> <li>Generalisability assessment</li> </ul>	<ul style="list-style-type: none"> <li>Dissemination log</li> </ul>
Level 2 Impact on, and outcomes for, providers (professionals, volunteers, organisations)					
<ul style="list-style-type: none"> <li>Governance</li> <li>Direct Care</li> <li>Patient information</li> <li>Professional development</li> </ul>	<ul style="list-style-type: none"> <li>GPs</li> <li>Other primary care providers</li> <li>Specialist palliative care providers</li> </ul>	<ul style="list-style-type: none"> <li>Sustainability assessment</li> </ul>	<ul style="list-style-type: none"> <li>Capacity Building assessment</li> </ul>	<ul style="list-style-type: none"> <li>Generalisability assessment</li> </ul>	<ul style="list-style-type: none"> <li>Dissemination log</li> </ul>
Level 3 Impact on, and outcomes for, the system (structures and processes, networks, relationships)					
<ul style="list-style-type: none"> <li>Governance</li> <li>Direct Care</li> <li>Patient information</li> <li>Professional development</li> </ul>	<ul style="list-style-type: none"> <li>System level impacts</li> <li>External relationships</li> </ul>	<ul style="list-style-type: none"> <li>Sustainability assessment</li> </ul>	<ul style="list-style-type: none"> <li>Capacity Building assessment</li> </ul>	<ul style="list-style-type: none"> <li>Generalisability assessment</li> </ul>	<ul style="list-style-type: none"> <li>Dissemination log</li> </ul>

A set of evaluation tools (the RPCP Evaluation Toolkit) was developed<sup>3</sup>. Some of these tools were designed for use across all sites. The remaining tools were included in the toolkit for discretionary use at the site level and are not reported here. Information about the toolkit can be found in Section 2.2.

The development and use of these tools was just one part of the evaluation. Table 2 below summarises the overall methodology employed and each of the steps involved. The evaluation employed a mix of qualitative and quantitative methods and was approved by the University of Wollongong / Illawarra Area Health Service Human Research Ethics Committee.

**Table 2 Summary of the evaluation methodology**

Activity	Description and comments
Activity 1	<p><b>Activate evaluation.</b></p> <p>This involved initial meetings with the Department and the AGPN to gain a shared understanding of the requirements and the proposed methodology</p>
Activity 2	<p><b>Ethics</b></p> <p>Obtain Ethics Committee approval for the Program-level evaluation from the University of Wollongong Human Research Ethics Committee (HREC) and other relevant Ethics Committees as required</p> <p>This involved working with and supporting each of the projects to ensure that each project was ethically sound and compliant with ethical requirements in their local jurisdiction.</p> <p>As part of the process, we provided access to those projects without access to their own ethics committee the opportunity to submit an ethics application to the University of Wollongong HREC.</p>

<sup>3</sup> This toolkit was substantially based on evaluation tools originally developed for the evaluation of the national Caring Communities Program (CCP).

Activity	Description and comments
	<p>We developed an information consent form for use by participant projects, to reduce duplication of effort and to meet the requirements of the HREC and Medicare Australia.</p> <p>We worked with projects in ensuring that appropriate mechanisms were built into their project implementation plans to address ethics issues at a local level.</p>
Activity 3	<p><b>Evaluation Strategy</b></p> <p>Development of a comprehensive Evaluation Strategy by which the Rural Palliative Care Program will be evaluated at both a Program and individual project level.</p>
Activity 4	<p><b>Communication plan</b></p> <p>Develop evaluation communication plan, in consultation with the AGPN, the Department and participant projects as required</p> <p>The focus of the communication plan was on mechanisms to gather and share information pertaining to the evaluation, with a view to ensuring consistency and awareness of evaluation requirements and to promote outcomes generated under the Program.</p>
Activity 5	<p><b>National workshops</b></p> <p>Participate in five national workshops.</p> <p>Work with the AGPN and the Department to determine the final format and timing of each workshop. The workshops focused on issues surrounding evaluation, communication and sustainability.</p> <p>The evaluation team facilitated each workshop and prepared necessary support and information material required.</p>
Activity 6	<p><b>Data collection and analysis</b></p> <p>Identify, collect, maintain and analyse data to inform performance of the Program and projects as agreed under the Evaluation Strategy.</p> <p>This included the development of a RPCP evaluation database.</p>
Activity 7	<p><b>Communication</b></p> <p>Maintain communication with the Department and the Australian Division of General Practice and implement communication plan.</p> <p>This included, but was not restricted to, the collecting of data at the program-level and gathering qualitative data to evaluate the implementation process for the program. It also included the production and distribution of 7 evaluation guidelines for RPCP sites</p>
Activity 8	<p><b>Site visits</b></p> <p>Undertake 6 monthly project level site visits and data collection. This involved six visits per project over the course of the project.</p> <p>Site visits activities included the provision of support in data identification and collection, key informant interviews, focus groups and educational activities.</p>

The evaluation involved four key elements:

- Evaluability assessment of each project
- Site visits
- Data collection and analysis
- National Workshops.

Each of these elements is summarised below.

### 2.1.1 Evaluability Assessment

An evaluability assessment was conducted for each project and reported as a baseline assessment in the *Evaluation of the Rural Palliative Care Program: First and Second Progress Reports*. Six projects were initially assessed as capable of being evaluated. For two projects, North East Tasmania and East Goldfields, it was not possible to evaluate either of these as a

stand-alone project. Both these projects were part of another program, Caring Communities Program.

Each NET progress report included a review of the risks and the evaluability of the eight projects. There were a number of risks for most projects reported along the way. Most of these risks were able to be mitigated, with details outlined in the five progress reports.

The only exception was the Pilbara when, in mid-2006, it was agreed to stop patient-level data being collected. It was decided that it was better and more ethically sound to allow project staff to concentrate on consolidating the gains they had made, rather than worrying about the full data collection requirements for the project.

### 2.1.2 Site visits

The National Evaluation Team planned to conduct 6 monthly project level site visits over the course of the program. There were a total of 41 site visits conducted. These ranged from 3 to 7 visits per project, with most projects having visits from the same evaluation team members over the three years (refer to Table 3).

Site visits activities included the provision of support in data identification and collection, key informant interviews, focus groups and educational activities.

**Table 3 Site visits during the course of the evaluation**

Project	When visited	Total visits	Team member/s
Adelaide Hills	August 2004	5	Alan Owen and Sheila Matete
	July 2005		Karen Quinsey
	Sept 2005		Karen Quinsey
	May 2006		Karen Quinsey
	February 2007		Karen Quinsey
Eastern Goldfields	April 2004	3	Malcolm Masso
	March 2005		Malcolm Masso
	April 2006		Malcolm Masso
Eurobodalla	March 2004	7	Alan Owen and Dave Fildes
	July 2004		Alan Owen and Dave Fildes
	March 2005		Dave Fildes
	August 2005		Dave Fildes
	February 2006		Dave Fildes
	September 2006		Dave Fildes
	December 2006		Dave Fildes
Mid North Coast	March 2004	6	Natasha Posner
	August 2004		Natasha Posner
	May 2005		David Bomba and Karen Quinsey
	Sept 2005		David Bomba
	March 2006		David Bomba
	November / December 06		Malcolm Masso and Karen Quinsey
North West Tasmania	April 2004	6	Natasha Posner
	October 2004		Malcolm Masso
	May 2005		Malcolm Masso



Project	When visited	Total visits	Team member/s
Pilbara	Sept 2005	3	Malcolm Masso
	April 2006		Malcolm Masso
	October 2006		Malcolm Masso
	June 2004		Malcolm Masso
	March 2005		Malcolm Masso
	April 2006		Malcolm Masso
South East Queensland	June/July 2004	5	Natasha Posner
	May 2005		Dave Fildes and Karen Quinsey
	Oct 2005		Karen Quinsey
	May 2006		Karen Quinsey
	November / December 06		Karen Quinsey
West Victoria	May 2004	6	Natasha Posner
	September 2004		Natasha Posner
	March 2005		Dave Fildes and Karen Quinsey
	Sept 2005		Dave Fildes
	March 2006		Dave Fildes
	November / December 06		Dave Fildes

### 2.1.3 Data collection and analysis

The National Evaluation Team collected a considerable amount of data to inform the evaluation of the program and the projects. Guidelines relating to data collection requirements were issued as Evaluation Bulletins and are described in Section 3.5.1.

A RPCP evaluation database was developed to collect any information that could not be collected in the information system selected by the projects.

A system was established to track data received from each project. The system listed all the data tools and items required, with the time lines across each sites. The data were reviewed by site and data quality checks carried out using Microsoft Excel and Access to find missing and/or invalid values. A detailed email was then sent to site coordinators containing the number of records in their database.

The data were analysed and results distributed to the sites and/or presented at workshops.

### 2.1.4 National workshops

The NET participated in five national workshops (October 2003, September 2004, June 2005, May 2006, November 2006). The NET worked with the AGPN and the Department to determine the final format and timing of each workshop. The workshops focused on issues surrounding evaluation, communication and sustainability. The evaluation team facilitated each workshop and prepared necessary support and information material required. The evaluation team conducted evaluations of the workshops and compiled evaluation reports that were distributed to participants and posted to the CHSD website.

More detail on the evaluation can be found in Section 3.5 and Section 3.6.

## 2.2 Evaluation Tool Kit

The Tool Kit developed for the Caring Communities Program was presented to project stakeholders at the first RPC national workshop in October 2003. Project participants agreed at this workshop that the CCP evaluation tool kit should be adopted for use in the RPC but administered in a different way with some tools becoming mandatory. Following this consensus, a final Tool Kit was distributed to each of the RPC project in December 2003 for feedback. No feedback was received that necessitated any changes.

Detailed protocols for use of the tools were discussed with individual projects and confirmed during the first site visit by the national evaluation team (NET). This was also supported by the development of detailed evaluation guides (see Section 3.5). The recommended use of these tools is set out in Table 4. Also highlighted in this table is the location within this report where detailed results from the analysis of these tools can be found.

The use of tools 1.5 and 1.6 (assessing community awareness), 2.2-2.6 and 3.2 (relating to volunteers and other providers other than specialist palliative care services) was optional and results of these tools are not reported in this final report.

**Table 4 Use of evaluation tools in the RPC Evaluation Tool Kit**

No	Tool	Source	Use	Results
<b>Evaluation Level 1: Impact On And Outcomes For Consumers (Patients, Carers, Friends, Communities)</b>				
1.1	Patient / client palliative care stage of illness data set	AAHPC (PCA)	Projects to incorporate in their clinical collection and IT system and routinely collect on all patients.	See Sections 0 and 4.5
1.2	Patient /client experiences – patient questionnaire	Modified from The Patient Outcome Scale (Higginson, I) and the McGill QoL Scale (Cohen R)	To be used as a national evaluation tool through a snapshot survey period at two points during the project, early on and a year later. This tool is relevant for all patients who have been registered with the palliative care service for at least one month. If the patient is not able or unwilling to complete tool 1.2 then the service provider could complete the staff rated version (tool 1.3) in consultation with the patient.	See Section 5
1.3	Patient /client experiences – staff-completed questionnaire	Modified from The Patient Outcome Scale (Higginson, I) and the McGill QoL Scale (Cohen R)	See above.	See Section 5
1.4	Carer experiences with palliative care	1 <sup>st</sup> section by CHSD based on interviews with carers in the GAPS project. 2 <sup>nd</sup> section are from the NSW/Qld ONI tool	To be used as a national evaluation tool through a snapshot survey period at two points during the project, early on and a year later to coincide with Tools 1.2 and 1.3 (see above). This tool is relevant for all carers who are looking after patients who have been registered with the palliative care service for at least one month.	See Section 6
1.5	Community Awareness of Palliative Care	CHSD	Not proposed for use as part of national level evaluation. Projects might wish to use for their own planning or quality improvement purposes.	n/a
1.6	Community Awareness: Remote Aboriginal	Wendy Scott, Kimberley Region Palliative Care Service, Broome, WA	Not proposed for use as part of national level evaluation. Projects might wish to use for their own	n/a

No	Tool	Source	Use	Results
	and Torres Strait Islander Communities	and CHSD	planning or quality improvement purposes.	
<b>Evaluation Level 2: Impact On And Outcomes For Providers (Professionals And Volunteers)</b>				
2.1	Palliative Care providers	Promoting Excellence in End-of-Life Care (modified by the CHSD)	Palliative Care providers in the local area to be asked to complete twice – at project beginning and project end. Providers who resign or leave the area throughout the project to also be asked to complete.	See Section 8
2.2	Volunteers currently working in palliative care	CHSD	Not proposed for use as part of national level. Projects might wish to use for their own planning or quality improvement purposes.	n/a
2.3	New Palliative Care Volunteers	CHSD	Not proposed for use as part of national level. Projects might wish to use for their own planning or quality improvement purposes.	n/a
2.4	People ending their time as a Palliative Care Volunteer	CHSD	Not proposed for use as part of national level. Projects might wish to use for their own planning or quality improvement purposes.	n/a
2.5	Health Professionals Not Working in Palliative Care Services	CHSD	Not proposed for use as part of national level. Projects might wish to use for their own planning or quality improvement purposes.	n/a
2.6	Remote Aboriginal Communities	Wendy Scott, Kimberley Region Palliative Care Service, Broome, WA and CHSD	Not proposed for use as part of national level. Projects might wish to use for their own planning or quality improvement purposes.	n/a
<b>Evaluation Level 3: Impact On And Outcomes On The System (Structure And Processes, Networks, Relationships)</b>				
3.1	Palliative Care Service Self-Assessment	US Center to Advance Palliative Care (modified by the CHSD)	National project manager to complete in consultation with each project management group at two points during the project, early on and towards the end. Any specialist Palliative Care services in the local area to also be invited to complete it.	See Section 9.5
3.2	General organisational survey	CHSD	Not proposed for use as part of national level. Projects might wish to use for their own planning or quality improvement purposes.	n/a
4	Sustainability Tool	Modified from: Hawe H, King L, Noort M, Jordens C and Lloyd B. NSW Health indicators to help with building capacity in health promotion (January 2000) NSW Department of Health	To be completed by national project management team and national evaluation team three times throughout the life of each project (at beginning, mid-point and end).	See Section 12
5	Capacity Building Tool	CHSD	To be completed by national project management team and national evaluation team three times throughout the life of each project (at beginning, mid-point and end).	See Section 13
6	Generalisability Tool	CHSD	To be completed by national project management team and national	See Section 14

No	Tool	Source	Use	Results
7	Dissemination Log	CHSD	evaluation team three times throughout the life of each project (at beginning, mid-point and end). Each project to set up own system and provide a copy of the log every six months with their progress report to DoHA.	See Section 15
8	System level impacts and outcomes of the Rural Palliative Care Project	Modified from the NSW Home and community Care (HACC) Comprehensive Assessment Pilots by the CHSD	Palliative Care providers in the local area to be asked to complete at two points during the project, early on and towards the end. Providers who resign or leave the area in the last year of the project to also be asked to complete.	See Section 16

### 2.3 Synthesis of results

The research team collected a large amount of data from the site visits, meeting with key stakeholders and analysis of data collected as required by the contract between each division of general practice and the AGPN. Rather than report the results for each of these activities separately the results have been synthesised around the following themes:

- governance
- direct care
- shared clinical information system
- professional development and education

## **Part Two – Program Level Evaluation**

## 3 Program delivery

### 3.1 Project selection

In October 2001, health services in Griffith, New South Wales, began a project to improve access to, and the integration of, local palliative care services. The Griffith Area Palliative Care Service (GAPS) project was funded as a national demonstration project with support from the Commonwealth and State governments and the Greater Murray Area Health Service. One motivation for the project was the recognition of various weaknesses in the organisation of services in Griffith. But another, broader, aim was to assess how the National Palliative Care Strategy could be translated into a model of care that is appropriate for rural Australia.

An evaluation report by the Centre for Health Service Development suggested that:

*‘for towns the size of Griffith, with around a dozen GPs, a regional hospital and community services, there appears to be no reason why the GAPS model of care could not be adopted’.*

Such locations would need to have sufficient resources and clinicians to support the essential structural elements within the model of care (case conferences, the 1800-number and on-call nursing roster, the patient held record and shared protocols). For smaller towns, these features would also seem to be workable, though they would need to be tied into a larger area so that on-call/after-hours work could be shared.

The evaluation subsequently proposed that further sites should test which components of the GAPS model are transferable or generalisable to other rural and remote settings.

In response to this, the Department of Health and Ageing (DoHA) contracted the Australian Divisions of General Practice (now known as the Australian General Practice Network, AGPN) in February 2003 to implement the RPCP. The aim was to support several rural Divisions of General Practice to develop and implement collaborative models that, over a three year period, would significantly improve rural community access to quality, coordinated palliative care. A total of \$5 million was made available to support this process. A National Reference Group was established to guide the program.

AGPN sought expressions of interests from rural Divisions of General Practice that were prepared to work in collaboration with other key service providers to develop and implement sustainable models of palliative care based upon the GAPS model. Liaison processes were established with key stakeholders such as state and territory health agencies during the selection process.

Invitations to lodge an expression of interest were sent to all Rural Divisions of General Practice on 17 April 2003. The program was also advertised in the Weekend Australian of 19 April 2003.

In support of this expression of interest phase, an information kit was developed for dissemination to eligible Rural Divisions of General Practice, which included:

- Information on the Rural Palliative Care Program;
- Expression of Interest Guidelines;
- Selection Criteria;
- Expression of Interest form; and
- Background information, including useful website links.

This information was also made available on the AGPN website on 17 April 2003.

By the closing date of 22 May 2003, 26 applications had been received. This represented 41% of the 61 eligible Rural Divisions.

An assessment panel comprising of five members of the National Reference Group was formed to review and consider each application in detail. Their brief was to make recommendations to the National Reference Group about which applicants should be invited to provide a full submission.

Accordingly, the assessment panel recommended that 11 Rural Divisions of General Practice be allowed four weeks to submit full funding proposals in support of their original applications.

Following the receipt of the full funding proposals, the assessment panel recommended that seven of the 11 projects be approved for funding under the RPCP. All recommendations were supported by the National Reference Group and a senior delegate in the DoHA signed off on these recommendations on 22 August 2003. In October that year, the eighth project from Eastern Goldfields Medical Division of General Practice was approved for funding to enable integration of an existing Caring Communities Program.

The final eight sites came from six States and range from 4-7 on the Rural, Remote and Metropolitan Areas classification (RRMA) as detailed in Table 5.

**Table 5 RRMA classification of RPC projects**

RPCP Site	State	RRMA
Mid North Coast Rural Palliative Care Project	NSW	4
Eurobodalla Palliative Care program	NSW	5
South Burnett RPC program	Qld	5
Kalgoorlie-Boulder Palliative Care Community Project	WA	6
Pilbara Palliative Care Coordination Project	WA	7
Adelaide Hills Rural Palliative Care Project	SA	5
West Vic Rural Palliative Care Project	VIC	5
North West Rural Palliative Care Project	Tas	4

**RRMA Classification**  
 4 = Small rural centres with population 10,000 - 24,999  
 5 = Other rural areas with population < 10,000  
 6 = Remote centres with population > 5,000  
 7 = Other remote areas with population < 5,000

Together these sites represent an approximate population base of 500,000 residents which is an estimated 3% of Australia's resident population. The program also covers a geographic area of 1,421,802 square kilometres, which equates to approximately 20% of Australia's total land mass.

The selected project sites were diverse in terms of their geographic location, population size, remoteness and existing systems of palliative care delivery. Each differs markedly from Griffith, NSW. From DoHA's perspective, it was sensible to test the GAPS model in different settings.

### 3.2 Program governance

The Department of Health and Ageing contracted the Australian Divisions of General Practice (ADGP), now known as the Australian General Practice Network (AGPN), to implement the RPCP. In turn, the AGPN sub-contracted the Murrumbidgee Division of General Practice to provide a consultancy service to the RPCP who, in turn, employed the National Consultant. Each of the eight projects funded under the RPCP entered into an agreement with AGPN for the provision of services that included provisions for project governance:



- Prepare and execute a project plan.
- Establish a governance group for the project.
- Formulate and implement a strategy to facilitate receiving advice and providing feedback to community members, consumers, industry groups, health and community care service providers and other stakeholders.
- Provide secretariat support to the governance group.

In addition, the agreements included detailed requirements for direct care delivery, professional participation and management and use of patient information for each project. Each division was required to participate in the external evaluation of the RPCP, primarily by collecting information in a specified minimum data set, and submit six-monthly progress reports.

From a program governance perspective, the RPCP was managed as eight separate projects within the framework of contracts between the AGPN and the individual divisions of general practice. Comments were made by some project coordinators that there was a certain lack of clarity regarding the role of the National Consultant, a view shared by the National Evaluation Team. But the core of the role was as a consultant to the eight projects, not as the manager of the RPCP. The lack of clear responsibility for managing the Program was a structural weakness of this arrangement.

This situation was confirmed by the reporting relationships whereby each project submitted a progress report every six months to the AGPN, which the National Consultant then used as the basis for a similar report to the Department of Health and Ageing from the AGPN. Similarly, the National Evaluation Team reported every six months to the Department of Health and Ageing. There was no 'governance mechanism' whereby the reports from the evaluators, individual projects and the National Consultant could be brought together to reflect on progress to date and, if necessary, make alterations to the direction and implementation of the RPCP. Progress with implementation was largely framed within the context of whether contracts were being met, rather than reviewing progress in a more proactive way to manage the program.

The national workshops did potentially provide a forum that could have been used in this way but this did not eventuate, with the workshops primarily used for information sharing and networking. While this was a valuable activity in its own right, the outcome is that the workshops focussed on the project level, rather than the program as a whole.

Contract management, while important, is only one aspect of program governance. Innovative programs such as the RPCP need a clear national management structure and process that allows for the program to develop and change as experience builds and as lessons are learned. This is critical if a 'Program' is to be more than simply the sum of each of the projects it funds.

### **3.3 Direction of the program and individual projects**

A clear sense of direction is critical to project success.<sup>4</sup> This raises the question of whether each RPC project had clear goals and objectives and the extent to which the goals and objectives matched the aim of the RPCP to promote a multidisciplinary team approach to care delivery and the strategic direction of local providers (health service, Division of GPs) regarding palliative care.

To identify what projects were trying to achieve all project plans (with the exception of the Eastern Goldfields) were reviewed and strategies in those plans categorised into the groups that formed the basis for much of the evaluation – governance, partnership and networking; direct care; professional development and education; and other strategies. The Eastern Goldfields plan was excluded because many components of the RPC model were implemented in that location as part

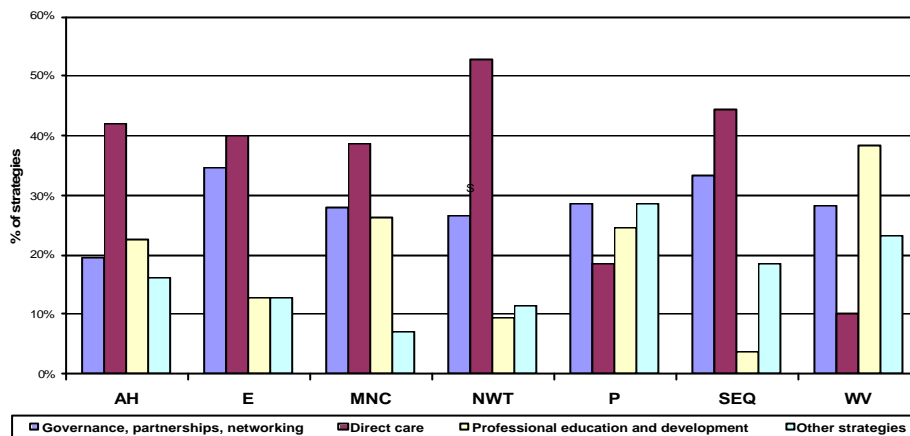
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<sup>4</sup> White D, Fortune J (2002) *Current practice in project management – an empirical study*, *International Journal of Project Management*, 20: 1-11.



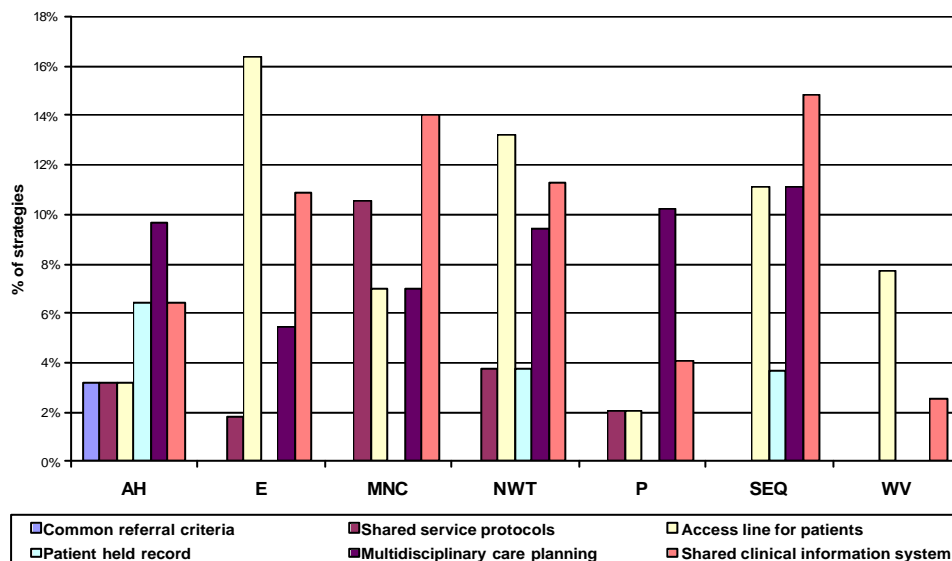
of an associated CCP project. The number of strategies in each plan varied between 27 and 57. Because of this variation the percentage of strategies in each category was used to analyse the relative importance of the different components of the plans. The distribution of strategies is shown in Figure 2.

**Figure 2 Distribution of strategies in RPC project plans**



Differences between projects are particularly evident for direct care strategies, as illustrated in Figure 3.

**Figure 3 Direct care strategies in RPC project plans**



Gauging relative importance from the percentage of strategies in each project plan devoted to an issue has its limitations and the results need to be treated with caution. One strategy may require considerable time and effort to achieve whereas a whole series of other strategies might be relatively easy to achieve. It is not unusual for a project plan to become out-of-date almost as soon as it is written but this is not always reflected in changes to the actual plan. Not including a strategy in the project plan does not mean that a particular issue will not be addressed as the project progresses. However, project plans are one of the principal accountability mechanisms. With these caveats the following results are worthy of note:

- All project plans included strategies to provide education for GPs and nurses to increase their skills and knowledge in palliative care.

- The Pilbara and West Victoria project plans had less emphasis on direct care than other projects.
- West Victoria had a very strong focus on education with 59% of strategies concerned with professional development and education or raising community awareness.
- Only one project plan (Adelaide Hills) included any reference to referral criteria and even this plan makes no mention of having common criteria for all disciplines.
- 21% of strategies in the Mid North Coast are concerned with improving palliative care in aged care facilities. Other project plans had little or no mention of aged care facilities.
- All project plans included some strategies for role delineation and networking but only two include strategies for developing formal arrangements between service partners.
- Inclusion of strategies concerned with the development or use of a patient held record did not feature strongly with four of the project plans including no reference at all.
- Strategies aimed at increasing GP involvement were largely focused on including GPs in educational programs and case conferences.
- Only one project plan (North West Tasmania) included strategies to develop GP hospital admission rights.

The request for submissions to be funded under the RPCP was quite explicit regarding the expectation that projects would be based on the model developed in Griffith with the following components:

- Governance structure
- 24 hour on-call service
- Multidisciplinary team meetings (weekly meetings suggested because the situation of a patient with terminal illness can change quickly)
- Use of EPC items for case conferencing and care planning to shift GPs from short-term, episodic, fragmented, care to a 'whole person care' integrated with other health care providers. EPC items were also seen as a way of funding GPs for their input.
- An integrated patient centred medical record which would achieve greater continuity of care, more efficient use of services and make information readily accessible to patients (in the form of a patient-held record).
- Use of a palliative care information system e.g. PalCIS, SNAPshot
- Links to specialist palliative care services
- Education programs.

Comments by project coordinators at the Adelaide workshop in 2006 indicated that most thought their projects had a clear sense of direction. However, this direction did not always match that of the RPCP. It is not surprising that the two projects (Pilbara and West Victoria) which had virtually no impact on direct care after three years of work were the two projects with the least emphasis on direct care at the beginning. Both projects had the least 'fit' with the aim of the RPCP.

### **3.4 Change management**

Dwyer and colleagues have made some interesting points regarding the management of projects:

- There is a basic paradox with projects - projects are often used to achieve change, but often run into problems because change is not adequately considered in the design and planning phases of projects.

- Stakeholders can be both the subjects and the objects of change – the change makers and the changed.<sup>5</sup>

Those attending the 3<sup>rd</sup> national RPCP workshop (about half way through the Program) indicated that change management issues did not receive much recognition at project commencement, with comments such as:

- ‘Change management was not ‘on the radar’ at the start of the project.’
- ‘We were unaware of change management at the start but it was a key issue working in a hostile environment.’
- ‘We had to change attitudes and behaviour first.’

There was a consensus at the workshop that in future staff working on projects should have an understanding of change management issues and that support for change management is required at project commencement. The review of project plans indicated a reliance on education as the main driver of change.

There is a paucity of useful evidence on which to base a model of rural palliative care and hence clinicians could justifiably argue that a more multidisciplinary team approach is not necessarily better than any other.<sup>6</sup> This results in a Catch-22 that lay at the heart of the RPCP. Lack of evidence is a good argument for undertaking projects such as the RPCP to build a knowledge base for future practice but lack of evidence provides ammunition for those resisting change to a different model of service delivery.

In general, projects faced many challenges because project coordinators were employed by divisions of general practice but the service provision they sought to influence was either provided by individual GPs or staff employed by various public, private or non-government organisations. In some cases there was resentment that funding for the RPC project was provided to divisions of general practice rather than local health services. The issues that emerged in the first 12-18 months of the RPCP tended to focus on the role of clinicians in the project, particularly GPs and community health nurses:

- Local palliative care team not fully engaging as active and willing partners (but rather treating it as a short-term project). The team sees the project as something that will ‘go away’ at the end of the project and until that happens they accept little ownership of the project and engage as little as possible. The team does not participate in educational activities (Mid North Coast).
- Community nurses not engaged in the project, seeing it more as a ‘GP project’ whereby the GPs get the funding and the community nurses are asked to do all the work” (Adelaide and Eurobodalla).
- Delineation between specialist and primary care services has proved to be difficult (NW Tasmania).

Resistance appears to have been a particular issue at those sites with established models of care based on employment of a CNC. As the RPCP progressed some projects (e.g. Adelaide, SE Queensland) developed a momentum for change that was not apparent earlier in the life of the projects.

<sup>5</sup> Dwyer J, Stanton P, Thiessen V (2004) *Project Management in Health and Community Services: Getting Good Ideas to Work*. Allen & Unwin, Crows Nest.

<sup>6</sup> Evans R, Stone D & Elwyn G (2003) *Organizing palliative care for rural populations: a systematic review of the evidence*, *Family Practice*, 20(3): 304-310.

## 3.5 Communication and support strategies

### 3.5.1 NET Communication and Support Strategies

Various activities to help promote communication were implemented by the national evaluation team (NET). They included:

- RPCP Evaluation Bulletins
- RPC Website
- RPCP Evaluation Hotline
- NET site visits

These are discussed in more detail below.

#### RPC Evaluation Bulletins

A series of seven evaluation guidelines were written and distributed to all projects via the AGPN RPC List Server. Each dealt with a specific evaluation issue:

- Evaluation Guide 1: Registering patients in a Rural Palliative Care Project
- Evaluation Guide 2: How to complete the Patient Hospital History Form
- Evaluation Guide 3: Protocol for use of Tool 1.1 (Palliative Care Stage of Illness Data Set)
- Evaluation Guide 4: Protocol for use of Tool 2.1 (Palliative Care Providers)
- Evaluation Guide 5: Tools 1.2 and 1.3 (Patient experiences – patient and staff rated versions)
- Evaluation Guide 6: Collecting Service Utilisation Data
- Evaluation Guide 7: Tool 1.4 Carer Experiences with Palliative Care

Also, an eighth evaluation guide was written which summarised all the data items required for collection, with specific timeframes for submission and the reporting feedback processes per site.

#### RPC Website

Agreement was reached at the inaugural national workshop that the NET should not establish a separate website for the RPC evaluation. Instead, relevant information was placed on the AGPN RPC website: <http://www.adgp.com.au/site/index.cfm?display=683>

Relevant information was also made available on the Palliative Care pages of the Centre for Health Service Development site. These pages include resources relevant to the RPCP projects such as a guide to ethical research in palliative care, another guide relating to the specific issues relating to evaluating palliative care projects and the palliative care evaluation toolkit. [http://chsd.uow.edu.au/palliative\\_care.html](http://chsd.uow.edu.au/palliative_care.html)

#### Evaluation Hotline

The establishment of a 24 hour telephone hotline service was another strategy to facilitate communication between the RPC projects and the NET. The purpose was to allow RPC project officers to ask questions about evaluation issues or to seek assistance or support. It was hoped that this would enable the NET to provide targeted assistance as required. The hotline was established in October 2003 and the telephone number was given out at the inaugural National Workshop.

The hotline was not well utilised by RPC project officers. Previous evaluations undertaken by the NET indicate that there are two possible explanations for this:

- Project officers prefer to liaise directly with their individual NET member rather than get referred on the hotline; and/or
- Calls are not really 'hot-line' type issues that require instant attention and feedback.

### Site Visits

Information about site visits is included in Section 3.6, page 20 (Role of the National Evaluation Team).

### 3.5.2 AGPN Communication and Support Strategies

The AGPN, in consultation with the NET, produced a draft Communications Strategy for the RPC Program. This was first published late in 2003 and was presented in draft form as it was proposed that it would be an 'organic' document that would change to reflect the evolving nature of the program.

The overall objectives of the communication strategy as presented in the document were to:

- Create awareness and understanding of the RPC Program;
- Ensure that the participants are sufficiently supported;
- Provide regular information updates to stakeholders regarding the status of the Program; and
- Clearly articulate the benefits derived from the RPC Program, both on an individual project level and across the program as a whole.

Key strategies proposed to achieve these objectives are included in Table 6.

**Table 6 AGPN communication strategies**

Mode	Means	Specific component	Comments
<b>Person to person</b>	Program consultant	On going assistance for project sites through visits and discussions of needs	Site visits conducted early on in the program
	Program officer	Deal with enquiries over the phone from project sites.	Good level of communication support provided
	Workshops	Networking and information sharing for program participants.	5 workshops held
	Seminars	Presentation and information sharing for program participants and the Divisions Network at the annual Divisions of General Practice Network Forum.	
	Teleconferences	<ul style="list-style-type: none"> <li>▪ Information sessions for program participants.</li> <li>▪ External speakers invited to speak on specified topics. (E.g. EPC)</li> <li>▪ Monthly teleconferences with each individual Project to identify and track issues.</li> </ul>	<ul style="list-style-type: none"> <li>▪ 1 held relating to evaluation data</li> <li>▪ 1 held relating to multidisciplinary team meetings</li> <li>▪ In practice these did not become routine</li> </ul>
<b>Virtual</b>	Website	Regularly updated information about projects, including the potential for an interactive component where participants can pose questions or provide news/updates on their projects.	Website created
	News/information bulletins	Regularly emailed newsletters to which each project will be encouraged to contribute information	7 newsletters produced with regular project contribution
<i>Rural Palliative Care Program Consolidated Evaluation Report</i>			<i>Page 19</i>

Mode	Means	Specific component	Comments
	Email discussion list	Regularly updated information about projects where participants can pose questions or provide news/updates on their projects.	344 emails from 17/5/04 (approx ten per month)
<b>Contractual</b>	Reporting processes	<ul style="list-style-type: none"> <li>▪ six-monthly progress reports</li> <li>▪ communication with DoHA where projects are identified as under-performing or where there is a significant risk for future under-performance</li> <li>▪ Additional ad-hoc information on the progress of specific projects</li> </ul>	<ul style="list-style-type: none"> <li>▪ Reporting cycle established with projects</li> <li>▪ Not required</li> </ul>

The most successful AGPN developed mechanism to facilitate communication between projects was the email discussion list. As noted in the above table approximately ten emails were exchanged per month. Project officers found this a good way to share resources and ideas relating to the program. From the perspective of the NET, the list server provided an excellent medium to distribute information relating to the National evaluation.

The regular AGPN Newsletters were also a good resource for project officers as they had regular updates from each of the projects. These were also available to download from the AGPN website allowing the potential to disseminate information about the program to a wider audience.

What was originally proposed as an 'organic' Communications Strategy for the RPC Program did not 'grow' and remained in its original form throughout the life of the program.

### 3.5.3 National workshops

Five national workshops were held over the life of the program. The workshops proved to be an effective program strategy to enhance communication, networking and problem solving between the projects. They were also an opportunity to inform AGPN and DoHA of the project's process and challenges. The evaluation team used the workshops to investigate program and project level evaluation issues.

It was evident that the workshops enabled the project coordinators to share their experiences, both successes and failures. Other project coordinators were able to take these lessons and include them in their own projects. Examples of this include the Link Nurse group, education programs, and linking with specialist palliative care services.

### 3.5.4 Informal networks

Throughout the life of the Program many of the project coordinators took the opportunity to actively network with other participants independently of the Program Consultant or the NET. This was carried out in informal networks over the telephone, at the regular RPCP workshops and at palliative care and other relevant conferences.

In terms of communication, these informal networks contributed to the feeling that the project coordinators were not working in isolation but were part of a bigger program.

## 3.6 Role of the National Evaluation Team

As outlined in Section 2.1 the National Evaluation Team worked closely with the RPCP sites over the three years and participated in site visits, workshops, teleconferences, the list service and phone contacts. This had some unintended consequences. In some cases the evaluation team member became part of the intervention. Often just the fact that a team member was actually on site meant that project coordinators had someone to problem solved with, ask to attend meetings or facilitate workshops.

Feedback from the project coordinators was that they found the visits useful and helpful. The evaluation team member was 'someone who they could discuss aspects of the project', 'someone to run ideas by' and/or 'someone who provided them with support for challenging issues'.

The NET has offered advice and support to individual projects in negotiations over their choices of information technology and tools, including the PaICIS system. In some instances this also included advice on how local palliative care-specific information and reporting systems could be integrated into Statewide and more generalist primary care systems.

There were some projects that conducted evaluation activities in addition to the national evaluation requirements. The evaluation team provided support, for example by proof reading articles and reports or assisting with data analysis.

Future programs might consider using a mixed local and national evaluator model for rural and remote communities, with a local evaluator linked with each project. This local evaluator may provide more on site support and facilitate local networking than was possible in the RPCP plus assist with local evaluation tasks, such as measure the outcomes of interventions. The role of the national evaluator would thus be one of designing the overall evaluation and synthesising the results of the various local evaluations.

## **Part Three – Impact and Outcomes for Consumers**



## 4 Palliative care patients and the services they received

### 4.1 Numbers enrolled in program and levels of consent

The numbers of patients registered in the RPCP are shown in Table 7 by level of consent. Table 8 is reproduced from the patient consent form. It provides a description of each of the levels of consent.

**Table 7 Patients registered in the RPCP**

Consent status	A	MNC	E	SEQ	NWT	WV	Total	Percent
Level 1	0	5	6	5	0	0	16	2.6%
Level 2	2	10	8	5	0	0	25	4.1%
Level 3	4	36	10	0	2	0	52	8.6%
Level 4	82	202	97	70	28	34	513	84.7%
<b>Total</b>	<b>88</b>	<b>253</b>	<b>121</b>	<b>80</b>	<b>30</b>	<b>34</b>	<b>606</b>	<b>100.0%</b>

**Project Codes**

A = Adelaide

MNC = Mid North Coast

E = Eurobodalla

SEQ = South East Queensland

NWT = North West Tasmania

WV = West Victoria

Note: Kalgoorlie was not required to submit any patient registration data.

**Table 8 Levels of Consent**

<p><b>Level One</b></p> <p><b>Information collection and sharing:</b> information about me being stored in the local Rural Palliative Care Program information system and shared with other relevant health and community care agencies to meet my service needs.</p>
<p><b>Level Two</b></p> <p><b>Evaluation Project:</b> information, <u>excluding any information that identifies me personally</u>, being used to evaluate the Palliative Care Program.</p>
<p><b>Level Three</b></p> <p><b>Evaluation Project:</b> information, <u>including information that identifies me personally</u>, being used to evaluate the Palliative Care Program. I consent to researchers from the Centre for Health Service Development (University of Wollongong) obtaining information from local hospitals about any hospital services I use.</p>
<p><b>Level Four</b></p> <p><b>Evaluation Project:</b> information, <u>including information that identifies me personally</u>, being used to evaluate the Palliative Care Program. I consent to researchers from the Centre for Health Service Development (University of Wollongong) obtaining information from the Health Insurance Commission (HIC) about the medical and diagnostic services I receive and the medicines that are prescribed for me. <i>Please fill in the attached HIC form with your details.</i></p>

Most sites reported spending an extra hour with each patient and/or their carer as they reviewed and discussed the consent process. Gaining patient consent was considered an onerous process.

### 4.2 Referrals

#### 4.2.1 Source of referrals

Information on the source of patient referral was not a mandatory data item and was only collected at sites using PaICIS for their data collection. These included Adelaide Hills, Mid North Coast, Eurobodalla and South East Queensland. The results are summarised in Table 9 below. Overall, the majority of referrals were made by General Practitioners with 'other' referral sources also making up over a quarter of referrals to palliative care. Community nurses made 16% of referrals

to palliative care with local nursing homes and local specialists making 10% and 9% of referrals respectively. In 6% percent of cases the referral source was the patient or their family.

**Table 9 Source of referral by site (percent)**

Project	Community Nurse	GP	Local Nursing Home	Local Specialist	Other	Patient/Family	Total
Adelaide Hills	0.0%	61.4%	0.0%	6.8%	26.1%	5.7%	100.0%
Mid North Coast	45.2%	18.3%	2.6%	0.9%	29.6%	3.5%	100.0%
Eurobodalla	11.3%	13.3%	20.2%	13.3%	32.7%	9.3%	100.0%
South East Queensland	8.0%	68.0%	0.0%	6.7%	14.7%	2.7%	100.0%
<b>Total</b>	<b>16.3%</b>	<b>30.2%</b>	<b>10.1%</b>	<b>8.6%</b>	<b>28.3%</b>	<b>6.5%</b>	<b>100.0%</b>

For the Adelaide Hills project General Practitioners and local specialists made the majority of referrals with no referrals made by a community nurse or a nursing home. Almost 6% of patients self referred or were referred by their family to the palliative care service. Just over one quarter of referrals came from 'other' sources of which the majority were referrals from a metropolitan hospital.

'Other' sources accounted for the highest proportion of referrals at the Mid North Coast project (30%) with the majority of these coming from the Oncology Unit at Coffs Harbour Hospital. Approximately 9% of patients self referred or were referred by their family.

The 'other' category accounted for almost one third (33%) of referrals at Eurobodalla. One fifth (20%) of referrals were made by local nursing homes, while GPs and local specialists each made 13.3% of referrals. The majority of other referral sources were from the Area Health Service Pharmacy and the hospital discharge planner Local nursing homes accounted for 5% of referrals and the remainder (2%) made by the patient or their family.

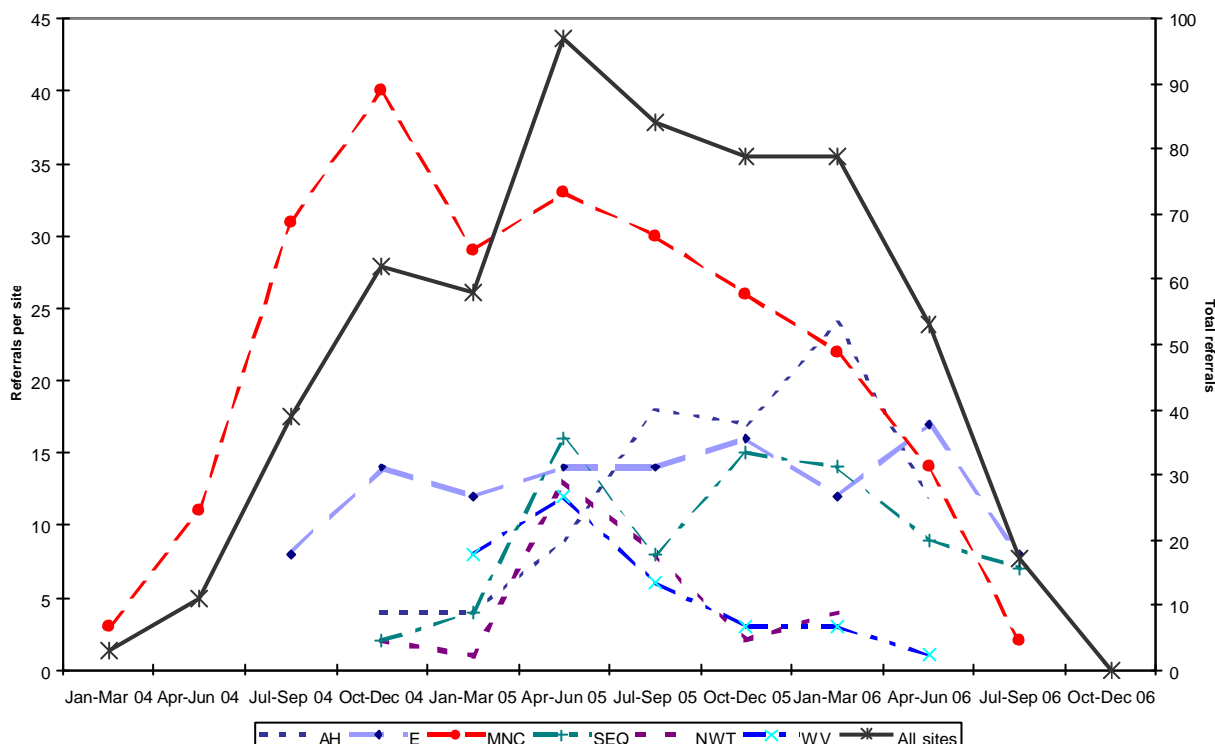
The majority of referrals at the South East Queensland project came from General Practitioners (68%). 'Other' sources made 15% of referrals. These were mainly referrals from a metropolitan hospital. The remaining referrals were made by community nurses (8%), local specialists (7%). No referrals were made by local nursing homes.

#### 4.2.2 Number of referrals

The number of referrals made per quarter at each site is presented in Figure 4. A total of 590 referrals were made across the sites where referral data were available. More than half of all referrals were made in 2005. This was due mainly to most sites not collecting data for a full year in either 2004 or 2006. When represented graphically the number of referrals made across the sites showed a relatively normal distribution, with the majority of referrals occurring during 2005 through to early 2006.

The quarter with the highest number of overall referrals was the second quarter in 2005, however, the project with the highest number of referrals in a quarter was the Mid North Coast in the fourth quarter of 2004. Overall the Mid North Coast recorded the highest number of referrals but also collected data for the longest period.

**Figure 4 Number of referrals by quarter and site**



### 4.3 Primary diagnosis of enrolled patients

Table 10 summaries the primary diagnosis of patients enrolled in the program by site. Examples of non-malignant conditions include Parkinson’s disease, pulmonary disease, renal failure, dementia and left ventricular failure. Primary diagnosis was not one of the registration requirements data items but was collected in five of the eight project sites. Overall, more than four fifths of diagnoses were cancer, while only 12% of patients had a non-malignant primary diagnosis. The remaining 7% did not have a recorded primary diagnosis.

**Table 10 Patient Diagnosis**

Project	Cancer		Non-malignant		No Diagnosis		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Adelaide Hills	73	83.0	10	11.4	5	5.7	88	100.0
Eurobodalla	105	91.3	1	0.9	9	7.8	115	100.0
Mid North Coast	179	72.2	45	18.1	24	9.7	248	100.0
SE Queensland	66	88.0	8	10.7	1	1.3	75	100.0
North West Tasmania	25	83.3	5	16.7	0	0.0	30	100.0
<b>Total</b>	<b>448</b>	<b>80.6</b>	<b>69</b>	<b>12.4</b>	<b>39</b>	<b>7.0</b>	<b>556</b>	<b>100.0</b>

Almost half of patients with a cancer diagnosis were enrolled into a stable phase, similarly to patients with a non-malignant diagnosis (Table 11). However, cancer patients had a shorter average enrolment period. Table 12 shows the average duration of enrolment in days for deceased patients.

**Table 11 Phase at referral by diagnosis**

Phase at referral	Cancer	Non-malignant	No Diagnosis	Total
Stable	49.5%	51.8%	27.8%	48.1%
Unstable	34.1%	33.9%	8.9%	31.4%
Deteriorating	23.0%	32.1%	12.7%	23.2%
Terminal	0.7%	0.0%	0.0%	0.6%
<b>Total</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>

**Table 12 Average duration of enrolment for deceased patients by diagnosis**

Phase at referral	Average Duration	number of deceased patients
Cancer	119.7	332
Non-malignant	169.6	43
No Diagnosis	84.2	35
<b>Total</b>	<b>121.9</b>	<b>410</b>

## 4.4 Palliative care phases

### 4.4.1 Phase on referral

Phase of care on referral to a palliative care service data are presented in this section for 560 patients. Phase of care was recorded as the initial phase of care or the phase of care at referral. Data from North West Tasmania did not explicitly include phase on referral. However, phase on referral was able to be determined for 20 patients, whose date of enrolment was the same as the date of commencement of the first recorded phase. The results are summarised in Table 13 below and indicate that phase/referral patterns differed across projects.

As shown in Figure 5, almost half of referrals (47%) were made into the stable phase with very few referrals made when the patient was in the terminal or bereaved phases (0.5% each). The remainder of referrals were divided between patients admitted during the unstable (30%) and deteriorating phases (21%). One exception to this pattern was the Adelaide Hills project where most (90%) patients were referred into the stable phase with few patients referred during the unstable and deteriorating phases and no patients referred in the terminal phase. At the other extreme is the Mid North Coast where only one third of patients were referred in the stable phase, while nearly half were referred when unstable. The Mid North Coast profile is more typical of a specialist palliative care service.

**Figure 5 Phase at referral by site**

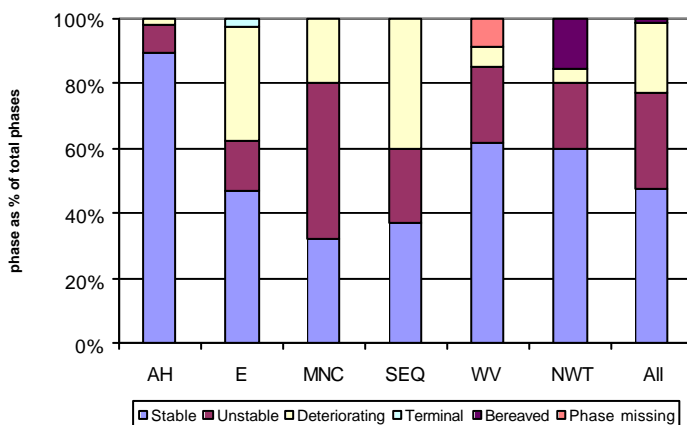


Table 13 presents a longitudinal view of referrals made during each phase for each year of the project. The number of referrals in 2004 was small compared to the other years as most sites did not start collecting data until late in 2004 and West Victoria began collecting data in 2005. The number of referrals in 2006 was also small due to projects discontinuing enrolment as they came toward the end of the year.

**Table 13 Phase on Referral by Site and Year**

Referral year	Site	Stable		Unstable		Deteriorating		Terminal		Bereaved		Phase missing		Total n
		n	%	n	%	n	%	n	%	n	%	n	%	
pre-2004	MNC	1	14.3	5	71.4	1	14.3							7
2004	AH	4	100.0											4
	E	7	31.8	5	22.7	10	45.5							22
	MNC	46	54.1	26	30.6	13	15.3							85
	SEQ	2	100.0											2
	WV													0
	NWT	1	100.0											1
<b>2004 Total</b>		<b>60</b>	<b>52.6</b>	<b>31</b>	<b>27.2</b>	<b>23</b>	<b>20.2</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>114</b>
2005	AH	44	91.7	4	8.3									48
	E	28	50.0	8	14.3	17	30.4	3	5.4					56
	MNC	26	22.0	71	60.2	21	17.8							118
	SEQ	20	46.5	8	18.6	15	34.9							43
	WV	20	69.0	6	20.7	2	6.9					1	3.4	29
	NWT	10	55.6	4	22.2	1	5.6			3	16.7			18
<b>2005 Total</b>		<b>148</b>	<b>47.4</b>	<b>101</b>	<b>32.4</b>	<b>56</b>	<b>17.9</b>	<b>3</b>	<b>1.0</b>	<b>3</b>	<b>1.0</b>	<b>1</b>	<b>0.3</b>	<b>312</b>
2006	AH	31	86.1	3	8.3	2	5.6							36
	E	19	51.4	5	13.5	13	35.1							37
	MNC	7	18.4	17	44.7	14	36.8							38
	SEQ	6	20.0	9	30.0	15	50.0							30
	WV	1	25.0	2	50.0							1	25.0	4
	NWT	1	100.0											1
<b>2006 Total</b>		<b>65</b>	<b>44.5</b>	<b>36</b>	<b>24.7</b>	<b>44</b>	<b>30.1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0.7</b>	<b>146</b>
Year missing (WV)												1	100.0	1
All years	AH	79	89.8	7	8.0	2	2.3							88
	E	54	47.0	18	15.7	40	34.8	3	2.6					115
	MNC	80	32.3	119	48.0	49	19.8							248
	SEQ	28	37.3	17	22.7	30	40.0							75
	WV	21	61.8	8	23.5	2	5.9					3	8.8	34
	NWT	12	60.0	4	20.0	1	5.0			3				20
<b>Grand Total</b>		<b>274</b>	<b>47.2</b>	<b>173</b>	<b>29.8</b>	<b>124</b>	<b>21.4</b>	<b>3</b>	<b>0.5</b>	<b>3</b>	<b>0.5</b>	<b>3</b>	<b>0.5</b>	<b>580</b>

#### 4.4.2 Phase records

Sites participating in the RPCP have been collecting patient/client palliative care stage of illness data using Tool 1.1. The tool is used to collect patient phase of care, symptom severity scores, RUG-ADL and Karnofsky scores. This section contains an analysis of all data collected, which

were submitted by six sites. At five of the six sites, data were retrospectively transferred into PaICIS (Palliative Care Information System) which is based on a Microsoft Access database. The remaining site used the Palliative Care Toolkit, a Microsoft Access database designed by the CHSD.

Data in Tool 1.1 are (theoretically) recorded at the level of phase. Date of phase commencement was recorded for each phase, but date of completion was not recorded. It has been assumed that for a given patient, a phase ends at the commencement of the next recorded phase. Whilst this seems reasonable, it does not account for the possibility of multiple episodes of palliative care. A patient may have discontinued palliative care on a given date and re-commenced on a later date. Such breaks in continuity were not recorded in the data. It is possible that this issue may lead to an overestimation of the average time spent in each phase and the average number of phases per episode.

Whilst data are supposed to be recorded at the level of phase, there are a large number of records which do not appear to conform. For many patients, there are (consecutive) records with the same recorded phase (e.g. three records for patient X, each recorded as “stable”, with no other intervening records for patient X). It is assumed that all such records actually constitute a continuation of the same episode and hence the same Phase. All affected records are treated accordingly, leading to a reduction in the apparent number of phases by almost one third (31%). This was a particularly important issue for West Victoria (50% of records), Mid North Coast (42%) and North West Tasmania (31%).

In total, data were received for 2,159 palliative care phases for 584 patients, an average of 3.7 phases per patient.<sup>7</sup> A summary of the frequency and average phase length is provided in Table 14. The most commonly occurring phases of care are Stable and Unstable, representing 26% and 25% of the data respectively. The least reported phase is Terminal, which represents 9% of the data.

Table 14 also shows the average length of each phase in days. The overall average is 45.8 days, ranging from 4.6 days for terminal phases and 72.2 days for stable phases. The average, however, is strongly influenced by phases with particularly long lengths, and so the median lengths of each phase are also shown. These are considerably lower than the corresponding averages.

The median length of each phase is as expected with the exception of the unstable phase. This phase is considerably longer than expected. Patients are classified to this phase if they experience the development of a new problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment. Patients can also be classified to this phase if family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team. Given that the phase is defined based on the need for urgent intervention, it is a concern that the median length of this phase was so long.

**Table 14 Frequency and average phase length**

Phase of Care	Frequency	Percent	Average length (days)	Median length (days)
Stable	568	26.3%	72.2	37
Unstable	536	24.8%	39.6	16
Deteriorating	455	21.1%	37.4	17
Terminal	191	8.8%	4.6	2
Bereaved	409	18.9%	n/a	n/a
<b>Total</b>	<b>2159</b>	<b>100%</b>	<b>45.8</b>	<b>16</b>

<sup>7</sup> There were 6 patients who were registered and consenting in the North West Tasmania project, but for whom we did not receive phase level data.

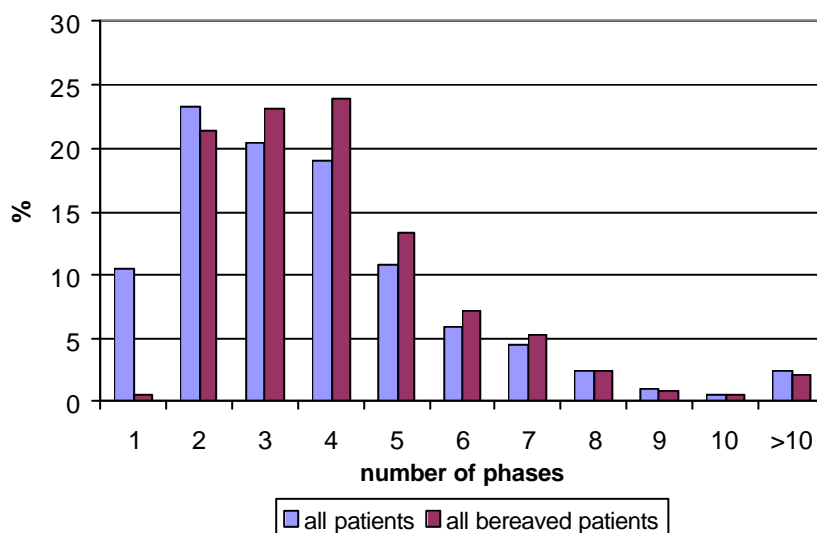
Table 15 shows considerable variation between sites in the distribution of phases of care. For example, 41% of Adelaide Hills' phases were 'stable', compared to just 17% of South East Queensland's activity. Conversely, 15% of South East Queensland's phases were terminal, compared to 5% for Adelaide Hills.

**Table 15 Distribution of phases of care by site**

Site	Stable (%)	Unstable (%)	Deteriorat-ing (%)	Terminal (%)	Bereaved (%)	Total (%)	Total phases
Adelaide Hills	41.0	25.0	10.1	4.9	19.0	100.0	268
Mid North Coast	19.9	24.9	26.2	8.2	20.8	100.0	864
Eurobodalla	29.7	19.0	21.4	8.3	21.7	100.0	448
South East Queensland	16.7	24.3	23.9	15.4	19.7	100.0	305
North West Tasmania	37.5	31.3	10.4	6.3	14.6	100.0	48
West Victoria	37.2	35.4	12.4	8.8	6.2	100.0	226
<b>Total</b>	<b>26.3</b>	<b>24.8</b>	<b>21.1</b>	<b>8.8</b>	<b>18.9</b>	<b>100.0</b>	<b>2159</b>

Patients may progress through a number of phases while in palliative care. The number of phases recorded for each patient in the data set was counted and the results shown graphically in Figure 6. The first series of data is for all patients, regardless of whether their episode of palliative care has been completed. Only one phase was recorded for 61 (10%) of these patients. More than one-quarter of patients (27%) had five or more phases. The second set of data is limited to completed episodes (patients who had died). 68% of patients who died had between two and four phases of care recorded.

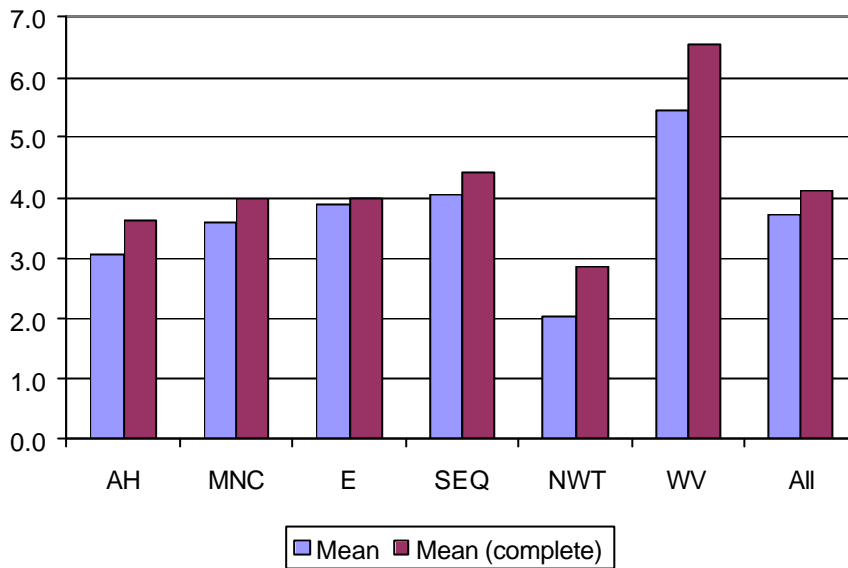
**Figure 6 Distribution of the number of phases per patient**



The average number of phases per patient by site is shown in Figure 7. The first series of data is for all patients. The highest average was observed for West Victoria (5.5 phases), while North West Tasmania had the lowest average (2.2 phases). The second series is restricted to patients who had died. Whilst the average is slightly higher for completed episodes, the relativities between sites were similar. Overall, patients who died had an average of 4.1 phases of care.



**Figure 7 Average number of phases per patient by site**



### 4.4.3 Phase length

Phase length is the number of days a patient remains in one phase before moving onto another phase. This was calculated for all completed non-bereavement phases. The distribution length is presented in Table 16.

As expected, patients tended to remain in the stable phase longer than in the other phases and lengths of stay in the terminal phase tended to be short. Overall, 607 of 1576 phases (39%) lasted between 0 and 10 days. Within phase, this percentage varied from 21% of stable phases to 89% of terminal phases. Some 8% of completed phases lasted over 120 days, including 18% of stable phases.

**Table 16 Length of phases of care**

Length of phase (days)	Stable	Unstable	Deteriorating	Terminal	Total
0-10	100	181	159	167	607
11-20	66	110	70	12	258
21-30	38	52	52	6	148
31-40	41	41	28	2	112
41-50	31	31	21	0	83
51-60	25	19	17	1	62
61-70	17	6	9	0	32
71-80	20	12	8	0	40
81-90	14	10	12	0	36
91-100	12	8	8	0	28
101-110	10	4	5	0	19
111-120	10	3	8	0	21
>120	83	24	23	0	130
<b>TOTAL</b>	<b>467</b>	<b>501</b>	<b>420</b>	<b>188</b>	<b>1576</b>

Table 17 shows that there is also considerable variation between sites in the average and median phase length. Across all phases of care, average phase length was highest in Mid North Coast (61.9 days), more than twice that of West Victoria (26.4 days). Mid North Coast had the largest mean phase length for each phase of care except for terminal phases. Mid North Coast and West



Victoria were particularly influenced by outlying long phases, as reflected by the much lower medians. However, there is also a large discrepancy in median lengths of stay by site. The highest median (Adelaide Hills; 28 days) was more than three times higher than the lowest (West Victoria; 9.0 days). West Victoria's relatively short median phase length was largely the result of its considerably shorter median length of stable phases, as compared to the other sites.

**Table 17 Phase length by site and phase of care (days)**

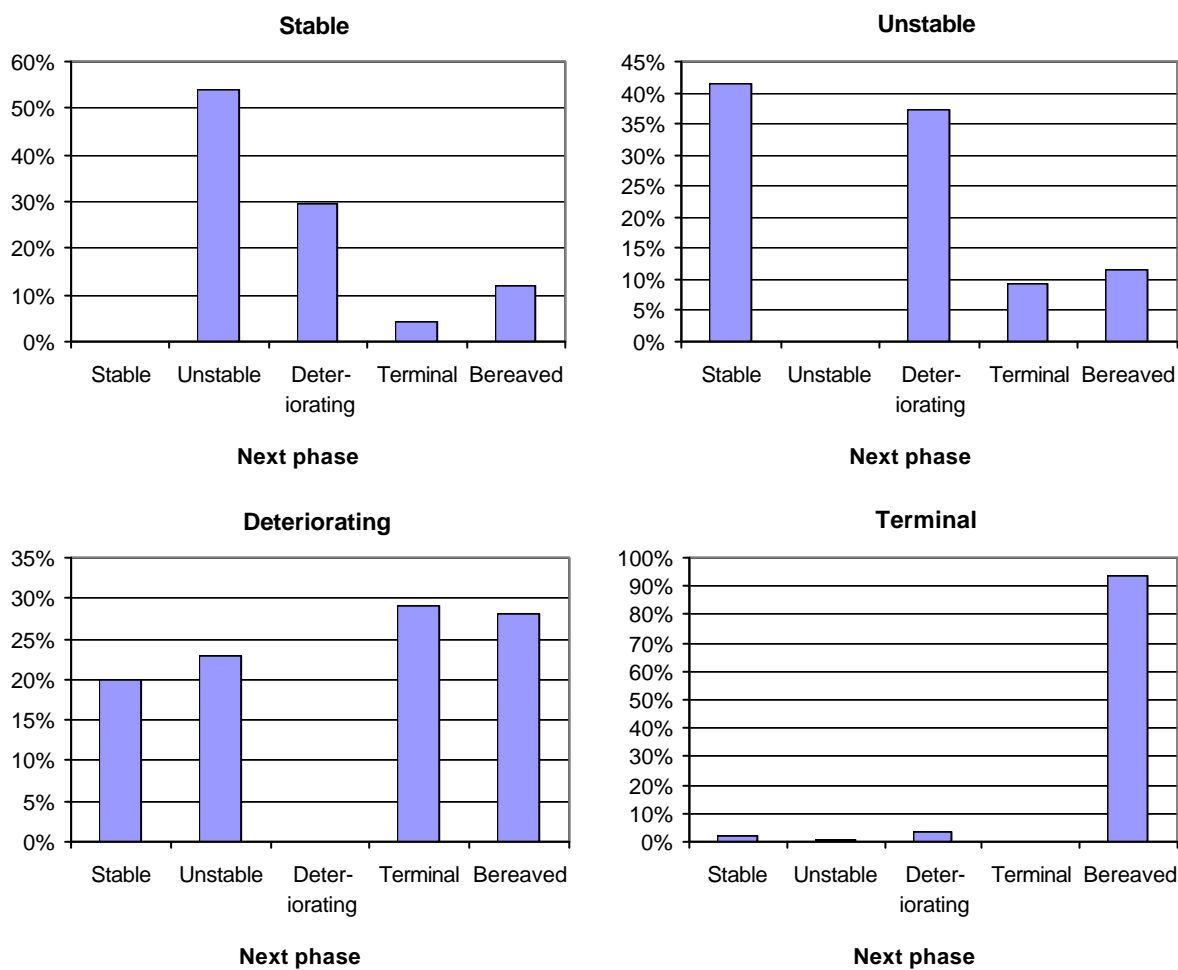
Site	Phase of Care	Mean length	Median length	Number of completed phases
Adelaide Hills	Stable	64.0	47.5	84
	Unstable	32.4	23.0	60
	Deteriorating	18.8	12.0	24
	Terminal	9.2	7.0	13
	All	43.6	28.0	181
Mid North Coast	Stable	99.7	46.5	142
	Unstable	65.4	27.0	207
	Deteriorating	51.9	22.5	202
	Terminal	4.5	2.0	71
	All	61.9	21.0	622
Eurobodalla	Stable	60.4	32.0	119
	Unstable	14.2	8.0	83
	Deteriorating	25.2	13.0	94
	Terminal	6.1	2.0	37
	All	32.9	13.0	333
South East Queensland	Stable	92.2	59.0	41
	Unstable	14.3	12.0	71
	Deteriorating	30.5	21.0	71
	Terminal	2.9	2.0	47
	All	30.8	14.0	230
North West Tasmania	Stable	35.2	33.0	9
	Unstable	54.9	22.0	8
	Deteriorating	3.0	3.0	3
	Terminal	2.0	2.0	3
	All	33.5	18.0	23
West Victoria	Stable	40.3	15.0	72
	Unstable	24.3	14.0	72
	Deteriorating	8.9	5.5	26
	Terminal	3.9	3.0	17
	All	26.4	9.0	187
All sites	Stable	72.2	37.0	467
	Unstable	39.6	16.0	501
	Deteriorating	37.4	17.0	420
	Terminal	4.6	2.0	188
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Site	Phase of Care	Mean length	Median length	Number of completed phases
	All	44.5	17.0	1576

#### 4.4.4 Phase changes

Figure 8 shows movements between phases of care. For instance, the first graph depicts the phase that patients moved into following a stable phase. The majority (54%) of stable phases are followed by an unstable phase, whilst a sizeable minority of stable phases (12%) are followed by bereavement (directly). This figure also shows a considerable difference between unstable and deteriorating phases. Unstable phases are most likely to be followed by stable or deteriorating phases. Deteriorating phases are most likely to be followed by bereavement or a terminal phase. Nevertheless, nearly half (43%) of deteriorating phases are followed by a stable or unstable phase. Most (94%) terminal phases end with the death of the patient. Most (94%) terminal phases end with the death of the patient.

**Figure 8 Movements between phases of care**



#### 4.5 Functional status and severity of illness by phase

When a patient's phase changes, Karnofsky scores, RUG-ADL scores and Palliative Care Severity scores are recorded. Within PalCIS, phase details, RUG-ADL and problem severity scores are recorded in one table. Karnofsky scores are recorded in a separate table. Some phases did not have a corresponding Karnofsky score and some Karnofsky scores could not be linked to a specific phase. Some RUG-ADL and some Problem Severity item scores were missing.

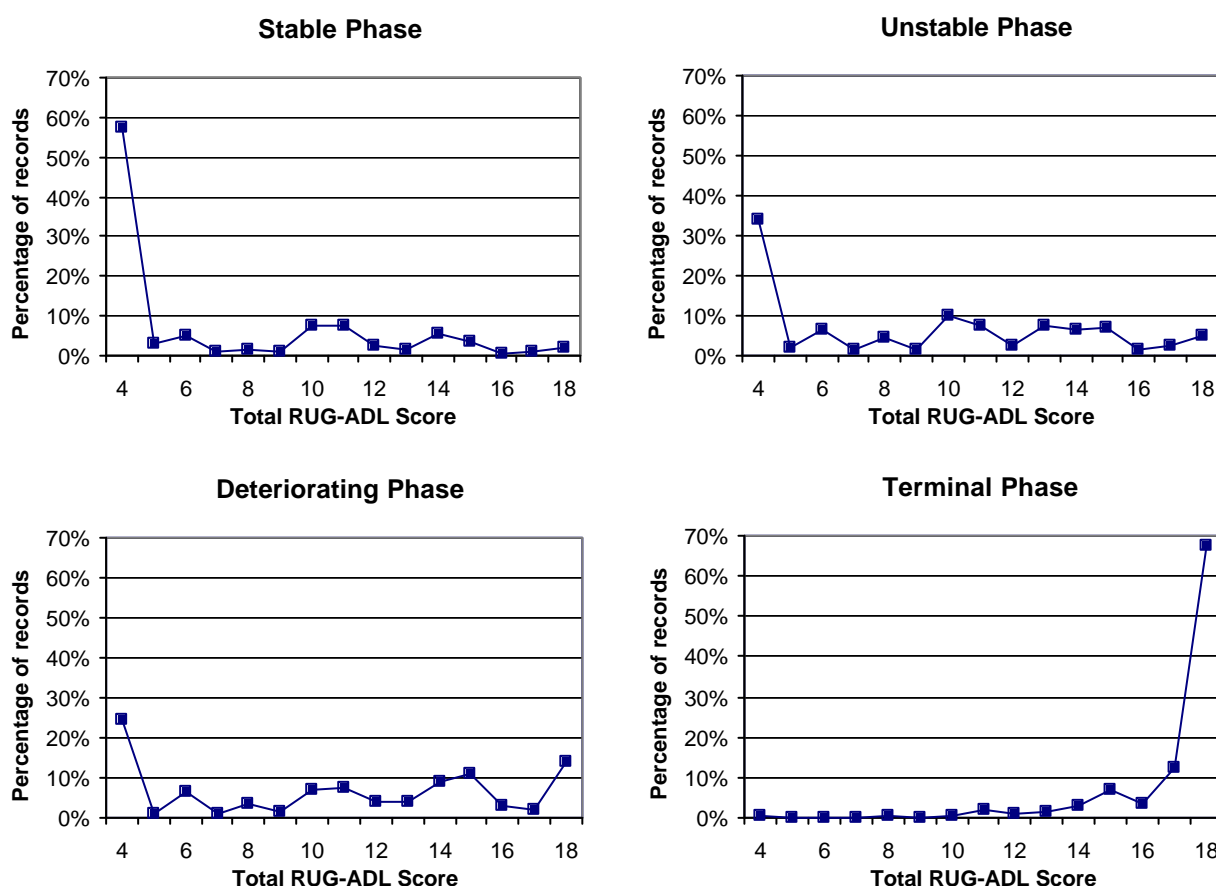
Karnofsky scores were available for 1187 (68%) non-bereavement phases. Complete RUG-ADL scores were available for 1745 (99.7%) of non-bereavement phases. Complete Palliative Care Severity scores were available for 1687 (96%) of non-bereavement phases.

### 4.5.1 RUG-ADL scores

Resource Utilisation Groups Activities of Daily Living scale (RUG-ADL) scores are recorded whenever a patient experiences a phase change. The scale consists of four domains: bed mobility, toileting, transfer and eating. The first three domains are rated at level 1 (independent or supervision only), level 3 (limited physical assistance), level 4 (other than 2 person physical assist) and level 5 (2 person physical assist). A rating level 2 is absent since the level of assistance needed to move from a level 1 to a level 3 is much larger than that needed to move between levels 3 to 5. Eating is rated at levels 1, 2 and 3 whereby levels 1 and 3 are similar to those of the other domains and level 2 represents limited assistance.

Total RUG-ADL scores range from 4 (total independence) to 18 (total dependence). The distribution of RUG-ADL scores within each phase are presented in Figure 9. For patients in the stable, unstable and deteriorating phases, the most commonly occurring score is 4. Most patients in the terminal phase, on the other hand, have a RUG-ADL score of 18.

**Figure 9 Distribution of Total RUG-ADL score frequencies for each phase**



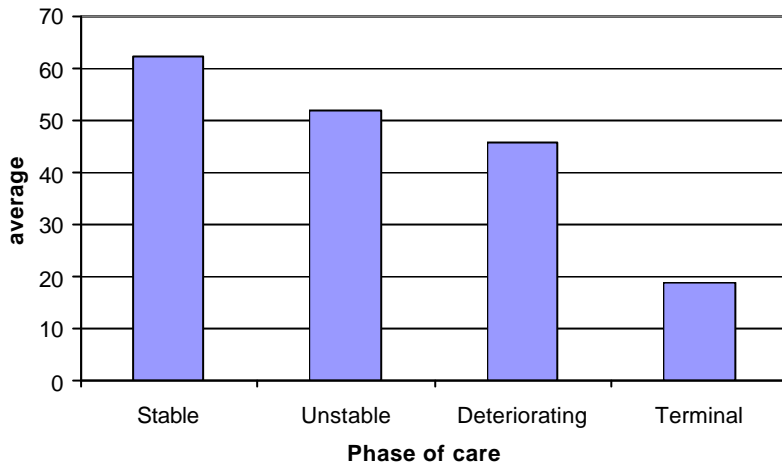
### 4.5.2 Karnofsky scores

Karnofsky scores are recorded whenever there is a phase change. The Karnofsky rating scale ranges from a score of 0 (death) to 100 (normal with no complaints or evidence of disease) and has a ten point difference between each score. Since Karnofsky scores are not recorded for patients at the bereaved phase, the average Karnofsky scores were calculated for the records

containing corresponding Karnofsky scores. Figure 10 describes average Karnofsky scores by phase of care.

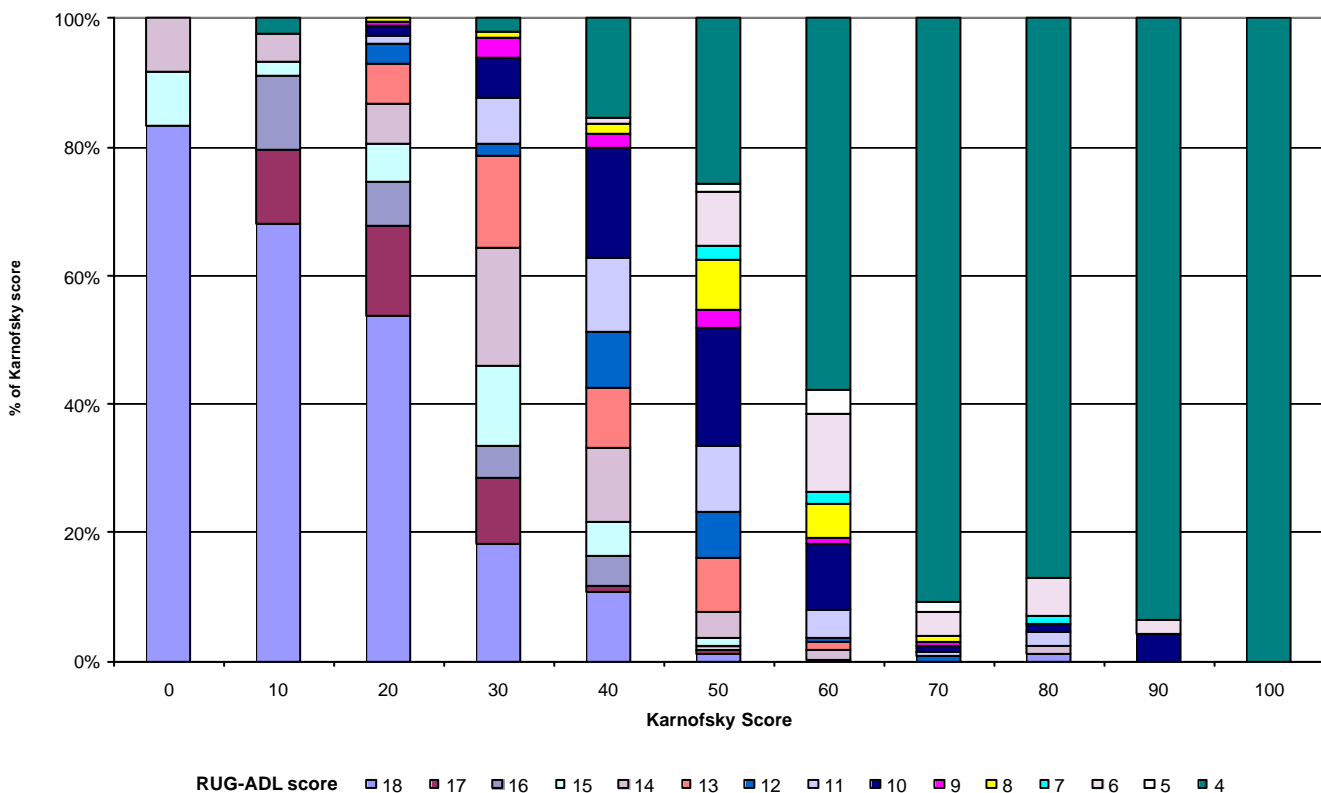
As expected, this figure reveals that Karnofsky scores are declining as patients move from the stable phase to the terminal phase. The average Karnofsky scores are 62 in the stable phase, 52 in the unstable phase, 46 in the deteriorating phase, and 19 in the terminal phase.

**Figure 10 Average Karnofsky scores by phase of care**



There is an interesting relationship between the Karnofsky scores and the RUG-ADL totals. Over one half of phases are scored in the middle range of the Karnofsky, where RUG-ADL provides a good discrimination between patients, as seen in Figure 11 and Table 18. The RUG-ADL gives a much greater level of detail, and distinguishes between a variety of patients with the same Karnofsky score, especially those rated between 30 and 60. In contrast, the Karnofsky scale distinguishes between patients who are rated 4 on the RUG-ADL. This justifies the collection of both instruments.

**Figure 11 Relationship between Karnofsky and RUG-ADL scores**



**Table 18 RUG-ADL scores by Karnofsky scores**

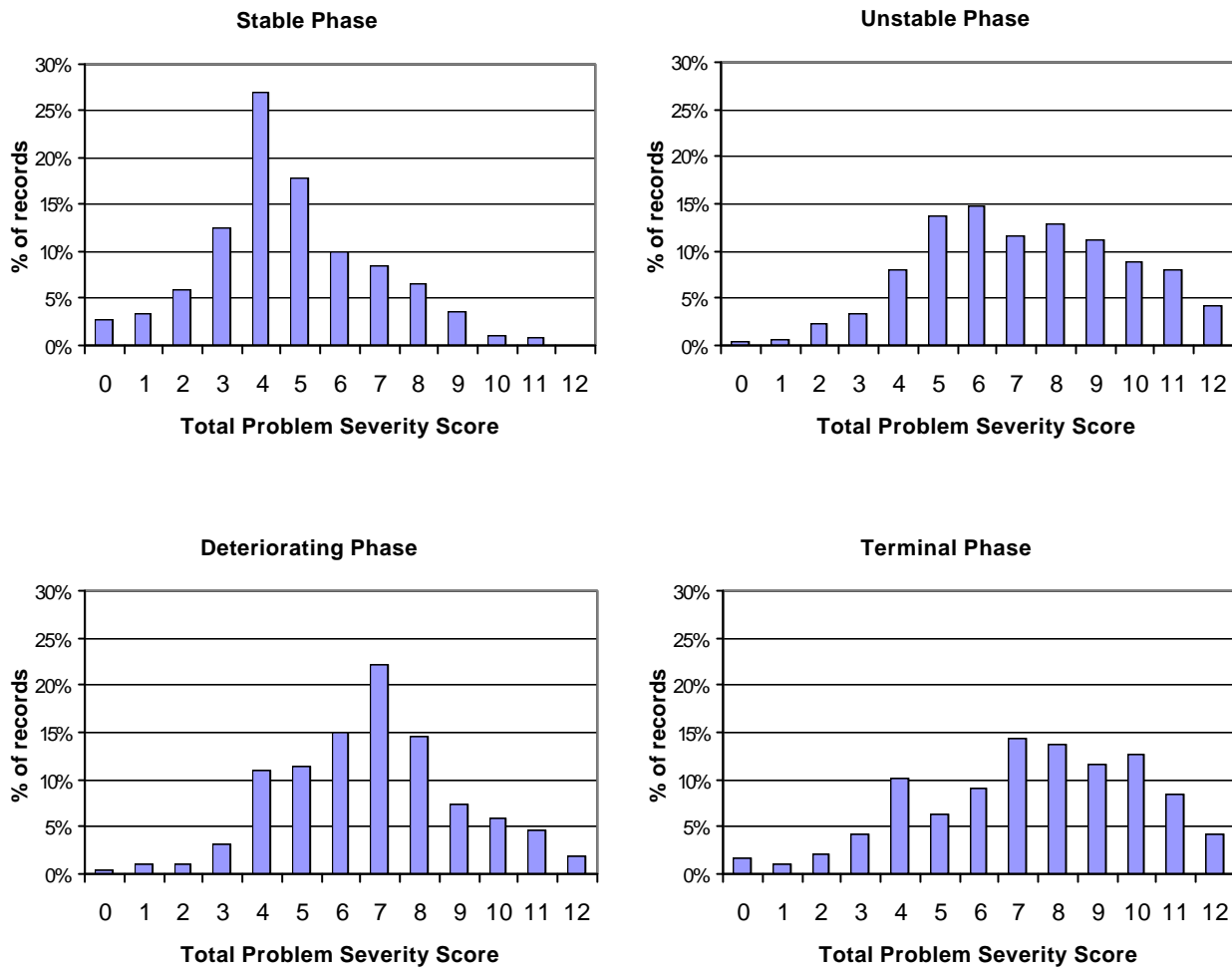
RUG-ADL score	Karnofsky score											Total
	0	10	20	30	40	50	60	70	80	90	100	
4	0	1	0	2	20	63	159	112	67	38	9	<b>40%</b>
5	0	0	0	0	0	3	10	2	0	0	0	<b>1%</b>
6	0	0	0	0	1	22	32	5	4	1	0	<b>5%</b>
7	0	0	0	0	0	5	6	0	1	0	0	<b>1%</b>
8	0	0	1	1	2	17	15	1	0	0	0	<b>3%</b>
9	0	0	0	2	2	8	3	1	0	0	0	<b>1%</b>
10	0	0	1	6	22	46	27	0	1	2	0	<b>9%</b>
11	0	0	2	6	14	24	11	1	2	0	0	<b>5%</b>
12	0	0	4	1	9	18	2	1	0	0	0	<b>3%</b>
13	0	0	10	13	12	21	4	0	0	0	0	<b>5%</b>
14	1	1	9	18	15	11	4	0	1	0	0	<b>5%</b>
15	1	1	9	10	7	3	0	0	0	0	0	<b>3%</b>
16	0	4	10	4	6	1	1	0	0	0	0	<b>2%</b>
17	0	5	21	10	0	2	0	0	0	0	0	<b>3%</b>
18	9	27	79	18	14	3	0	0	1	0	0	<b>13%</b>
<b>Total</b>	<b>1%</b>	<b>3%</b>	<b>12%</b>	<b>8%</b>	<b>10%</b>	<b>21%</b>	<b>23%</b>	<b>10%</b>	<b>7%</b>	<b>3%</b>	<b>1%</b>	<b>100%</b>

### 4.5.3 Problem severity scores

Problem severity scores are recorded whenever a patient experiences a phase change. The scale consists of four domains: pain, other symptoms, psychological/spiritual and family/carer and are rated on a scale of 0 – 3 (from no problem to severe). The lowest possible total problem severity score is 0, whereby a patient is rated at 0 for all four domains. The highest possible score is 12 whereby a patient is rated at level 3 for all four domains.

The frequency of total problem severity scores for each phase is presented in Figure 12. As expected, Problem Severity scores for patients in a stable phase tend to be lower than those in the other phases. The distributions of scores in the unstable, deteriorating and terminal phases appear to be quite similar.

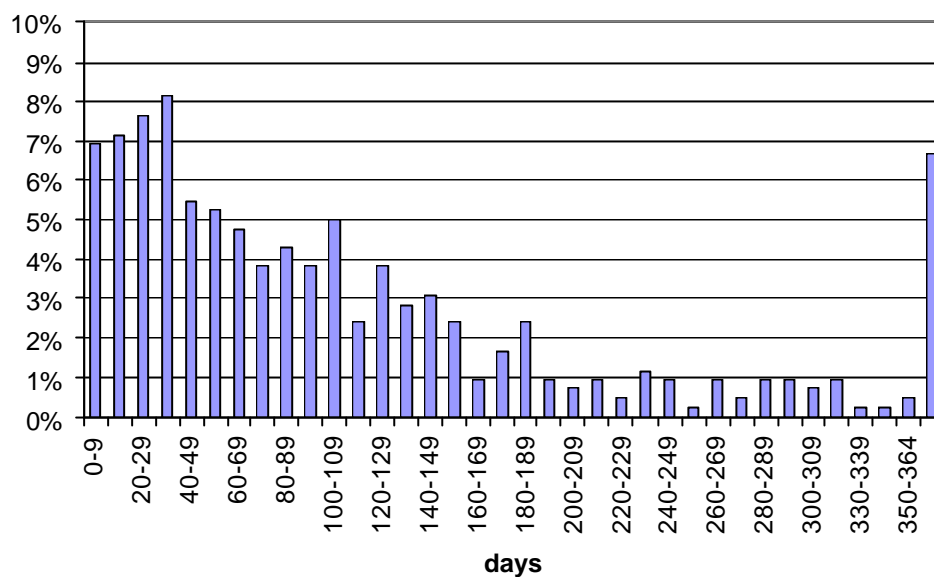
**Figure 12 Distribution of problem severity scores by phase**



#### 4.6 Duration of enrolment

Duration of enrolment has been calculated for the 420 patients who died during the study period and for whom we have sufficient data.

Figure 13 shows that enrolment duration varied greatly by patient. More than one fifth (21.7%) of patients died in less than 30 days from time of referral. On the other hand, close to one fifth (19.3%) of patients were enrolled for over six months before they died, including 6.7% who were enrolled for more than one year. The average (mean) duration of enrolment was 122.5 days and the median was 73 days (Table 19). Both the mean and the median varied considerably by site. The mean ranged from 49.4 days in North West Tasmania to 157.2 days in Mid North Coast. There was a similar variation in the median.

**Figure 13 Distribution of enrolment duration (days) (all sites)****Table 19 Average duration of enrolment (days) by site**

Length of phase (days)	Adelaide	Mid North Coast	Eurobodalla	South East Queensland	West Victoria	North West Tasmania	All
Mean	105.1	157.2	82.3	95.8	148.1	49.4	122.5
Median	68.0	103.0	51.0	61.0	117.0	25.5	73.0
Number of patients	52	193	97	60	10	8	420

Average duration was longer for people who were assigned into stable or unstable phases on referral than for people who were already in the deteriorating phase on referral (see Table 20). Only three people were in the terminal phase on referral and at least one of those was incorrectly classified.

**Table 20 Average duration of enrolment (days) by phase at referral**

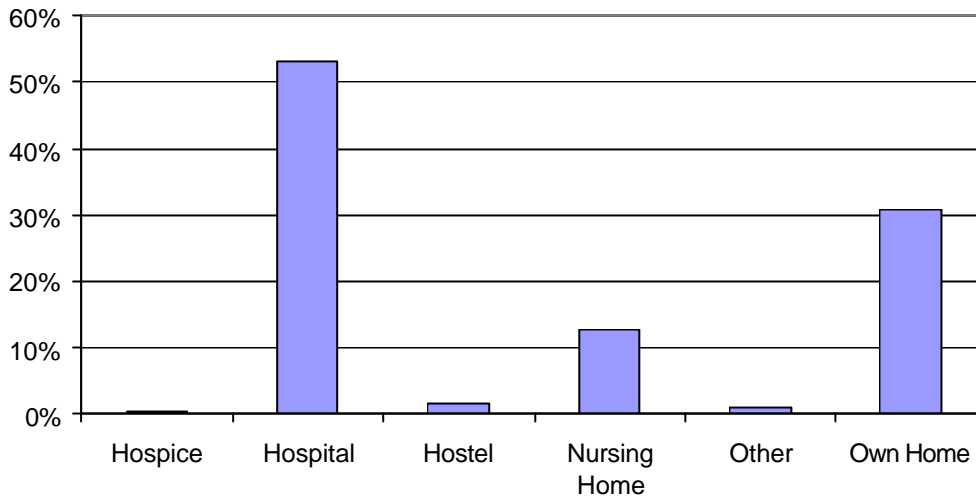
Duration	Stable	Unstable	Deteriorating	Terminal	All
Mean	135.8	125.8	94.0	110.7	122.5
Median	85.0	93.0	46.0	1.0	73.0
Number of cases	182	136	99	3	420

#### 4.7 Place of death

Sites were not required to collect place of death. This data item was, however, submitted by four of the sites and summary results are reported here. It was recorded for 402 patients who died during the study period.

Figure 14 shows that over half (53.2%) of patients' deaths occurred in hospital, while almost one third (30.8%) were at home and 12.7% were in a nursing home.

**Figure 14 Place of death**



The place of death profile did not vary greatly between Adelaide Hills, Mid North Coast and Eurobodalla. South East Queensland, however, had a considerably larger proportion (77%) of patients who died in hospital (Table 21).

**Table 21 Place of death by site**

	Adelaide Hills	Mid North Coast	Eurobodalla	South East Queensland	All
Hospice	1.9%	0.5%	0.0%	0.0%	0.5%
Hospital	48.1%	46.1%	55.7%	76.7%	53.2%
Hostel	0.0%	3.6%	0.0%	0.0%	1.7%
Nursing Home	7.7%	19.7%	5.2%	6.7%	12.7%
Other	3.8%	0.5%	1.0%	0.0%	1.0%
Own Home	38.5%	29.5%	38.1%	16.7%	30.8%
Total	100.0%	100.0%	100.0%	100.0%	100.0%

Table 22 examines changes over time in the percentage of patients who died in their own home. Overall, this percentage decreased between 2004 and 2006, though the number of cases was small in 2004. Nevertheless, this decrease was large for the Mid North Coast (down from 41.9% in 2004 to 27.3% in 2006), and it also fell for South East Queensland between 2005 and 2006.

**Table 22 Percent of patients who died in their own home by year and site**

Year	Adelaide Hills (%)	Mid North Coast (%)	Eurobodalla (%)	South East Queensland (%)	All (%)
2004	0.0	41.9	22.2	0.0	37.5
2005	39.1	27.1	44.7	25.0	32.3
2006	35.5	27.3	34.1	10.5	27.5
All	38.5	29.5	38.1	16.7	30.8
<b>Number of deaths</b>					
2004	0	31	9	0	40
2005	23	107	47	24	201
2006	29	55	41	35	160
year missing				1	1
<b>All</b>	<b>52</b>	<b>193</b>	<b>97</b>	<b>60</b>	<b>402</b>



## 4.8 Service utilisation

Service utilisation data were received from six projects, and are summarised in Table 23. No data were received from the Pilbara project. Overall, across the six projects, 471 patients received a total of 22,340 recorded services. This suggests that some of the consenting patients (Section 4.1) received no services and/or that service utilisation data are not complete for all patients. It is not possible to distinguish between these possibilities. In each project, the majority of services were rendered by nurses.

GP service data have not been included for the Mid North Coast. These data were requested from Medicare Australia in January 2007, but have not received at the time of writing.

There was much variation in the average number of recorded services per patient across projects. This statistic varied from a low of 24.6 services per patient at Adelaide Hills to a high of 164.7 at West Victoria. This may partly reflect different levels of success in capturing service episodes across projects, or even different attitudes to what services should be included.

There was less variation in average length of service (excluding travel time) across projects. This varied from 35.5 minutes at North West Tasmania to a high of 46.2 minutes at West Victoria.

**Table 23 Summary of service utilisation data by project**

Project	No. of patients	No. of services	Average services per patient	Main provider (%)	Average service time (mins)
Adelaide Hills	83	2,392	28.8	Nurse (39.3)	50.1
Mid North Coast	174	4,273	24.6	Nurse (90.4)	43.5
Eurobodalla	91	6,323	69.5	Nurse (89.0)	36.6
South East Queensland	67	2,792	41.7	Nurse (45.1)	37.8
North West Tasmania	23	1,125	48.9	Nurse (49.2)	35.5
West Victoria	33	5,435	164.7	Nurse (54.9)	46.2
<b>Total</b>	<b>471</b>	<b>22,340</b>	<b>47.4</b>	<b>Nurse (68.2)</b>	<b>41.8</b>

\* Note: number of consenting patient who received one or more services for whom service utilisation data were received.

Table 24 provides a more detailed breakdown of services by provider type and site. According to the data submitted, 68.2% of all services were provided by nurses, varying from 39.3% in Adelaide Hills to 90.4% in Mid North Coast. A large proportion (21.6%) of services were grouped into the residual 'other' category, which includes services that were inadequately described. This included 42.3% of West Victoria's service utilisation data and 38.0% of North West Tasmania's data.

**Table 24 Services by Provider and Project (row %)**

Project	GP	Nurse	Allied Health	Other	Total
Adelaide Hills	27.7%	39.3%	4.1%	29.0%	100.0%
Mid North Coast	0.7%	90.4%	3.7%	5.3%	100.0%
Eurobodalla	0.0%	89.0%	6.3%	4.7%	100.0%
South East Queensland	22.5%	45.1%	0.9%	31.5%	100.0%
North West Tasmania	12.7%	49.2%	0.0%	38.0%	100.0%
West Victoria	0.0%	54.9%	2.8%	42.3%	100.0%
<b>All</b>	<b>6.5%</b>	<b>68.2%</b>	<b>3.7%</b>	<b>21.6%</b>	<b>100.0%</b>

"Other" includes services that were inadequately described

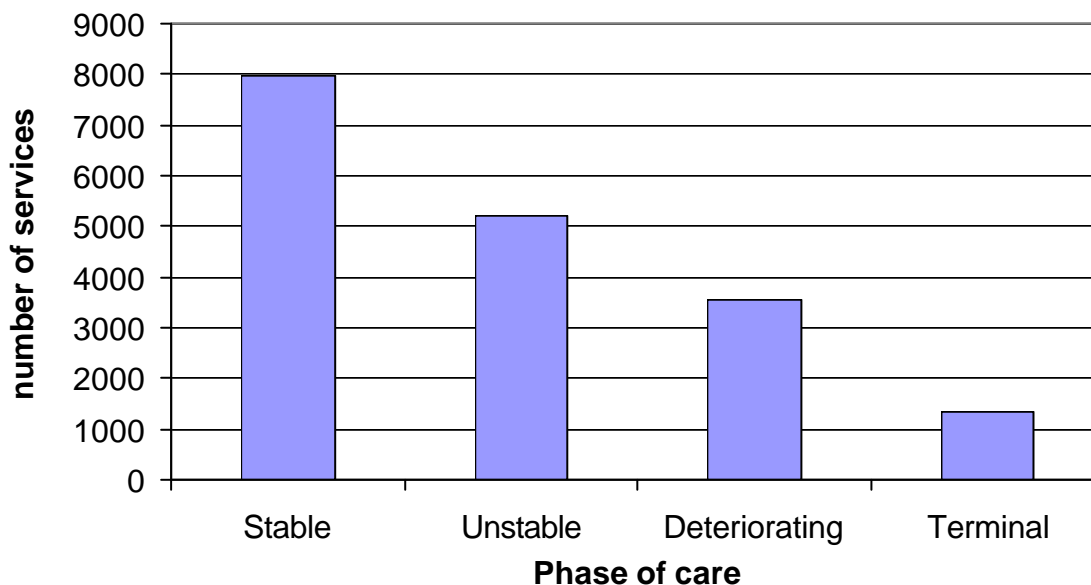
The Mid North Coast site submitted data in three different formats which were combined by the project team. There were some overlapping records in two of the three sources, but these records were not uniquely identifiable. An algorithm was developed to approximately identify such records. All records in each source were summarised by patient identifier, date and service type. Any records thus summarised that appeared in both sources were assumed to be duplicates and were hence excluded from the analysis. This may lead to some underestimation of Service Utilisation data for the Mid North Coast. Some data on service length of time were provided as a range of time rather than as a single value (e.g. 20-40 mins). In such cases, data have been rounded to a single value (e.g. 30 mins) in order to facilitate estimation of average time per service.

#### 4.8.1 Service utilisation by phase

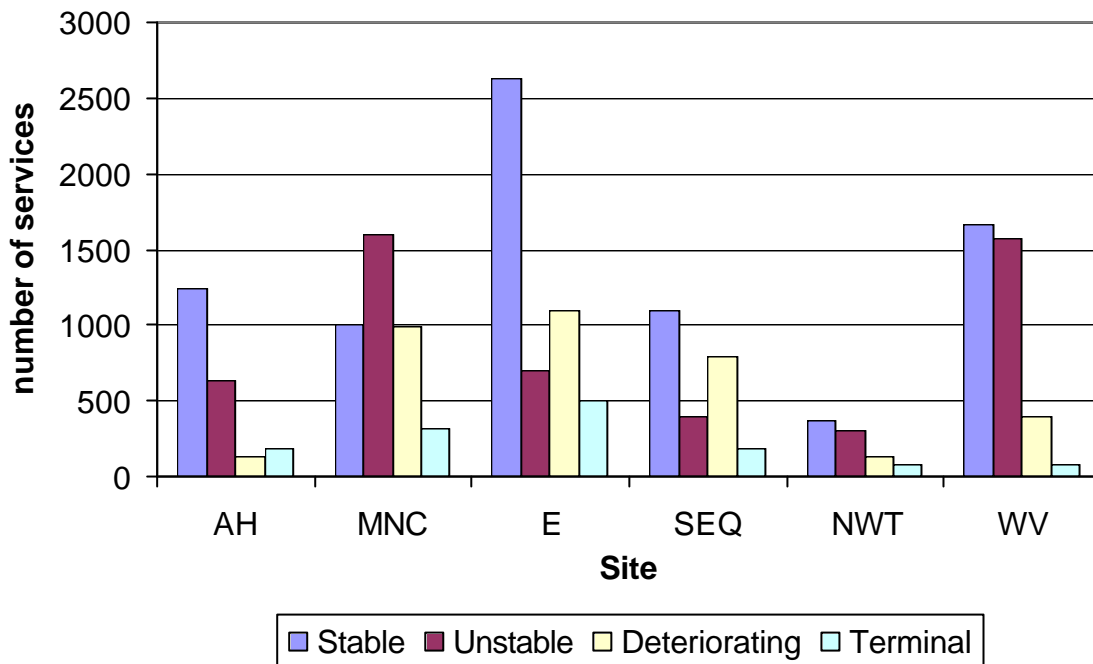
In this section, we report on the services utilised by phase of care. Since phase data and service utilisation are not adequately linked in the existing data, the data were linked using the patient ID and date fields. When a service was recorded on the same day as a phase change, it was assumed to be part of the new phase. An exception was made for services that occurred on the day of bereavement, which were assumed to occur in the terminal phase. Some data could not be linked with the phase data. The following analysis uses 81% of the service utilisation data.

As shown in Figure 15, most services were received by patients in the stable (44%) and unstable (29%) phases. This result is consistent with those in Table 14, which shows that the majority of recorded phases were Stable or Unstable and that such phases were longer than other phases on average. There was some variation by site (Figure 16). At Mid North Coast, more services were received by patients in the unstable phase than in the stable phase, reflecting their higher number of unstable phases, as shown in Table 15.

**Figure 15 Total services utilised by phase of care**



**Figure 16 Services Utilised by Phase of Care and Site**



Another way to examine these data is to consider the number of services utilised *per phase*, this removes the effect of different phase caseloads from the comparisons. Figure 17 shows that patients received an average of 9.4 services per phase. This is slightly lower than implied by the data contained in Table 14 (number of phases) and Table 23 (number of services). This is because not all services were able to be linked with a phase.

Patients in a stable phase received an average of 13.3 services before changing phase, whilst an average of 3.6 services was received in terminal phases.

**Figure 17 Average number of services utilised per phase**

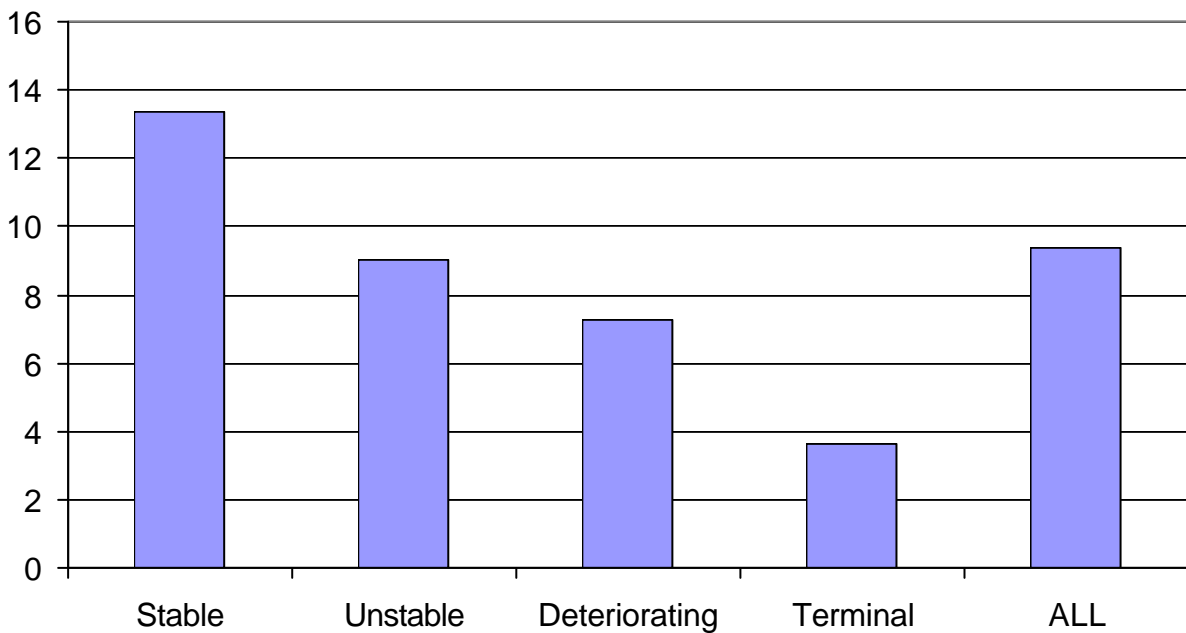


Table 25 reveals large differences in services per phase by site. Overall, the number of services per phase varied from 5.4 for Mid North Coast to 17.3 for West Victoria. For all sites other than Mid North Coast, the stable phase had the highest number of services per phase.

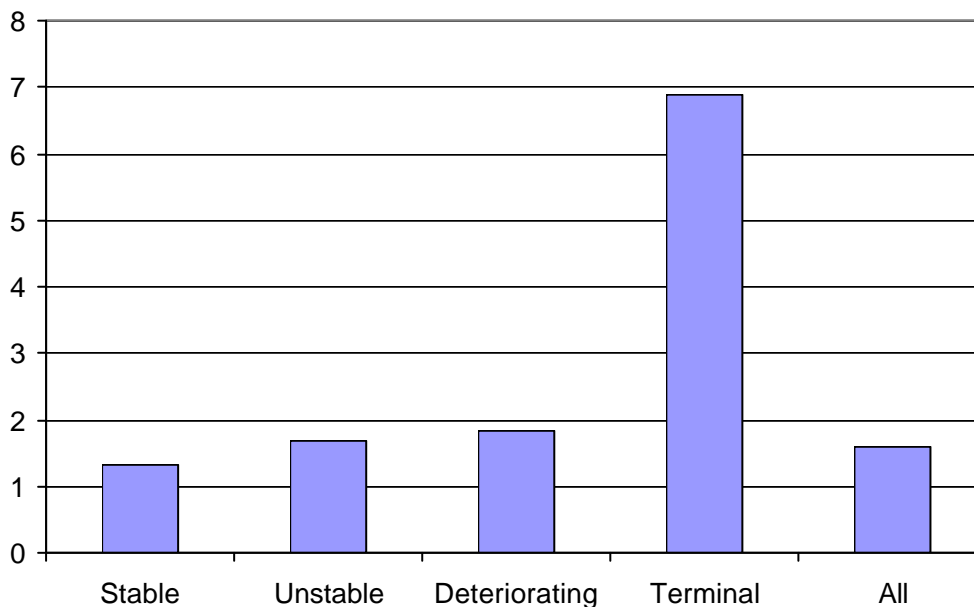
**Table 25 Average number of services utilised per phase by site**

Project	Stable	Unstable	Deteriorating	Terminal	All
Adelaide	11.0	9.1	4.9	8.5	9.5
Mid-North Coast	5.6	7.2	4.3	2.6	5.4
Eurobodalla	18.0	7.8	10.2	5.5	12.1
South-East Queensland	20.0	4.9	10.3	3.3	9.3
North-West Tasmania	15.8	9.5	7.8	2.0	10.4
West Victoria	19.8	19.7	14.1	1.8	17.3
<b>All</b>	<b>13.3</b>	<b>9.0</b>	<b>7.2</b>	<b>3.6</b>	<b>9.4</b>

#### 4.8.2 Service intensity by phase

The above results are partially driven by large differences in average length between phase changes (Table 14). This section considers service intensity, which is defined as the average number of services per week. The analysis was based only on completed phase records. Overall, patients received an average of 1.6 services per week. As expected, the intensity of services was highest for patients in terminal phases (6.9 services per week), and lowest in stable phases (1.3 service per week).

**Figure 18 Average number of services utilised per week by phase**



Service intensity apparently varied considerably by site, varying from 0.48 services per week in North West Tasmania to 3.63 services per week in West Victoria (Table 26). For the majority of sites, service intensity was highest in the terminal phase and lowest in the stable phase.

**Table 26 Average number of services utilised per week by phase and site**

Project	Stable	Unstable	Deteriorating	Terminal	All
Adelaide	1.09	1.77	1.67	6.24	1.38
Mid-North Coast	0.47	0.98	0.90	5.11	0.78
Eurobodalla	2.40	4.11	3.00	9.62	2.87
South-East Queensland	1.73	2.48	2.46	7.32	2.18
North-West Tasmania	0.53	0.39	0.53	2.05	0.48
West Victoria	2.78	3.96	5.82	5.67	3.63
<b>All</b>	<b>1.33</b>	<b>1.70</b>	<b>1.83</b>	<b>6.90</b>	<b>1.60</b>

## 4.9 Admission to hospital

### 4.9.1 Patient hospital history

Patient hospital history includes data from patients who recorded at least one hospital admission while they were enrolled in the project. Not all patients provided consent for their data to be used to evaluate the project. There were 692 patients enrolled in the evaluation, of which 532 patients gave the relevant level of consent. Of these, 247 (46.4%) had an inpatient hospital admission. Between them, these 247 patients had a total of 633 inpatient admissions from the six projects. Table 27 below summarises the hospital history data.

**Table 27 Summary of patient hospital history by project**

Project	No. of patients	No. of patients presenting to hospital	No. of hospital episodes	Average episodes per patient	No. of ED/OP attendances	Average length of stay *
Adelaide Hills	82	28	99	1.2	0	6.0
Mid North Coast	203	138	302	1.5	0	9.7
Eurobodalla	97	32	88	0.9	8	9.3
South East Queensland	70	24	89	1.3	4	4.0
North West Tasmania	28	6	10	0.4	0	9.4
West Victoria	52	19	45	0.9	11	9.0
<b>Total</b>	<b>532</b>	<b>247</b>	<b>633</b>	<b>1.2</b>	<b>23</b>	<b>7.9</b>

\* Average Length of Stay excludes ED/OP Episodes.

For the Adelaide Hills project, the average number of episodes per patient was the same as the overall average of 1.2 episodes. Eurobodalla, North West Tasmania and West Victoria reported lower than the average number hospitalisations, whilst the Mid North Coast and South East Queensland reported levels slightly above the average. Data on the number of hospital episodes per patient may be sensitive to several factors, such as the length of time that projects have been recruiting patients and/or collecting patient hospital history data, and the ability of different projects to obtain access to the relevant information.

The incidence of emergency/outpatient department (ED/OP) visits was low, with only 23 such episodes reported across all six projects, accounting for only 3.6% of total hospital episodes. The exceptions here were for West Victoria, for which 24.4% (11) of patient hospital history episodes reported were ED/OP admissions, and Eurobodalla, which reported approximately 9% (8) of hospital admission as ED/OP admissions.

Average length of stay (ALOS) for non-ED/OP hospital episodes was, for all projects, 7.9 days. Eurobodalla, Mid North Coast, North West Tasmania and West Victoria had ALOS figures above this average, whilst South East Queensland and Adelaide Hills had somewhat shorter stays at 4 and 6 days respectively.

#### 4.9.2 Phase of Care at inpatient admission

Phase of care at time of admission was determined for each hospital episode and is summarised in Table 28 below. Phase at time of admission was the last recorded phase prior to admission. This last recorded phase may have been recorded on the day of admission or in the days immediately prior to admission however for some patients the last recorded phase may have been some time before admission. We have not looked at changes in phase between admission and discharge and those records where a phase was not given a completion date (this only occurred when data collection ceased) have been excluded from the analysis.

**Table 28 Number of Admissions by Phase and Site**

	Stable	Unstable	Deteriorating	Terminal	Total
Adelaide Hills	68	18	6	0	92
Mid North Coast	77	101	80	5	263
Eurobodalla	17	10	8	1	36
South East Queensland	25	14	15	1	55
North West Tasmania	4	3	1	0	8
West Victoria	14	8	4	0	26
<b>Total</b>	<b>205</b>	<b>154</b>	<b>114</b>	<b>7</b>	<b>480</b>

The numbers show that there were more admissions during the stable phase than in any other phase. This is most likely due to the stable phase being the phase that patients spend most time in. Patients may also be admitted to hospital for reasons not related to their illness during this phase.

There were a considerable number of admissions during the unstable and deteriorating phase. However numbers continued to drop as the phases approached the terminal phase of care.

There were very few admissions in the terminal phase. This is unsurprising, as patients in the terminal phase could have been admitted while they were in another phase of care or have chosen to die at home.

Patient deaths during a hospital episode were reported in Section 4.7 above.

## 5 Patient experiences

Patient experiences were collected by using a modified version of the Patient Outcome Scale (POS). The original POS was devised following a systematic review of outcome measures used in palliative care<sup>8</sup>. This review concluded that there was a paucity of clinical questionnaires that could adequately reflect the holistic nature of palliative care<sup>9</sup>. The POS was designed to overcome some of the limitations associated with existing outcome measurement scales in palliative care. It evolved using a literature review of measures, work by a multi-professional project group with individuals who worked in different palliative care settings and a patient representative. The POS was then piloted in hospice, home, hospital and other community settings. The questionnaire covers: physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs.

### Coverage

Over the period April 2005 - December 2006, 97 patient experiences surveys were received from six projects. There were two main collection periods earlier in the period and towards the end of the period. For the purposes of this report the two collections will be called Time 1 (T1) and Time 2 (T2). The two different collections contain responses from individuals entered into the palliative care program/service at those times and are not the same group of people surveyed a second time. Therefore general comparisons only have been made between the two groups. Table 29 summarises responses by project and collection.

**Table 29 Number of tool 1.2/1.3 survey responses by project**

	Responses in Time 1 Number (%)	Responses in Time 2 Number (%)	Total
Adelaide Hills	15 (18.8)	24 (22.6)	39 (21.0)
Mid North Coast	28 (35.0)	43 (40.6)	71 (38.2)
Eurobodalla	9 (11.3)	12 (11.3)	21 (11.3)
South East Queensland	8 (10.0)	11 (10.4)	19 (10.2)
North West Tasmania	9 (11.3)	8 (7.5)	17 (9.1)
West Victoria	11 (13.8)	8 (7.5)	19 (10.2)
<b>Total</b>	<b>80 (43.0)</b>	<b>106 (57.0)</b>	<b>186 (100.0)</b>

With the exception of the Mid North Coast Project, the numbers of responses were quite modest, making it difficult to engage in meaningful comparisons across projects. The majority of analyses presented here will necessarily refer to patient experiences between collection periods and across projects as a whole.

### Patient characteristics

The demographic data collected by the Patient Experiences Tools collected were gender, age and race/ethnicity of the patient. In the first collection 51 patients were male (64.6%) and 28 female (35.4%). In the second collection 50 (49.0%) were male and 52 (51.0%) were female. In the first collection West Victoria had the highest percentage of male respondents (90.9%) and North West Tasmania the most females (55.6%), but the differences are not statistically significant.

With respect to age, this was only recorded for 66 patients in the first collection and 81 patients in the second collection. Patient ages ranged from 40 to 89 in the first collection and from 38 to 90 years in the second collection. The average age was 71.09 years in the first collection and 71.15 years in the second collection. There were some indications of differences in age structure across

<sup>8</sup> Hearn J, Higginson IJ. *Development and validation of a core outcome measure for palliative care: the palliative care outcome scale* *Quality in Health Care* 1999; 8: 219-27

<sup>9</sup> Hearn J and Higginson IJ (1997) *Outcome measures in palliative care for advanced cancer patients: a review* *Journal of Public Health* Volume 19, Number 2 Pp. 193-199



projects. In the first collection average ages ranging from a low of 61.7 years at the North West Tasmanian Project to a high of 75.9 years at Eurobodalla Project. In the second collection average ages ranged from 64.5 years at the North West Tasmanian project to 72.3 at the Adelaide Hills project. However, once again these differences were not statistically significant at conventional levels, possibly due to small numbers of responses from most projects. No patients described themselves as being of Aboriginal or Torres Strait Islander background, and only four identified with any specific ethnic origin.

### Question 1 - Over the past 3 days, have you been affected by pain?

**Table 30** *Extent of pain in past three days by collection and project*

Project	No		Slightly/Moderately		Severely/Overwhelmingly	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	4 (26.7)	3 (12.5)	9 (60.0)	18 (75.0)	2 (13.3)	3 (12.5)
Mid North Coast	2 (7.1)	8 (18.6)	18 (64.3)	22 (51.2)	7 (25.0)	9 (20.9)
Eurobodalla	0 (0.0)	1 (8.3)	8 (88.9)	11 (91.7)	1 (11.1)	0 (0.0)
South East Queensland	1 (12.5)	2 (18.2)	7 (87.5)	5 (45.5)	0 (0.0)	3 (27.3)
North West Tasmania	2 (22.2)	0 (0.0)	4 (44.4)	6 (75.0)	3 (33.3)	2 (25.0)
West Victoria	4 (36.4)	4 (50.0)	4 (36.4)	3 (37.5)	3 (27.3)	1 (12.5)
<b>Total</b>	<b>13 (16.5)</b>	<b>18 (17.8)</b>	<b>50 (63.3)</b>	<b>65 (64.4)</b>	<b>16 (20.3)</b>	<b>18 (17.8)</b>

Overall, most patients (approximately 63.9%) described their recent pain levels as having been either Slight or Moderate with slightly more indicating their pain levels were slight or moderate in the second collection. A further 17.2% reported no pain, with this being slightly higher in the second collection. Around 19% reported recent pain levels had been Severe or, in rare cases, Overwhelming, however, less patients reported these levels of pain in the second collection. There was very little variation from this pattern across the projects.

### Question 2 - Over the past 3 days, have other symptoms (eg, feeling sick, having a cough or constipation) been affecting how you feel?

**Table 31** *Effects of other symptoms in past three days by project*

Project	No		Slightly/ Moderately		Severely/ Overwhelmingly	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	3 (20.0)	10 (41.7)	9 (60.0)	11 (45.8)	3 (20.0)	3 (12.5)
Mid North Coast	2 (7.4)	13 (32.5)	22 (81.5)	24 (60.0)	3 (11.1)	3 (7.5)
Eurobodalla	0 (0.0)	2 (18.2)	5 (55.6)	8 (72.7)	4 (44.4)	1 (9.1)
South East Queensland	3 (37.5)	5 (50.0)	5 (62.5)	4 (40.0)	0 (0.0)	1 (10.0)
North West Tasmania	2 (22.2)	2 (25.0)	5 (55.6)	5 (62.5)	2 (22.2)	1 (12.5)
West Victoria	3 (27.3)	3 (37.5)	7 (63.6)	4 (50.0)	1 (9.1)	1 (12.5)
<b>Total</b>	<b>13 (16.5)</b>	<b>35 (34.7)</b>	<b>53 (67.1)</b>	<b>56 (55.4)</b>	<b>13 (16.5)</b>	<b>10 (9.9)</b>

Overall, there was an increase in the proportion patients who reported that they had not experienced any effects from other symptoms in the past three days. Most reported either Slight or Moderate symptoms (61%) with just over 13% reporting Severe or Overwhelming effects. There were improvements in the effects of other symptoms reported in each collection with more patients reporting no other recent symptoms and decreases in the proportion of patients reporting slight, moderate, severe or overwhelming effects from other symptoms.



The main exception to this pattern was in Eurobodalla where there was an increase in patients reporting slight/moderate effects from other symptoms. Eurobodalla also seemed to report lower levels of patients experiencing no effects from other symptoms, although small numbers may have affected the results both overall and for this particular project.

**Question 3. Over the past 3 days, have you been feeling anxious or worried about your illness or treatment?**

**Table 32 Anxiety & worry in past three days by project**

Project	No		Occasionally / Sometimes		Most of the time/ Completely Preoccupied	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	3 (20.0)	9 (37.5)	11 (73.3)	14 (58.3)	1 (6.7)	1 (4.2)
Mid North Coast	5 (18.5)	14 (36.8)	11 (40.7)	16 (42.1)	11 (40.7)	8 (21.1)
Eurobodalla	1 (11.1)	3 (25.0)	6 (66.7)	8 (66.7)	2 (22.2)	1 (8.3)
South East Queensland	2 (25.0)	2 (20.0)	4 (50.0)	6 (60.0)	2 (25.0)	2 (20.0)
North West Tasmania	2 (22.2)	0 (0.0)	4 (44.4)	7 (87.5)	3 (33.3)	1 (12.5)
West Victoria	3 (33.3)	4 (50.0)	3 (33.3)	3 (37.5)	3 (33.3)	1 (12.5)
<b>Total</b>	<b>16 (20.8)</b>	<b>32 (32.0)</b>	<b>39 (50.6)</b>	<b>54 (54.0)</b>	<b>22 (28.6)</b>	<b>14 (14.0)</b>

Overall, there were more patients who reported anxiety and worry only occasionally or sometimes. Those who reported no worry or anxiety in the last three days increased from 20% to 32%. Those reporting that they were worried or anxious most of the time or were completely preoccupied with worry and anxiety decreased during the evaluation. There was little indication of any disparities across sites (or by age or sex), particularly given the small number of responses for most projects.

**Question 4. Over the past 3 days, have any of your family or friends been anxious or worried about you?**

**Table 33 Family & friends anxiety & worry in past three days by project**

Project	No		Occasionally / Sometimes		Most of the time/ Always Preoccupied	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	4 (26.7)	5 (20.8)	8 (53.3)	11 (45.8)	3 (20.0)	8 (33.3)
Mid North Coast	4 (14.8)	9 (23.1)	10 (37.0)	14 (35.9)	13 (48.1)	16 (41.0)
Eurobodalla	1 (11.1)	0 (0.0)	2 (22.2)	6 (50.0)	6 (66.7)	6 (50.0)
South East Queensland	3 (37.5)	1 (10.0)	1 (12.5)	5 (50.0)	4 (50.0)	4 (50.0)
North West Tasmania	1 (11.1)	0 (0.0)	6 (66.7)	3 (37.5)	2 (22.2)	5 (62.5)
West Victoria	1 (9.1)	3 (37.5)	7 (63.6)	2 (25.0)	3 (27.3)	3 (37.5)
<b>Total</b>	<b>14 (17.7)</b>	<b>18 (17.8)</b>	<b>34 (43.0)</b>	<b>41 (40.6)</b>	<b>31 (39.2)</b>	<b>42 (41.6)</b>

Indications are that patients perceived that their families & friends were more anxious about them than they were themselves. Whereas, overall, just over 21% of patients felt anxious/worried most or all of the time (Q3), just over 40% felt that their family/friends were in these categories.

**Question 5 - Over the past 3 days, how much information have you and your family or friends been given?**

**Table 34 Information given in past three days by project.**

Project	Full		Hard to Understand/ Would have like more		Very Little / None	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	13 (86.7)	17 (70.8)	1 (6.7)	0 (0.0)	1 (6.7)	7 (29.2)
Mid North Coast	15 (55.6)	24 (63.2)	8 (29.6)	10 (26.3)	4 (14.8)	4 (10.5)
Eurobodalla	6 (66.7)	6 (54.5)	2 (22.2)	3 (27.3)	1 (11.1)	2 (18.2)
South East Queensland	6 (75.0)	8 (80.0)	1 (12.5)	1 (10.0)	1 (12.5)	1 (10.0)
North West Tasmania	7 (77.8)	8 (100.0)	1 (11.1)	0 (0.0)	1 (11.1)	0 (0.0)
West Victoria	8 (72.7)	2 (28.6)	1 (9.1)	1 (14.3)	2 (18.2)	4 (57.1)
<b>Total</b>	<b>49 (67.1)</b>	<b>65 (66.3)</b>	<b>14 (19.2)</b>	<b>15 (15.3)</b>	<b>10 (13.7)</b>	<b>18 (18.4)</b>

Overall, nearly two thirds of patients reported that they had received full information in the previous three days. A further 17% reported receiving either information that was hard to understand or insufficient information. Around 16% felt they had received very little or no information at all with an increase in patients reporting that they received little or no information in the second collection.

#### Question 6 - Over the past 3 days, have you been able to share how you are feeling with your family or friends?

**Table 35 Sharing feelings with family/friends in past three days by project.**

Project	As much as I wanted/ Most of the time		Sometimes / Occasionally		Not At All	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	13 (86.7)	19 (79.2)	2 (13.3)	4 (16.7)	0 (0.0)	1 (4.2)
Mid North Coast	24 (88.9)	24 (61.5)	3 (11.1)	8 (20.5)	0 (0.0)	7 (17.9)
Eurobodalla	9 (100.0)	9 (75.0)	0 (0.0)	3 (25.0)	0 (0.0)	0 (0.0)
South East Queensland	8 (100.0)	9 (90.0)	0 (0.0)	1 (10.0)	0 (0.0)	0 (0.0)
North West Tasmania	9 (100.0)	9 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
West Victoria	7 (63.6)	6 (75.0)	3 (27.3)	0 (0.0)	1 (9.1)	2 (25.0)
<b>Total</b>	<b>70 (88.6)</b>	<b>76 (74.5)</b>	<b>8 (10.1)</b>	<b>16 (15.7)</b>	<b>1 (1.3)</b>	<b>10 (9.8)</b>

Most patients (82%) reported that they had been able to share their feelings with family/friends at least most of the time. Approximately 5% reported not being able to share feelings with family or friends with an increase from approximately 1% to 10% over the two collections.

#### Question 7. - Over the past 3 days, have you been feeling depressed?

**Table 36 Feeling depressed in past three days by project**

Project	No	Occasionally / Sometimes		Most of the time / Yes, definitely		
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	8 (53.3)	12 (50.0)	7 (46.7)	10 (41.7)	0 (0.0)	2 (8.3)
Mid North Coast	11 (40.7)	17 (44.7)	13 (38.1)	16 (42.1)	3 (11.1)	5 (13.2)
Eurobodalla	2 (22.2)	0 (0.0)	7 (77.8)	9 (75.0)	0 (0.0)	3 (25.0)
South East Queensland	2 (25.0)	2 (20.0)	6 (75.0)	6 (60.0)	0 (0.0)	2 (20.0)

Project	No		Occasionally / Sometimes		Most of the time / Yes, definitely	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
North West Tasmania	2 (22.2)	1 (12.5)	6 (66.7)	7 (87.5)	1 (11.1)	0 (0.0)
West Victoria	4 (36.4)	3 (37.5)	7 (63.6)	4 (50.0)	0 (0.0)	1 (12.5)
<b>Total</b>	<b>29 (36.7)</b>	<b>35 (35.0)</b>	<b>46 (58.2)</b>	<b>52 (52.0)</b>	<b>4 (5.1)</b>	<b>13 (13.0)</b>

Only 9% of patients reported feeling depressed all or most of the time in the previous three days, with an increase in numbers in the second collection. However, 55% reported depression 'Occasionally' or 'Sometimes', whilst just under 36% reported no or depression at all. Again, age, sex and project were found not to be reliable predictors of responses to this question.

**Question 8. - Over the past 3 days, how much time do you feel has been wasted on appointments relating to your health care (e.g. waiting around for transport or repeating tests)?**

**Table 37 Time wasted on healthcare in past three days by project**

Project	None		Up to half a day		More than half a day	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	14 (93.3)	21 (87.5)	1 (6.7)	2 (8.3)	0 (0.0)	0 (0.0)
Mid North Coast	22 (88.0)	38 (95.0)	3 (12.0)	2 (5.0)	0 (0.0)	0 (0.0)
Eurobodalla	6 (66.7)	10 (83.3)	2 (22.2)	2 (16.7)	1 (11.1)	0 (0.0)
South East Queensland	7 (100.0)	10 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
North West Tasmania	9 (100.0)	8 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
West Victoria	11 (100.0)	7 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
<b>Total</b>	<b>69 (90.8)</b>	<b>94 (94.0)</b>	<b>6 (7.9)</b>	<b>6 (6.0)</b>	<b>1 (1.3)</b>	<b>0 (0.0)</b>

Table 37 clearly suggests that waste of time on healthcare appointments is not perceived by patients as being an important factor. Overwhelmingly (92.4%), patients reported that no time had been wasted in this way in the previous three days. Only Eurobodalla produced slightly different results, but given the small number of responses this may well be an aberration.

**Question 9. - Over the past 3 days, have any practical matters resulting from your illness, either financial or personal, been addressed?**

**Table 38 Practical matters addressed in the last three days**

Project	Yes, affairs up to date/ Currently being addressed		Not addressed		No Problems	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	11 (73.4)	14 (58.3)	1 (6.7)	2 (8.3)	3 (20.0)	8 (33.3)
Mid North Coast	19 (73.1)	18 (46.2)	1 (3.8)	0 (0.0)	6 (23.1)	21 (53.8)
Eurobodalla	7 (77.7)	7 (63.7)	0 (0.0)	1 (9.1)	2 (22.2)	3 (27.3)
South East Queensland	7 (87.5)	10 (100.0)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)
North West Tasmania	6 (66.7)	3 (37.5)	0 (0.0)	2 (25.0)	3 (33.3)	3 (37.5)
West Victoria	9 (81.8)	5 (71.5)	0 (0.0)	0 (0.0)	2 (18.2)	2 (28.6)
<b>Total</b>	<b>59 (75.6)</b>	<b>57 (57.6)</b>	<b>2 (2.6)</b>	<b>5 (5.1)</b>	<b>17 (21.3)</b>	<b>37 (37.4)</b>

Overall, there was little evidence of problems being encountered by patients in having their financial and personal affairs attended to, with only 4% of patients reporting that these matters were not being addressed. Over 75% reported that matters were either up to date or being addressed in the first collection but this decreased to just under 58% in the second collection. Approximately 30% reported that no such problems existed in the previous three days. There was little evidence of any significant variation in this pattern across projects in the first collection, however, in the second collection all patients at the South East Queensland project reported that their affairs were up to date or being addressed whilst Adelaide Hills and Tasmania both had two patients who reported their problems were not being addressed.

**Question 10 - Have you been involved in decisions about your treatment or practical matters as much as you would like?**

**Table 39 Involvement in decisions by project**

Project	Yes, all of the time/ Most of the time		Sometimes/ Occasionally		No, not at all	
	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)	T1 n(%)	T2 n(%)
Adelaide Hills	14 (93.3)	20 (83.3)	1 (6.7)	2 (8.3)	0 (0.0)	2 (8.3)
Mid North Coast	24 (88.9)	20 (55.6)	1 (3.7)	7 (19.4)	2 (7.4)	9 (25.0)
Eurobodalla	5 (55.6)	10 (83.3)	4 (44.4)	2 (16.7)	0 (0.0)	0 (0.0)
South East Queensland	6 (87.5)	8 (88.9)	1 (14.3)	1 (11.1)	0 (0.0)	0 (0.0)
North West Tasmania	8 (88.9)	7 (87.5)	1 (11.1)	1 (12.5)	0 (0.0)	0 (0.0)
West Victoria	10 (90.9)	6 (75.0)	1 (9.1)	2 (25.0)	0 (0.0)	0 (0.0)
<b>Total</b>	<b>67 (85.9)</b>	<b>71 (73.2)</b>	<b>9 (11.5)</b>	<b>15 (15.5)</b>	<b>2 (2.6)</b>	<b>11 (11.3)</b>

Overall, almost 80% of patients reported high levels of involvement in decision making, however, levels seemed to drop in the second collection. Respondents reporting no involvement increased at the Adelaide Hills and Mid North Coast projects although none of the respondents at the remaining projects reported no involvement in either the first or second collections. However, it is difficult to establish whether this is a statistically reliable finding due to both small numbers of responses and lack of persons reporting little involvement at most projects. Neither sex nor age seems to be related to perception of involvement in decision-making.

**Comments on Quality of Life**

Patients and staff who completed tools 1.2 or 1.3 were asked to describe the things that had the greatest effect on the patients quality of life in the past three days. They were also asked to note whether each thing described made their life better or worse during this time. Comments typical of those made by patients or staff regarding those things that made quality of life better or worse appear below.

**Comments relating to better quality of life**

**Patient**

- Before seeing palliative care nurse 3 days ago I was in incredible pain. After consulting with PCN we agreed to try some steroids. Until this time of consultation quality of life did not exist as I was consumed by pain and worry. After consultation and commencing steroids, pain decreased therefore the worry decreased. Everything has been explained to me, which has also made quality of life better as I am now empowered with information.
- Walking with dogs makes you feel good and clears' the negative thoughts. Out in the garden and sun.
- Quality of family relationships and support makes my quality of life better.

- Having a BPAP machine set up - 100% better. Honest answers from the doctor. Support of palliative care team - excellent, gives me great confidence and reassurance. Returning home and support of wife and family has made me feel wholly better - physically and spiritually.
- My quality of life under the circumstances is very good. All my family are very understanding and I do not concern myself with my health problems. Doctors' and staff from visiting Palliative Care are excellent and would have no hesitation in ringing them at any time, and they are always caring of my immediate family.
- Able to change colostomy independently and manage the stoma etc better
- Have perm appointments with GP - makes me feel more in control
- Knowing at the end of my life my dignity should be preserved.

#### **Carer/Staff**

- Getting food organised and on time (gets anxious if late or uncertain)
- Paid carers coming in daily to help patients partner with showering, dressing, in and out of wheelchair etc.
- The satisfaction that my wife should be cared for without help of family.
- Would like to make an advanced care directive. LMD to be contacted re same. Very fearful re type of death. Wants to be 'peaceful' if possible.
- Oxygen concentrator made my quality of life much better. Morphine has controlled my pain satisfactory to date. Community nursing is to be complimented in every way.
- New stair lift (not DVA supplied) helps from ground level to living level.
- [Patient] needed to come to hospital, unable to be cared for at home. Patient had not wanted to come to hospital. Family all in attendance. Being managed better now on End-of-Life Pathway.
- He is on Durogesic Patch 25mgs 3rd daily which has significantly improved his quality of life as seen by increase in his appetite and attempting to communicate.

#### **Comments relating to worse quality of life**

##### **Patient**

- With the amount of morphine I take (320ml a day) I have to take senna to counteract the side effects, this in turn makes my motions very unpredictable, I have to, some days, not go out at all, which is most distressing, because I can't control it.
- The cost of all my medications are causing extreme problems
- loss of independence has made life worse & frustrating for me
- Relying on other people to do things for me
- Lack of being able to get about like I used to is the main problem. I have to go for more tests in a weeks' time and will have to wait for transport to take me and later take me home
- It's constant pain and it's curbing it as it doesn't go away. Can't sleep even with drugs, so 12 hours or longer spend in bed so days are short to do all that has to be done.
- A skin growth is being treated by my doctor, but I do not feel that he has explained to me adequately what he is doing, why and what the options are.
- Breathing is difficult for me. Having to be attached to an oxygen machine night and day, even walking around the room becomes hard, plus with my hypertension I can't seem to be able to exert myself in any small way. Each day my mobility seems to be less.

##### **Carer/Staff**

- Patients partner (full time carer) highly stressed and anxious. Not coping and verbalises this to client.

- Severe pain when necessary to sit as a result of cancer in lower pelvic and anal area.
- Less mobility due to pain
- Patient not having access to hand-held telephone
- Margaret has no quality of life - calls out continuously "excuse me" or "nurse". Increase of epilim has not made any difference to mental anguish.
- Resident's quality of life has remained the same possibly due to the fact she is not aware fully of her prognosis (memory impairment). Her husband becomes very obsessed with her condition and worries she is in pain. However, no obvious indications that she is in pain.
- Depression due to isolation from family especially the children wish to have family around. Distressed with loss of licence felt a feeling of finality.

## 6 Carer experiences

This section reports on 139 Tool 1.4 Surveys submitted to CHSD by six projects early in the evaluation (Time1) and towards the end of the evaluation (Time 2). Table 40 summarises responses by project.

**Table 40 Number of tool 1.4 survey responses by project**

Project	No. of responses at T1	No. of responses at T2	Total
Adelaide Hills	11	18	29
Mid North Coast	28	17	45
Eurobodalla	9	9	18
South East Queensland	8	9	17
North West Tasmania	9	2	11
West Victoria	17	2	19
<b>Total</b>	<b>82</b>	<b>57</b>	<b>139</b>

With the exception of Adelaide Hills and the Mid North Coast, the number of responses were quite modest. This makes it difficult to make meaningful comparisons across projects. Hence, the majority of analyses presented here will necessarily refer to carer experiences across projects as a whole with the main comparison's drawn between Time 1 (T1) and Time 2 (T2).

The *Carer Experiences With Palliative Care Survey* (Tool 1.4) also collected data on gender, age and race/ethnicity of the carer. As expected, given that females on average outlive their male partners, the majority of carers (68.5%) were female. In the first collection 53.3% were female and 63.3% were female in the second collection. With respect to age, this was only recorded for 121 of the 137 carers, whose ages ranged from 36 to 86 years in the first collection and 32 to 90 years in the second collection. The average age was 65.9 years in the first collection and 67.0 in the second collection. Given small numbers of responses from most projects, there was little indication of differences in age structure. In the first collection average ages ranged from a low of 62.4 years for the Tasmania Project to a high of 72.43 years at Eurobodalla. Average ages in the second collection ranged from 61.9 years in the South East Queensland Project to 69.5 years in the Tasmanian Project.

Only two carers described themselves as being of Aboriginal or Torres Strait Islander background, and three others identified with a specific ethnic origin (English, Greek and German).

### Carer experiences with palliative care services

Carers were asked to rate a series of 11 statements about palliative care services, with possible responses limited to 'Agree', 'Disagree' and 'Don't Know' (the latter could also have indicated that the statement was not applicable to the carer). Overall responses are summarised in Table 41 as



percentages. There were a small number of carers who did not complete one or more of these items across the two collections. For the first eight statements, either two or three carers failed to provide a response, whilst five carers omitted to answer the final three statements.

**Table 41 Carer ratings of statements regarding palliative care services (percent)**

Statement	Agree		Disagree		Don't know	
	T1	T2	T1	T2	T1	T2
I feel that adequate attention is paid by the service to my needs as a carer	95.3	96.3	0	0	4.7	3.7
I have been provided with all the equipment I need to help me in my caring role	89.2	86.5	0	0	10.8	13.5
I feel confident about using the equipment that has been supplied	90.8	82.7	0	0	9.2	17.3
I have been supplied with clear instructions about what to do in an emergency	86.2	90.4	4.6	3.8	9.2	5.8
I feel confident that every effort is being made to keep the person I am looking after free of pain	95.4	100.0	1.5	0	3.1	0
I know who to contact for help if I need it	100.0	98.1	0	0	0	1.9
I feel secure that help and advice is available 24 hours a day for me	93.8	98.1	1.6	0	4.7	1.9
The palliative care staff are helpful and friendly	100.0	100.0	0	0	0	0
I feel comfortable with the palliative care staff visiting my home	100.0	98.0	0	0	0	2.0
Respite is available so that I can have a break if I need it	81.3	74.5	6.3	3.9	12.5	21.6
I know there are people I can contact for support after the person I am caring for has died.	88.7	75.5	3.2	1.9	8.1	22.6

The results presented in Table 41 reveal that carers overwhelmingly agreed with all 11 statements for both the first collection and the second collection. Given that carers were instructed to use 'Don't Know' as a proxy for 'Not Applicable', it is difficult to say whether the drop in agreement to statements regarding the supply and use of equipment, respite care and support contacts indicate a lack of knowledge or a perception that the statement is not relevant to that carer. It is interesting to note that disagreement with these statements either fell or remained at zero over the two different collections. It is encouraging that there were increases in the number of carers agreeing that they had been supplied with clear instructions on what to do in an emergency and that the person they care for is being kept free of pain.

### Overall Support and Assistance

Carers were asked to rate the following statement "Overall the support and assistance I have received has been" as either: excellent, good, satisfactory or poor. Table 42 summarises the responses received for the first and second data collection.

**Table 42 Carer rating of overall support and assistance**

Rating	T1 – n (%)	T2 – n (%)
Excellent (no improvement necessary)	68 (84.0)	33 (67.3)
Good (my needs are met, but the service could be improved)	11 (13.6)	10 (20.4)
Satisfactory (most of my needs are met)	2 (2.5)	6 (12.2)
Poor (few of my needs are met)	0 (0)	0 (0)
<b>Total</b>	<b>81</b>	<b>49</b>

Across the two collections all but eight respondents rated the overall support and assistance received as either 'Excellent' or 'Good'. Over the two collections there was a drop in the number of respondents who rated the service as excellent and an increase in the number of respondents who rated the service as only satisfactory; however no-one rated the service as poor in either collection. Chi square testing showed that changes observed between collections were significant at the 0.05 level.

Across the projects it was difficult to make comparisons, in particular for Tasmania and West Victoria due to insufficient data. For Adelaide Hills, Mid North Coast, Eurobodalla and South East Queensland there was a drop in respondents who rated the service as 'Excellent' or 'Good' from 100% in the first collection to between 93.8% at the Mid North Coast to 75% in South East Queensland for the second collection.

## Other Questions

Tool 1.4 also asked four supplementary questions. Table 43 below summarises responses to these questions.

**Table 43 Responses to supplementary questions by collection**

Question	Rating	T1 n (%)	T2 n (%)
Have you had someone to help you with practical tasks?	Yes	42 (51.9)	21 (43.8)
	Not Enough	3 (4.9)	3 (6.3)
	Not Needed	27 (33.3)	22 (45.8)
	No	8 (9.9)	2 (4.2)
	Total	80	48
Did anyone give you information on whether you would qualify for a carer payment or allowance?	Yes	59 (77.6)	36 (72.0)
	Not Enough	2 (2.6)	3 (6.0)
	Not Needed	7 (9.2)	9 (18.0)
	No	8 (10.5)	2 (4.0)
	Total	76	50
Did someone give you information about available support services?	Yes	57 (71.3)	32 (61.5)
	Not Enough	11 (13.8)	6 (11.5)
	Not Needed	11 (13.8)	12 (23.1)
	No	1 (1.3)	2 (3.8)
	Total	80	52
Did someone give you practical training in lifting, managing medicine or other tasks?	Yes	31 (38.8)	9 (17.3)*
	Not Enough	1 (1.3)	3 (5.8)
	Not Needed	31 (38.8)	29 (55.8)*
	No	17 (21.3)	11 (21.2)
	Total	80	52

\* significant difference observed at the 0.05 level

Overall, the majority of respondents responded to these additional questions by recording 'Yes' or 'Not Needed'. There was a drop in the number of 'Yes' responses in the second collection, however, most of this shift was taken up by an increase in the number of respondents using the 'Not Needed' response. Only in the final question about practical training in lifting, managing medication and other tasks were these changes observed as significant. The observed proportion of respondents who indicated 'No' to this question (approximately 21%) did not change in the second collection.



There were also the following notable differences in response patterns across Projects:

- For the first question (help with practical tasks), the only significant shift occurred in the South East Queensland Project where 'Yes' responses dropped from 75.0% to 66.7% and 'Not Needed' responses rose from 25.0% to 83.3%.
- For the second question (information on Carer Payment/Allowance), the Mid North Coast Project observed a drop in those answering both 'Yes' (75.0% to 66.7%) and 'No' (20.8% to 0%) and a corresponding rise in respondents who indicated this information was 'Not Needed' (4.2% to 26.7%). Eurobodalla observed a very different shift with respondents indicating 'Yes' rising from 57.1% to 100%.
- For the third question (information on available support services), all projects (omitting West Victoria) recorded a drop in respondents who indicated that there was not enough information, except for Eurobodalla, however, numbers were too small in this project to show anything conclusive.
- For the final question ('practical training in lifting, managing medicine or other tasks'), there was a significant increase (37% to 81.3%) in respondents indicating that training was not needed with a corresponding fall in respondents choosing both 'Yes' and 'No' for this question.

### Other Comments

Finally, carers were invited to add any comments about their experience that they would like to share, and just over 40% (56 of 137) provided substantive comments in this section. The majority of comments were of a positive nature, and by far the largest number were in praise of the services provided, and particularly the staff with whom carers had contact. Typical of these comments were the following:

- 'The palliative care nurses are a great support system that is priceless. For useful hints and help. Also the extremes they go to make sure things are rolling along smoothly. And very helpful. Nothing is a problem for them.'
- 'I am very impressed with the level of support offered to my mother. Knowing that this support exists, eases my anxiety about supporting her to stay at home. She is very keen to stay in her own unit.'
- 'I was experiencing a lot of depression. Since the nurse has been calling a weight has been lifted from myself - I still sometimes suffer with depression, however not nearly as much. The visits from the staff have opened up problem areas for discussion (between my husband and myself) and we tend to cope with our situation better - not so much in the dark! We do appreciate all the help and kindness afforded to us by the staff.'
- 'I have found the Palliative Care Unit ... to be absolutely fabulous to us. They are always there when you need them. They are so caring and are looking out for your best interests. I would have felt totally lost without them I cannot say enough about them.'
- I do not have a carer other than my husband and Palliative Care nurse calls once a week to see if all ok but feel very secure that they are only a phone call away, and will have no hesitation in calling them.

There were approximately ten comments which could be construed as being critical of services offered. These are reproduced below. Note that the only issue which appears more than once (approximately four comments) is that of carer allowances.

- 'The services provided have been very professional and extremely helpful. However the ability of care packages is not adequate e.g. Being male and looking after my mother. Showering and dressing my mother when packages are available is good but there is no ongoing package to provide this care. If not for the assistance of family friends and my sister who travels 400km return each weekend to provide showering and dressing assistance the

cost of providing daily assistance would be prohibitive and thus my mothers level of cleanliness and comfort would be affected.'

- 'I feel that people (families) in our position need more respite breaks i.e. 4 day weekends. I feel that this would lighten the load.'
- Respite could be more readily available, especially at short notice. Not all needs can be planned.
- 'My greatest concern about the palliative care my relative is receiving is that, even though it is an exceptional facility that is staffed by very good people, no one managerially or clinically is thinking innovatively or using professional initiative. A routine is in place, and that routine is applied without thought or review. The only time that the routine is thought about is when something goes wrong. Even then we have to suggest enhancements or changes.'
- 'Due to small community, there are privacy issues. The woman who was to do her husband's personal care was a family friend therefore was inappropriate to do his showers, as he felt uncomfortable. His wife has had to continue with his personal care, she has her own health problems related to osteoarthritis, needs hip joint replaced.'
- 'Commenced carer pension one month ago, however have been carer for over 12 months. Possibly need to improve carers earlier for their entitlement.'
- 'Carers allowance was applied for and declined by Centrelink due to (name deleted) (registered nurse) saying that Mum's condition was temporary. Have not bothered to apply again and not interested.'
- I feel the way the person I care for was informed there was no more treatment options for him was done in a callous, off-hand manner. It caused undue stress and fear and should probably have been done by a pall care dr. The past ten days from this appt has been appalling/distressing.
- For country people (we) should not have to fill in so much paperwork for travel and accommodation, all hospital appointments should be co-ordinated to be on same day.
- More time is needed to talk to patient and reassure them that they are being given all the care possible.

The ten negative comments were spread across the RPC Projects and there was no real difference between the number of negative comments in the first collection compared to the second collection.

## **Part Four – Impact and Outcomes for Providers**

## 7 Professional participation and development

### 7.1 Multidisciplinary participation

The evaluation team defined multidisciplinary participation as involvement of medical, nursing, allied health, pastoral care and volunteers in the development and implementation of the project or the care of individual patients and their carers. It does not include education and training activities.

At project commencement, two projects planned to include multidisciplinary participation, with the six other projects planning to partially include this element of the GAPS model.

The key strategies used to develop or enhance multidisciplinary participation were other elements of the GAPS model. These elements are discussed elsewhere in this report and include:

- Governance, especially the Governance committees, clinical committees and other sub committees (see Section 9)
- Multidisciplinary team meetings or case conferences (see Section 10.1)
- Shared protocols, including referral guidelines and forms (see Section 10.2)
- Patient held record (see Section 10.4)
- Management and use of patient information (see Section 11)

Other strategies developed and implemented in addition to the GAPS model were also designed to enhance multidisciplinary participation, and these are also discussed elsewhere in the report:

- Link Nurse groups (see Section 10.5.2)
- Links with specialist palliative care services (see Section 10.5.1).

Professional education and development was used by some projects to both develop knowledge and skill, plus develop multidisciplinary participation. For example, projects strategically offered education sessions for all health providers and traditional GP sessions were opened up to allied health providers, with case studies presented aimed to develop multidisciplinary patient care.

### 7.2 Professional development and education

The evaluation team defined professional development and education as education or training with a general palliative care focus. Includes activities to identify professional development needs of health professionals.

At project commencement, six projects planned to implement professional development and education, with the two other projects planning to partially include this element of the GAPS model.

Professional development and education was a strong focus for all projects. All eight projects identified strategies for professional education and development in their project plans. Western Victoria planned the most strategies for professional education and development, followed by governance, other strategies and direct care (see Figure 2 on page 15). Other projects planned more strategies that were focused on direct care.

Projects undertook training needs assessments. Some projects used the results from Tool 2.1 survey. Other projects established the needs of individual health providers, such as GPs or Link nurses or RACFS staff. One project conducted focus groups that were independently facilitated involving GPs, health service staff and volunteers to establish training needs. The Eastern

goldfields DGP identified the educational needs of GPs through one to one interviews with GPs once a year by the CEO of the Division and collecting feedback from each educational session that is organised.

One project organised 'The Kingaroy Palliative Carer Education Day', with the program developed, facilitated and evaluated by the Mt Olivet Palliative Care Research Unit. Forty-one health providers attended the parallel day long workshops (10 GPs and 31 nurses). The evaluation report concluded that the program was a success in improving both the educational and clinical outcomes as well as the workshop satisfaction outcomes of the participants. The educational model proved to be educationally and clinically effective, clinician acceptable and a cost efficient means of up-skilling primary health care providers in palliative care. This workshop also identified training needs that the project was then able to address across the remainder of the project.

Many educational sessions were designed and delivered during the life of the project. The subject matter was diverse and education programs well received. The numbers participating were impressive. For example, the Mid North Coast project provided 185 palliative care learning and development events implemented for 2,496 health care providers over the life of the program.

There were many professional development and education sessions or programs for GPs. The North West Tasmanian project coordinator became accredited with the Royal Australian College of GPs for the provision of continuing professional education, an initiative that proved to be valuable in promoting education to GPs. Both North West Tasmania and Adelaide Hills successfully facilitated Small Group Learning sessions for GPs. The Mid North Coast facilitated 16 GP field placements with the specialist palliative care team. They reported that this was a vital networking strategy that assisted in validating GP's palliative care competencies.

The training of International Medical Graduates (IMGs) was a unique strategy for West Victoria. IMGs make up 51% of the GP workforce in the local area. Of these, 21 of the 38 are not vocationally registered. The training is facilitated by the GP consultant and the senior project manager. During the life of the project 21 GPs from Egypt, Pakistan, China, Eastern Europe and Peru received training.

A cultural awareness package was developed at the Pilbara project for use in Western Australia.

The need to increase palliative care knowledge in RACFs was identified by five projects. The Mid North Coast project offered a 16 hour palliative approach competency course, with 54% of all care assistants employed in local RACFs completing the course. In addition, the RACF based Link Nurses were provided with 40 hours of palliative care education including a 16 hour field placement with the specialist palliative care team. The West Victoria project conducted regional forums through the Aged Care GP Panels. These were attended by 44 aged care facilities within the local area. For this project, the Panels program will be the vehicle to deliver ongoing palliative care education sessions into the future.

Education sessions conducted by the projects included an evaluation. As one example, an evaluation of a Link Nurse education program in South East Queensland found that all respondents agreed that their knowledge had increased in all areas of palliative care.

A range of guidelines and resources were provided by the project to GPs and service providers to support the training and education programs. Some of these were developed by the projects and others were external resources. Projects developed newsletters for health professionals designed as informative and educational tools. The Adelaide Hills GP Advisor distributed clinical updates to health providers that were well received. Some projects used websites to post resources and guidelines. The Adelaide Hills was able to monitor hits on its website, with community and professional information being the top two topics.

Another strategy implemented by some projects was to sponsor individuals to attend various programs. For example a GP champion was sponsored to completed the Certificate of Palliative Care (8 credit points) through Monash University, five local registered nurses where sponsored to attend the National Palliative Care Conference and four participants (an RN and three volunteers) were sponsored to attend a grief counselling day.

Six projects linked in with an existing PEPA program. In Eurobodalla, four members of the steering committee and a local hospital pharmacist participated in PEPA. As part of the program each member worked for 32 hours in the palliative care ward. This proved to be an excellent capacity building exercise that will strengthen the professional palliative care links between Sydney and Eurobodalla.

All the projects were able to develop, implemented and evaluation a range of professional development and education strategies. The challenge was to provide education strategies that were sustainable in the region. Projects attempted to address this through strategies such as developing champions, that is, GP champions or Link Nurse champions through the Small Group Learning sessions or the Link Nurse groups. Another strategy was to establish links with specialist palliative care services that could provide ongoing education. A third strategy was to use existing programs that will continue after the end of the program, such as PEPA and MSOAP.

In future programs consideration should be given as to whether professional development and education should be funded by the projects or self-funded by participating organisations (which should be part of their core business). Perhaps a balance between both would be appropriate, with professional education only being eligible for funding if the aim is to do more than traditional continuing professional development and included, for example, training in how to develop partnerships, develop clinical guidelines or develop links with specialist services. For most RCPG projects, professional development and education was more than traditional training sessions. They used training to develop partnerships, develop clinical guidelines and develop links with specialist services. In addition, the project coordinators used professional development events to bring stakeholders together from a range of funding bodies.

## 8 Changes in Palliative Care Provider's views and attitudes

This section reports on palliative care providers' views and attitudes. The data were collected through Tool 2.1, 'Palliative Care providers' views and attitudes', which is based on the 'Attitudes towards death survey' by Strumpf<sup>10</sup> and 'A survey instrument to measure physician self-confidence and concerns about end-of-life clinical skills and decision-making'.<sup>11</sup> The tool was designed to measure confidence about knowledge and skills, attitudes towards palliative care and perceived educational need among providers.

The data were collected at two time points in order to assess how confidence, attitudes and perceptions of educational need may have changed during the life of the project. The initial data collection period was between February and May 2005. The second collection was held between July and December 2006. As shown in Table 44, the total number of responses was 543 in the 'base-line' sample and 409 in the 'end-point' sample. The number of responses from each project was often quite different between the two samples. This is particularly so for West Victoria.

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<sup>10</sup> Strumpf, N. *Attitudes towards death survey*, University of Pennsylvania

<sup>11</sup> Weissman, DE and Ambuel, B (1996). *A survey instrument to measure physician self-confidence and concerns about end-of-life clinical skills and decision-making*, Medical College of Wisconsin.



**Table 44 Tool 2.1 data submitted by Projects**

RPCP Projects	Number of responses (base-line)	Number of responses (end-point)
Adelaide Hills	78	148
South East Queensland	64	13
Eurobodalla	61	26
Mid North Coast	86	183
West Victoria	171	6
North West Tasmania	66	13
Pilbara	17	20
<b>Total</b>	<b>543</b>	<b>409</b>

## 8.1 Profile of respondents

Respondents to Tool 2.1 were asked to report their sex, indigenous status, age, professional discipline and the amount of training specific to palliative care that they had completed. Respondents differed in these characteristics between projects and over time, as reported below. These differences need to be taken into account when interpreting the results that follow. Some respondents did not complete all items. The numbers of missing responses are reported in the following tables, although they are not included in the percentage calculations.

Sex was recorded for 349 of the 362 responses during the baseline responses and 372 of the 409 endpoint responses. There were 280 female providers (80.2%) and 69 males (19.8%) during baseline responses. During endpoint responses there were 334 (89.8%) female responses and 68 (18.2%) male responses. The high female provider population is consistent during both sampling periods. Only two out of the 362 providers who completed the baseline survey identified themselves as Aboriginal or Torres Strait Islander (ATSI). During the endpoint survey, six out of 409 providers identified themselves as from ATSI.

The ages of palliative care providers varied from 18 years of age to 75 years of age. The average was 44.0 years in the baseline sample, and slightly older (46.8 years) in the endpoint sample. The most common age category in both sets of data was 45-54 years (41.3% in the baseline sample and 46.6% in the endpoint sample). Table 45 shows the age distribution by project for the baseline sample and Table 46 shows the corresponding distribution for the endpoint sample.

**Table 45 Provider age at baseline**

Age Range	No. providers (all projects)	% All projects	AH (%)	SEQ (%)	E (%)	MNC (%)	WV (%)	NWT (%)	P (%)
15 - 24	23	4.8	3.1	1.7	0.0	2.4	8.9	7.4	0.0
25 - 34	49	10.1	10.8	8.5	3.8	8.5	10.8	11.1	33.3
35 - 44	149	30.8	30.8	30.5	32.7	28.0	36.3	18.5	26.7
45 - 54	200	41.3	38.5	33.9	46.2	47.6	36.9	51.9	40.0
55 - 64	56	11.6	16.9	23.7	13.5	12.2	6.4	7.4	0.0
65 +	7	1.4	0.0	1.7	3.8	1.2	0.6	3.7	0.0
missing	59								
Total	543	100.0							

**Table 46 Provider age at endpoint**

Age Range	No. providers (all projects)	% All projects	AH (%)	SEQ (%)	E (%)	MNC (%)	WV (%)	NWT (%)	P (%)
15 - 24	9	2.4	0.8	0.0	0.0	3.6	0.0	0.0	11.1
25 - 34	31	8.4	9.8	25.0	0.0	5.3	0.0	8.3	33.3
35 - 44	81	22.0	24.8	12.5	8.7	20.1	33.3	41.7	22.2
45 - 54	172	46.6	48.1	12.5	69.6	47.9	50.0	16.7	27.8
55 - 64	70	19.0	15.8	50.0	8.7	21.9	16.7	33.3	5.6
65 +	6	1.6	0.8	0.0	13.0	1.2	0.0	0.0	0.0
missing	40								
Total	409	100.0							

Respondents were asked to record their professional discipline and the results are summarised in Table 47. There were five categories of nurses who completed the survey. These included director of nursing, registered nurse, resident carer, nurse unit manager, and aids in nursing. Responses from these five categories were grouped and classified as 'nurses'. Allied health specialists include physiotherapists, occupational therapists, psychologists and dieticians. The 'Other' category included medical and nursing students, personal care assistants, and volunteers.

At baseline, the majority of providers who completed the survey were nurses (67.1% of respondents), followed by general practitioners (GPs) (13.7%). No specialist palliative care doctor completed the survey. In the endpoint survey, a larger majority (81.0%) of respondents were nurses. The distributions of respondents' disciplines at the end of the program are shown by project in Table 48.

It is clear that the mix of professional disciplines of the respondents was quite different across the projects. At baseline the Adelaide Hills project observed the most even spread between nurses, GPs and allied health staff. In contrast, over 86% of respondents in the West Victoria project were nurses with only 3% from Allied Health, no GPs and 10% classified as other. Of course, the mix of professions amongst respondents may not be the same as the mix of professions amongst the palliative care providers as a whole.

At endpoint there were no projects that showed an even spread between nurses, GPs and allied health staff. All respondents in the West Victoria and North West Tasmania projects were nurses and almost 100% of respondents in the Mid North Coast project were nurses. In contrast, GPs made up 48% of respondents in Eurobodalla with only 28% of respondents being nurses.

**Table 47 Professional discipline of providers at baseline**

Discipline	No. (all projects)	% All projects	AH (%)	SEQ (%)	E (%)	MNC (%)	WV (%)	NWT (%)	P (%)
Medical specialist	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
GP	57	13.7	32.1	7.3	26.2	5.8	0.0	20.8	33.3
Nurse	279	67.1	39.6	70.9	59.0	76.7	86.5	54.7	41.7
Allied health	37	8.9	28.3	0.0	14.8	2.3	3.1	15.1	0.0
Other	43	10.3	0.0	21.8	0.0	15.1	10.4	9.4	25.0
Missing	127								
<b>Total</b>	<b>543</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>



**Table 48 Professional discipline of providers at endpoint**

Discipline	No. (all projects)	% All projects	AH (%)	SEQ (%)	E (%)	MNC (%)	WV (%)	NWT (%)	P* (%)
Medical specialist	0	0	0	0	0	0	0	0	
GP	28	8.4	14.6	14.3	48.0	0	0.0	0	
Nurse	269	81.0	58.3	85.7	28.0	99.5	100.0	100.0	
Allied health	16	4.8	12.6	0.5	8.0	0.5	0.0	0.0	
Other	19	5.7	14.6	0.0	16.0	0.0	0.0	0.0	
Missing	77								
<b>Total</b>	<b>409</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	

\* no data for Pilbara

The types of training received by the palliative care providers are outlined in Table 49 and Table 50. At baseline, the most common type of formal training was that described as “Short Course/Formal Training” (34% of all respondents). At the endpoint, this percentage was much higher (55.7%). The increase in respondents who had taken a short course / formal training was particularly large for Mid North Coast, increasing from 29.1% to 71.4%. Fewer than 3% of respondents reported a specialist palliative care qualification at baseline. This was only slightly higher at the endpoint (3.7%). The overall percentage of respondents reporting “no training” was small and had decreased (14.2% at baseline and 8.9% at endpoint).

**Table 49 Types of palliative care training at baseline**

Training Type	Total Responses	All projects (%)	AH (%)	SEQ (%)	E (%)	MNC (%)	WV (%)	NWT (%)	P (%)
Specialist qualification	16	2.9	5.1	0.0	3.4	1.2	2.9	4.5	5.9
Short course/formal training	187	34.4	35.9	42.2	42.4	29.1	31.0	36.4	29.4
On job training	287	52.9	48.7	51.6	49.2	69.8	49.7	48.5	58.8
No training	77	14.2	11.5	21.9	5.1	4.7	20.5	15.2	11.8

\* Includes multiple selections

**Table 50 Types of palliative care training at endpoint**

Training Type	Total Responses	All (%)	AH (%)	SEQ (%)	E (%)	MNC (%)	WV (%)	NWT (%)	P (%)
Specialist qualification	15	3.7	4.7	0.0	3.8	2.8	0.0	0.0	10.0
Short course/formal training	180	55.7	51.4	53.8	30.8	71.4	16.7	7.7	25.0
On job training	215	47.0	52.0	7.7	61.5	45.2	83.3	23.1	40.0
No training	36	8.9	8.8	0.0	3.8	6.1	0	38.5	30.0

## 8.2 Patient/family interactions and clinical management

Respondents were presented with a series of twelve issues regarding patient/family interactions and clinical management, and asked to indicate their levels of confidence in dealing with these issues. They were given four options, ranging from 'need further basic instruction' to 'perform independently'. The responses are summarised in Table 51.

At baseline, issues for which respondents expressed the greatest confidence by selecting either that they required minimal consultation or that they were independent were those numbered 11, 2, 7 and 10 (82%, 82%, 80% and 79% respectively). This indicates that respondents were most confident in dealing with patients when they reported constipation or pain and with supporting the patient or family member when they become upset. At the endpoint, these were also the issues that respondents felt most comfortable with.

For almost all the issues listed, the percentage of respondents who chose 'minimal consultation' or 'independent' increased between baseline and endpoint. The only exception was Issue 6 (Answering queries about the effects of certain medications), for which the percentage decreased slightly from 53.4% to 51.6%. This is also the issue that attracted the fewest positive responses in each sample.

**Table 51 Provider confidence in Patient/Family Interactions and Clinical Management**

Issue		Level of Confidence				Total
		Need Further Basic Instruction	Perform with Close Supervision/ Coaching	Perform with Minimal Consultation	Perform Independently	
1. Answering patients questions about the dying process	Pre	14.0	21.0	37.4	27.6	100
	Post	7.0	19.6	37.4	35.9	100
2. Supporting the patient or family member when they become upset	Pre	4.1	14.1	34.3	47.5	100
	Post	2.5	8.3	32.8	56.5	100
3. Informing people of the support services available	Pre	16.9	22.3	37.7	23.1	100
	Post	14.1	21.7	40.7	23.5	100
4. Discussing different environmental options (eg hospital, home, family)	Pre	16.0	22.6	33.3	28.1	100
	Post	9.8	22.8	33.2	34.2	100
5. Discussing patients wishes for after their death	Pre	12.6	21.0	32.0	34.5	100
	Post	7.8	18.0	32.7	41.5	100
6. Answering queries about the effects of certain medications	Pre	22.3	24.3	34.5	18.9	100
	Post	21.3	27.2	34.9	16.7	100
7. Reacting to reports of pain from the patient	Pre	4.5	15.8	40.2	39.5	100
	Post	3.2	15.5	35.4	45.9	100
8. Reacting to and coping with terminal delirium	Pre	13.1	27.2	38.4	21.3	100
	Post	7.8	20.3	41.3	30.6	100
9. Reacting to and coping with terminal dyspnoea (breathlessness)	Pre	10.5	23.0	40.1	26.4	100
	Post	6.8	18.9	41.9	32.3	100
10. Reacting to and coping with nausea / vomiting	Pre	5.5	15.1	41.7	37.7	100
	Post	4.5	11.9	37.9	45.7	100
11. Reacting to and coping with reports of constipation	Pre	5.1	12.8	39.2	42.8	100

Issue		Level of Confidence				
		Need Further Basic Instruction	Perform with Close Supervision/ Coaching	Perform with Minimal Consultation	Perform Independently	Total
	Post	4.6	10.4	34.5	50.5	100
12. Reacting to and coping with limited patient decision-making capacity	Pre	8.3	22.1	44.3	25.3	100
	Post	5.1	16.9	41.2	36.9	100

Table 52 provides a break down by project of the same data. For brevity, it shows the proportion of respondents who selected 'minimal consultation' or 'independent' for each issue.

**Table 52 Percentage of providers who are confident in the delivery of palliative care**

Competency		% 'Independent' and 'Minimal Consultation'						
		Adelaide	E'bodalla	Mid North Coast	North West Tasmania	Pilbara	South-East Qld	West Victoria
1. Answering patients questions about the dying process	Pre	70.4	86.9	75.3	63.5	75.0	50.0	55.0
	Post	67.6	100.0	73.5	92.3	57.9	87.5	83.3
2. Supporting the patient or family member when they become upset	Pre	87.3	91.8	90.7	85.7	94.1	62.5	76.0
	Post	84.8	100.0	91.2	100.0	85.0	75.0	100.0
3. Informing people of the support services available	Pre	69.9	76.7	55.3	76.2	70.6	46.9	52.6
	Post	55.6	92.3	65.7	76.9	50.0	87.5	83.3
4. Discussing different environmental options (eg hospital, home, family)	Pre	68.6	78.7	67.5	74.6	76.5	51.6	46.4
	Post	59.2	100.0	67.6	84.6	57.9	75.0	100.0
5. Discussing patients wishes for after their death	Pre	66.2	82.0	79.5	72.9	70.6	57.8	55.3
	Post	68.5	100.0	73.7	92.3	75.0	75.0	66.7
6. Answering queries about the effects of certain medications	Pre	54.9	74.6	50.6	63.5	70.6	35.9	48.0
	Post	52.8	92.0	40.3	76.9	50.0	75.0	100.0
7. Reacting to reports of pain from the patient	Pre	86.1	90.2	85.7	74.6	94.1	60.9	77.8
	Post	78.1	100.0	79.8	92.3	85.0	75.0	100.0
8. Reacting to and coping with terminal delirium	Pre	69.0	83.6	66.3	50.8	70.6	36.5	54.8
	Post	68.3	100.0	72.6	53.8	60.0	75.0	100.0
9. Reacting to and coping with terminal dyspnoea (breathlessness)	Pre	73.6	85.2	65.5	61.9	82.4	52.4	62.6
	Post	72.0	100.0	73.6	76.9	52.6	75.0	100.0
10. Reacting to and coping with nausea / vomiting	Pre	84.5	91.8	86.9	69.8	94.1	62.5	77.6
	Post	81.8	100.0	82.4	84.6	84.2	75.0	100.0
11. Reacting to and coping with reports of constipation	Pre	88.7	93.4	90.6	77.8	88.2	68.8	76.9
	Post	82.5	100.0	85.0	84.6	78.9	87.5	100.0
12. Reacting to & coping with limited patient decision-making capacity	Pre	75.0	86.7	79.8	67.7	76.5	57.8	60.8
	Post	71.7	100.0	79.6	76.9	78.9	87.5	83.3
All issues	Pre	74.5	85.1	74.5	69.9	80.3	53.6	62.0
	Post	70.2	98.7	73.8	82.7	68.0	79.2	93.1

Competency	% 'Independent' and 'Minimal Consultation'						
	Adelaide	E'bodalla	Mid North Coast	North West Tasmania	Pilbara	South-East Qld	West Victoria
Average change	-4.3	13.6	-0.7	12.8	-12.3	25.5	31.1

### 8.3 Views about death and dying

In the next section of Tool 2.1, respondents are presented with a series of ten issues regarding views on death and dying and are asked to indicate the degree to which they agree or disagree with the statements. They are given five options, ranging from 'agree strongly' to 'disagree strongly'. In our analysis, we calculated the percentage of providers who selected each option. The responses are summarised in Table 53.

The majority of respondents either disagreed or strongly disagreed with all statements except for statement nine where the majority agreed that families have the right to refuse treatment, even if it prolongs life. Responses to questions three – eight and question ten all saw an increase in their disagreement/strong disagreement levels between baseline and endpoint, however, there was a slight decrease observed for questions two and three. There was a slight increase in levels of agreement/strong agreement for question nine.

**Table 53 Provider views about death and dying**

Issue		Agree Strongly	Agree	Unsure / Mixed	Disagree	Disagree Strongly	Total
1. The end of life is a time of great suffering.	Pre	3.3	6.5	22.9	44.6	22.8	100
	Post	2.3	6.2	24.7	44.7	22.1	100
2. Little can be done to help someone achieve a sense of peace at the end of life.	Pre	0.4	0.8	2.1	44.4	52.4	100
	Post	1.0	0.8	2.5	38.2	57.5	100
3. The use of strong pain medication can cause the person to stop breathing.	Pre	1.4	19.2	22.5	36.6	20.3	100
	Post	3.0	15.2	16.8	37.3	27.7	100
4. I am not comfortable caring for a dying patient.	Pre	1.3	2.8	7.3	40.1	48.4	100
	Post	0.8	1.0	4.3	38.6	55.3	100
5. I am not comfortable talking to families about death.	Pre	0.4	6.6	13.6	44.3	35.1	100
	Post	0.5	2.8	11.1	42.3	43.3	100
6. When a patient dies I feel that something went wrong.	Pre	0.8	1.1	5.9	43.3	49.0	100
	Post	0.5	0.8	3.8	36.5	58.4	100
7. Feeding tubes should be used to prevent starvation at the end of life.	Pre	0.8	3.3	23.0	38.0	34.9	100
	Post	1.0	0.8	19.2	38.7	40.3	100
8. Nursing homes/hospitals are not good places to die.	Pre	1.1	6.1	19.0	41.8	32.0	100
	Post	0.5	3.8	13.5	42.5	39.7	100
9. Families have the right to refuse a medical treatment, even if that treatment prolongs life.	Pre	29.2	45.8	16.4	4.4	4.2	100
	Post	30.7	45.8	14.4	5.3	3.8	100
10. Dying patients should be referred to a hospice or acute care.	Pre	3.7	10.8	24.0	42.7	18.8	100
	Post	1.3	3.1	17.9	46.2	31.6	100

Table 54 shows responses to the same issues by site. Questions three, four and five showed the most consistent increase in disagreement across sites although North West Tasmania observed a large drop in disagreement with statement number three. Increase in disagreement with statement number eight also showed some consistency across sites except for North West Tasmania and Eurobodalla. An increase in disagreement with all other statements was inconsistent across sites. Not taking into account question nine, where agreement with this statement was the desired response, the greatest improvement in disagreement with these statements was in South East Queensland followed by the Mid North Coast, Adelaide and the Eurobodalla projects.

**Table 54 Provider views about death and dying by site**

Issue		% 'Disagree' and 'Strongly Disagree'						
		Adelaide	E'bodalla	Mid North Coast	NW Tasmania	Pilbara	South-East Qld	West Victoria
1. The end of life is a time of great suffering.	Pre	66.7	67.8	68.7	64.5	75.0	71.9	65.3
	Post	68.5	76.9	64.0	37.5	75.0	87.5	50.0
2. Little can be done to help someone achieve a sense of peace at the end of life.	Pre	98.6	98.3	96.4	95.2	100.0	95.3	96.5
	Post	93.9	100.0	96.2	88.9	100.0	100.0	100.0
3. The use of strong pain medication can cause the person to stop breathing.	Pre	40.6	61.0	67.1	69.0	46.7	46.0	58.1
	Post	59.6	61.5	70.4	22.2	75.0	50.0	100.0
4. I am not comfortable caring for a dying patient.	Pre	86.1	96.7	94.1	87.1	82.4	87.5	85.4
	Post	91.8	100.0	95.0	88.9	95.0	100.0	83.3
5. I am not comfortable talking to families about death.	Pre	83.6	90.0	85.5	76.2	82.4	71.9	74.7
	Post	84.9	100.0	85.6	100.0	70.0	75.0	83.3
6. When a patient dies I feel that something went wrong.	Pre	94.4	95.0	96.4	85.5	94.1	95.3	89.4
	Post	95.2	100.0	95.5	88.9	90.0	87.5	83.3
7. Feeding tubes should be used to prevent starvation at the end of life.	Pre	79.4	79.7	80.0	68.9	66.7	57.1	72.4
	Post	75.2	92.3	80.7	55.6	85.0	87.5	66.7
8. Nursing homes/hospitals are not good places to die.	Pre	70.0	79.7	82.1	61.7	62.5	63.5	78.2
	Post	76.2	76.9	89.0	33.3	85.0	87.5	100.0
9. Families have the right to refuse a medical treatment, even if that treatment prolongs life.	Pre	5.7	13.3	9.6	3.2	5.9	10.9	9.0
	Post	9.5	3.8	9.9	0.0	10.0	12.5	0.0
10. Dying patients should be referred to a hospice or acute care.	Pre	67.1	75.0	87.8	66.7	73.3	60.9	39.1
	Post	69.9	73.1	88.9	55.6	58.8	62.5	66.7

#### 8.4 Attitudes about palliative care

Following the section on views about death and dying in Tool 2.1, respondents are presented with a series of 15 statements relating to attitudes towards palliative care and asked to rate their level of agreement or disagreement. They are given five options, ranging from 'agree strongly' to 'disagree strongly'. In our analysis, we calculated the percentage of providers who selected each option. The responses are summarised in Table 55.

**Table 55 Provider attitudes about palliative care**

Statement		Agree Strongly	Agree	Unsure / Mixed	Disagree	Disagree Strongly	Total
1. Pain at the end of life is an inevitable part of the dying process	Pre	0.6	2.5	12.1	53.8	31.1	100
	Post	0.3	3.5	12.9	48.0	35.4	100
2. Pain medication should be given as needed to terminally ill patients	Pre	57.6	36.6	2.3	1.1	2.4	100
	Post	53.9	37.7	2.8	2.5	3.1	100
3. Spiritual care should include counselling the terminally ill patient	Pre	28.5	52.3	16.3	2.3	0.6	100
	Post	29.0	43.0	23.2	2.8	2.0	100
4. I do not like talking about death and dying with patients	Pre	0.6	5.3	19.6	51.9	22.6	100
	Post	0.5	3.8	14.6	51.0	30.1	100
5. Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness	Pre	28.2	42.9	19.5	7.1	2.3	100
	Post	38.6	40.9	10.5	7.4	2.6	100
6. Patients should have the right to determine their own degree of medical intervention	Pre	45.5	48.7	4.1	0.9	0.8	100
	Post	51.8	41.7	3.8	1.5	1.3	100
7. Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live	Pre	34.5	47.7	12.6	4.0	1.1	100
	Post	37.7	43.0	12.2	6.3	0.8	100
8. Opening discussions of end-of-life care should be deferred until there is no further effective curative treatment available	Pre	1.7	8.4	13.9	54.0	22.0	100
	Post	2.8	5.8	10.1	55.3	26.0	100
9. Estimation of pain by an MD or RN is a more valid measure of pain than patient self-report	Pre	0.8	2.7	11.8	50.8	34.0	100
	Post	1.5	3.3	11.2	50.5	33.5	100
10. Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition such as cancer	Pre	26.9	53.1	11.8	7.4	0.8	100
	Post	31.9	51.3	8.9	6.9	1.0	100
11. Patients have the right to determine their own degree of psychosocial intervention	Pre	27.6	62.5	9.0	0.8	0.2	100
	Post	33.7	58.2	6.8	0.8	0.5	100
12. The most appropriate person to make end-of-life decisions is the patient's primary care provider	Pre	2.3	12.7	38.4	36.9	9.7	100
	Post	3.3	11.0	34.8	40.7	10.2	100
13. A patient should experience discomfort prior to receiving the next dose of pain medications	Pre	1.9	1.5	3.0	44.0	49.5	100
	Post	2.3	2.0	3.0	41.3	51.4	100
14. Patients should be maintained in a pain-free state	Pre	40.4	46.4	7.9	3.6	1.7	100
	Post	46.5	40.5	8.0	2.8	2.3	100
15. As a rule, terminally ill patients prefer not to talk about death and dying	Pre	0.4	5.3	32.5	49.1	12.7	100
	Post	1.8	3.8	31.7	48.0	14.7	100

Those statements where respondents tended to agree or agree strongly included statements 2, 3, 5, 6, 7, 10, 11 and 14 with the remaining statements tending towards disagreement. Those statements to which respondents tended to agree or agree strongly where agreement increased included statements 5, 10, 11 and 14. Those statements where initial high agreement levels tended to drop included statements 2, 3, 6 and 7. Those statements to which respondents tended to disagree or disagree strongly where disagreement increased included statements 4 and 12.



Those statements where initial high disagreement levels tended to drop included statements 1, 8, 9 and 13.

Table 55 shows responses to the same issues by site. For those statements where respondents tended to agree, the most consistent improvement in agreement across sites was for statement 3 followed by statement 2 and then statements 5, 6 and 7. For statements 10, 11 and 14, improvement in agreement with these statements was inconsistent across sites.

For those statements where respondents tended to disagree, the most consistent increase in disagreement across sites was for statements 8 and 12. There tended to be an inconsistent increase in disagreement for statements 4, 9, 13 and 15 across sites with more sites observing a decrease in disagreement for question 1.

The site with the most consistent improvement in statements where either agreement or disagreement were appropriate responses was Eurobodalla. In addition North West Tasmania observed an overall improvement in agreement for statements where this response was appropriate and South East Queensland showed an overall increase in disagreement with those statements where this was the appropriate response.

**Table 56 Attitudes towards palliative care by site (% of respondents that disagree or strongly disagree)**

Issue		Project						
		AH	E	MNC	NWT	P	SEQ	WV
1. Pain at the end of life is an inevitable part of the dying process	Pre	90.3	89.8	86.6	84.1	94.1	84.4	79.5
	Post	87.1	92.0	79.7	88.9	78.9	87.5	66.7
2. Pain medication should be given as needed to terminally ill patients	Pre	1.4	6.7	3.5	4.8	0.0	6.3	2.3
	Post	7.6	7.7	3.4	11.1	5.0	0.0	16.7
3. Spiritual care should include counselling the terminally ill patient	Pre	1.4	0.0	3.6	6.3	0.0	1.6	3.6
	Post	3.4	3.8	6.1	11.1	0.0	0.0	16.7
4. I do not like talking about death and dying with patients	Pre	74.6	76.7	82.1	74.6	82.4	64.5	72.8
	Post	84.9	76.9	80.1	66.7	70.0	87.5	83.3
5. Palliative care should be the standard medical treatment for patients who are suffering from a terminal	Pre	11.1	17.2	6.0	3.2	17.6	9.5	8.9
	Post	11.8	3.8	9.0	22.2	10.0	12.5	0.0
6. Patients should have the right to determine their own degree of medical intervention	Pre	2.8	0.0	2.4	0.0	5.9	0.0	2.3
	Post	0.7	3.8	3.3	11.1	5.0	12.5	0.0
7. Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live	Pre	5.5	1.7	6.0	3.2	0.0	7.9	5.8
	Post	9.0	0.0	6.6	22.2	5.0	0.0	0.0
8. Opening discussions of end-of-life care should be deferred until there is no further effective curative treatment	Pre	83.6	71.7	80.0	82.5	70.6	64.1	74.9
	Post	78.2	84.6	84.4	55.6	85.0	75.0	83.3
9. Estimation of pain by an MD or RN is a more valid measure of pain than patient self-report	Pre	83.1	81.4	81.0	84.1	88.2	82.3	89.4
	Post	85.6	96.2	80.4	66.7	100.0	87.5	66.7
10. Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition	Pre	9.6	13.3	5.9	10.2	6.3	6.3	7.0
	Post	9.0	23.1	3.3	44.4	5.0	0.0	20.0
11. Patients have the right to determine their own degree of psychosocial intervention	Pre	1.4	0.0	1.2	0.0	0.0	1.6	1.2
	Post	0.7	0.0	0.5	22.2	0.0	0.0	16.7
12. The most appropriate person to make end-of-life decisions is the patient's primary care provider	Pre	45.8	42.4	56.6	54.8	70.6	40.6	40.4
	Post	55.2	50.0	45.6	88.9	47.4	62.5	50.0

Issue		Project						
		AH	E	MNC	NWT	P	SEQ	WV
13. A patient should experience discomfort prior to receiving the next dose of pain medications	Pre	90.0	93.3	96.4	91.7	94.1	87.5	96.5
	Post	93.1	100.0	91.7	77.8	90.0	100.0	100.0
14. Patients should be maintained in a pain-free state	Pre	2.7	5.0	7.1	3.2	17.6	3.1	5.8
	Post	5.4	7.7	3.3	0.0	10.0	0.0	33.3
15. As a rule, terminally ill patients prefer not to talk about death and dying	Pre	63.9	69.5	64.7	64.5	64.7	46.0	61.4
	Post	62.8	84.6	57.5	77.8	68.4	87.5	50.0

## 8.5 Caring Issues

Following the section on attitudes towards palliative care in Tool 2.1, respondents are asked to rate the level of importance of a further nine specific issues in terms of the problems they create in caring for a dying patient. They are given five options, ranging from 'very important' to 'not important'. In our analysis, we calculated the percentage of providers who selected each option. The responses are summarised in Table 57.

In general respondents tended to see all aspects caring as important or very important except the last aspect. There were a comparable proportion of respondents who felt 'unsure' concerning the 'uncertainty about what is best care'. There were also a number of respondents who thought legal concerns were less important but this appeared to decrease in the post survey.

**Table 57 Importance placed on different aspects of caring**

Issue		Level of Importance (%)					Total
		Very Important	Important	Unsure	Less Important	Not Important	
1. Control of pain	Pre	86.0	12.1	0.2	1.1	0.6	100
	Post	88.8	10.0	0.5	0.2	0.5	100
2. Managing depression	Pre	56.2	40.0	2.1	1.5	0.2	100
	Post	63.6	33.9	1.2	0.7	0.5	100
3. Legal concerns	Pre	27.6	45.4	12.9	13.7	0.4	100
	Post	37.0	44.6	7.6	9.6	1.3	100
4. Ability to meet spiritual needs	Pre	48.1	44.7	4.2	2.7	0.4	100
	Post	55.4	36.2	6.2	2.2	0.0	100
5. The patient's emotional needs	Pre	68.1	29.2	1.7	0.8	0.2	100
	Post	77.4	21.1	0.5	1.0	0.0	100
6. Communication with family	Pre	71.0	27.3	0.6	0.8	0.4	100
	Post	77.5	21.5	0.3	0.5	0.3	100
7. Communication with other palliative care staff	Pre	60.3	34.6	1.9	2.9	0.4	100
	Post	72.6	24.9	1.2	1.0	0.2	100
8. Communication with (other) doctor/s	Pre	52.7	40.7	3.0	3.2	0.4	100
	Post	63.6	31.2	2.7	2.2	0.2	100
9. Uncertainty about what is best care	Pre	34.4	31.3	27.3	6.2	0.8	100
	Post	36.0	28.4	30.6	3.9	1.1	100



Table 58 shows responses to the same issues by site. Across the sites most issues were seen as important by respondents, however there were some sites where specific issues appeared to be viewed as less important.

There appeared to a large drop in respondents viewing managing depression as important in West Victoria. In addition less than half of respondents from South East Queensland, Eurobodalla and North West Tasmania viewing managing depression as important in the post survey.

Low importance was placed on legal issues across all sites and the ability to meet spiritual needs was not viewed with as great an amount of importance as other issues in Eurobodalla and Pilbara. There did not seem to be a high level of importance placed on the uncertainty about what is best care across sites, however, this most likely reflects the relatively high level of respondents who felt unsure about this issue as seen above.

**Table 58 Importance Placed on Caring Issues by site (% very important)**

Issue		Project						
		AH	E	MNC	NWT	P	SEQ	WV
1. Control of pain	Pre	75.3	85.2	92.8	83.6	70.6	90.6	88.2
	Post	84.2	76.0	94.0	92.3	95.0	75.0	83.3
2. Managing depression	Pre	47.9	50.8	69.5	54.1	29.4	59.4	57.4
	Post	57.5	44.0	74.9	46.2	65.0	37.5	16.7
3. Legal concerns	Pre	23.3	23.0	33.7	21.3	35.3	36.5	26.2
	Post	30.6	12.0	47.5	46.2	30.0	25.0	0.0
4. Ability to meet spiritual needs	Pre	41.7	36.1	57.8	44.3	58.8	48.4	50.6
	Post	47.9	32.0	66.1	61.5	40.0	50.0	50.0
5. The patient's emotional needs	Pre	63.0	52.5	75.9	67.2	58.8	68.3	73.4
	Post	72.4	56.0	85.2	76.9	85.0	62.5	50.0
6. Communication with family	Pre	73.6	60.7	75.9	73.8	58.8	65.6	73.4
	Post	77.9	76.0	78.7	76.9	70.0	75.0	66.7
7. Communication with other palliative care staff	Pre	60.3	42.6	69.5	61.7	47.1	62.5	62.1
	Post	72.1	52.0	76.4	76.9	75.0	50.0	66.7
8. Communication with (other) doctor/s	Pre	46.6	41.7	60.2	59.0	47.1	54.7	53.0
	Post	59.2	48.0	70.9	53.8	60.0	62.5	50.0
9. Uncertainty about what is best care	Pre	31.8	19.6	50.0	38.6	37.5	33.9	31.3
	Post	34.8	13.0	41.9	25.0	35.7	37.5	16.7

## **Part Five – System Level Impact and Outcomes**

## 9 Governance

### 9.1 Governance arrangements

Each project established a governing body, all of which included project staff and representatives from the local division of general practice. Further details regarding each governing body are summarised in Table 59.

**Table 59 Governing body arrangements**

Project	Governing Body	Representation
Adelaide Hills	Governance Committee with working groups for specific issues.	GP, community health, CNC, residential aged care, public hospital, private hospital, consumer
Eastern Goldfields	Advisory Group (formed in 2003 for a project that was part of the Caring Communities Program.	GPs, volunteer service, residential aged care, carer respite, dementia respite, pastoral care, university, public hospital, community member, community nursing,
Eurobodalla	Advisory Group with three working groups (indigenous issues, education, communication strategies)	GPs, residential aged care, local health service, pastoral care, volunteers, visiting PC specialist, hospital pharmacist, private nursing agencies
Mid North Coast	Advisory Group with seven clinical advisory groups (indigenous issues, Punjabi issues, interdisciplinary team, data management, education, after hours service, RACF and inpatient beds)	Aged Care Assessment Team, cancer services, community health, NGOs, indigenous health, residential aged care
NW Tasmania	Advisory Committee and Executive Committee	Public hospital, ambulance service, university, GP, politician, community member, pastoral care, residential aged care.
Pilbara	Governing Council	Cancer council, GP, public hospital, Home Care, residential aged care.
SE Queensland	Project Steering Committee and Clinical Committee to focus on project implementation  Volunteer Committee that disbanded after its objectives were met.  Two new committees formed approximately mid-way through the project (aged care and indigenous PC).	GP, public hospital, private hospital, community nursing, medical administrator, indigenous community, local MP, pastoral care.
West Victoria	Project Steering Committee	GP, clinical director of regional palliative care team, consumer.

There have been some variations in membership over the course of each project but the table indicates that there has been a wide range of representatives on the governing bodies.

The most successful governing body was that for the SE Queensland project where the group moved to become the 'palliative care collaborative' for the local area, taking on responsibilities beyond governance for the project. The most difficult governing bodies to sustain were in the more remote settings of Kalgoorlie and the Pilbara. The most complex governance issues were in West Victoria, which had three local bodies trying, in parallel, to integrate palliative care service delivery in one way or another. Firstly, the Division of General Practice used the RPC project to try and develop a primary care model focused around the GP. Secondly, the Palliative Care Consortium aimed to develop a more collaborative model of service delivery based around a

specialist palliative care service. Thirdly, the Grampians Integrated Cancer Services aims to develop a multidisciplinary approach for cancer patients.

Issues impacting on project governance have primarily been due to changes in personnel, either of the project team, or the governing body, or both. For example:

- Frequent changes in management of the local area health service (Eurobodalla).
- Constant turnover of personnel on the governing body (Kalgoorlie).
- Several changes in the coordinator position resulting in significant changes in emphasis regarding project implementation, indicating a weakness in project governance (Pilbara).

## 9.2 Models of care

There are four main options for providing palliative care in rural communities:

- the 'traditional' health care model (diagnosis and management by individual practitioners and referral to other practitioners where necessary)
- coordination of care by a clinical nurse consultant (CNC)
- coordination of care by a formally established team
- a visiting consultation service with 'fly-in, fly-out' specialists who may or may not work with some form of local team.<sup>12</sup>

Any such categorisation should be used with caution as there are inevitably local variations (including a mix of different models) but these four models do provide a useful framework for considering what service provider arrangements were in place at the beginning of each project. All four of these models were found in the RPC projects at the commencement of the program. Three sites started with a 'traditional' model of care (Eurobodalla, Pilbara, SE Queensland), three with a CNC-led model of care (Adelaide Hills, Mid North Coast, West Victoria), one with a fledgling team approach to care coordination (Kalgoorlie) and one with an existing specialist (medical) palliative care service that included clinical nurse specialists (NW Tasmania) (Table 60). Whilst the RPCP was ostensibly about implementing one model at eight different sites the reality was more complicated than that. Each site started with a different level of resources devoted to palliative care and differences in the local context within which each project sought to establish itself. The RPCP was essentially about moving from one of the other models of palliative care to a 'formally established team' model that involved GPs, although projects did not typically characterise their aim as changing from one model to another.

**Table 60 Model of care at project commencement for each site**

Project	Model of care
Adelaide Hills	Existing palliative care service with approximately 100 new referrals per annum. Two specialist nurses, one of whom is a CNC.
Eastern Goldfields	Palliative care team established as part of associated CCP project. Nurses meet to plan care but no GP involvement prior to RPC commencing.
Eurobodalla	Traditional model of care. No existing palliative care service.
Mid North Coast	Existing palliative care team led by CNC (job-shared position) with 60-70 clients at any one time. Team meets for case management and review but does not involve GPs.
NW Tasmania	Existing specialist palliative care service with CNC and medical specialist. Specialist team meets for case management and review but with no GP involvement.
Pilbara	Existing palliative care service provided by Pilbara Home Care for part of the area but this is restricted to home care and nursing care. Effectively a traditional model of care.

<sup>12</sup> Woods D. (2001) *Models of care for rural palliative care services*. In: Proceedings of the 6th National Rural Health Conference; March; Canberra, Australia.

Project	Model of care
SE Queensland	Traditional model of care. No existing palliative care service.
West Victoria	Two existing palliative care services with significant case loads and established processes based in Horsham and Ararat, each with a CNC.

### 9.3 Agency partnerships and collaboration

Agency partnerships refer to the establishment of formal arrangements between agencies or individual providers e.g. memorandums of understanding (MOU). For the purposes of the RPCP it also includes the granting of hospital admission rights to GPs. The various strategies employed at each site to promote agency partnerships and collaboration are summarised in Table 61.

**Table 61 Agency partnerships established by each project**

Project	Agency partnerships and collaboration
Adelaide Hills	Work was undertaken to develop an MOU between the Division of General Practice and the local health service. This was finalised in mid 2006.
Eastern Goldfields	MOU between Division of GPs and Emotional and Social Wellbeing Centre to provide support for GPs working with indigenous palliative care clients. Admission policy to facilitate direct admission of palliative care clients to hospital.
Eurobodalla	Nil
Mid North Coast	MOU between Division of General Practice and local health service to facilitate data collection. It should be noted that a decision was made at the beginning of the project not to include increased GP involvement in inpatient care as part of the project.
NW Tasmania	Nil
Pilbara	Nil
SE Queensland	Work to develop an MOU between South Burdett Health Service and Division of GPs. Formation of South Burnett Palliative Collaborative. Weekly clinical committee to implement project.
West Victoria	Nil

In general, little attention was paid to developing formal partnerships between agencies at project commencement (by inclusion of such strategies in project plans) so it not surprising that few such arrangements were established during the course of the RPCP. In particular, there was little use of MOUs between providers or development of GP admission rights at local hospitals (in some locations GPs already had admission rights).

The lack of formal partnership arrangements means that no findings can be made about the extent to which the presence or absence of such arrangements may have contributed to project outcomes.

### 9.4 Role delineation and networking

Role delineation and networking refers to communication, consultation, liaison, and meetings between providers used to improve networking and understanding of different roles and responsibilities. For the purposes of the evaluation it does not include case conferences, which are dealt with elsewhere in this report. It includes networking with, and access to, specialist palliative care providers (including arrangements to access specialist assistance after-hours). The various strategies employed at each site to promote role delineation and networking are summarised in Table 62.

**Table 62 Role delineation and networking strategies used by each project**

Project	Role delineation and networking
Adelaide Hills	Multidisciplinary team meeting that became a clinical advisory Group for the Governing Committee. Phone links organised between GPs in the area and specialists in Adelaide. Establishment of Link Nurse Group.
Eastern Goldfields	Fortnightly multidisciplinary team meetings including nursing, medical and allied health. GPs were initially involved in these meetings but representation decreased in the last year of the project.
Eurobodalla	Meeting of palliative care providers at the end of discharge planning meetings at Moruya and Bateman's Bay hospitals. This was convenient for nurses and allied health staff but not GPs. 'Fly-in fly-out' service of palliative care specialist commenced. Multidisciplinary team meetings to coincide with monthly visits of the specialist. Formation of Links Group.
Mid North Coast	Establishment of seven clinical advisory groups. Weekly team meetings to discuss new referrals and patients experiencing symptom control problems 'Fly-in fly-out' service of palliative care specialist commenced. Meeting between visiting medical specialist and 54 local GPs. Monthly video conference with specialist at Calvary Health Care Sydney. Establishment of Link Nurse Group. Focus groups with GPs and residential aged care nurses.
NW Tasmania	Monthly 'mentoring' meetings involving project staff, community nurses, GPs and director of palliative care. Focus groups with GPs, health service staff and volunteers. Links with state-wide implementation of a model of palliative care for Tasmania with four levels of care for primary and specialist providers.
Pilbara	Various informal meetings between service providers.
SE Queensland	Two committees for aged care and indigenous palliative care. Developed a document outlining roles and responsibilities of stakeholders. Consultation with stakeholders using Tool 3.1. Workshop with stakeholders to map current services in line with the national PC standards that resulted in agreement to work together on a model of service delivery for palliative care in the region. Links established with a palliative care specialist for ongoing advice and support to GPs.
West Victoria	Establishment of palliative care advisory group in the Central Grampians (which does not involve GPs)

There was no consistent pattern across the eight projects with regard to the mechanisms used to clarify the roles of different palliative care providers and encourage networking. Each project developed local solutions to meet local needs. For example, the focus in NW Tasmania was on improved understanding between GPs and the specialist palliative care service, and hence regular meetings between the two were initiated and sustained. In SE Queensland there was a focus on planning for future service delivery and hence assessing services against palliative care standards was undertaken to clarify roles and responsibilities. There was no 'one size fits all' on this issue.

## 9.5 Palliative care self-assessments

Palliative care self-assessments were undertaken using Tool 3.1 from the RPCP Tool Kit. The Tool is based on work undertaken by the Center to Advance Palliative Care, based in the USA, and modified by the CHSD for the RPCP. The Tool involves self-assessment of palliative care services and incorporates 10 categories. The Tool commonly uses the word 'standard' to describe what is being assessed but also uses the word 'statement'. The two are effectively

interchangeable within the context of undertaking a self-assessment. Tool 3.1 requires that each standard/statement be rated:

- as present or not present
- according to the degree to which the statement is true
- as a priority for future action.

The protocol for the evaluation required two self-assessments, one each at project start and project end, the first of which was typically undertaken in the first few months of 2004. The results from these self-assessments were presented at the RPCP Adelaide Workshop in June 2005 where it was agreed to undertake an additional self-assessment soon after the workshop. This was undertaken at each site between June and October 2005 (called mid-point assessments) and the results were included in our fourth progress report on the evaluation in November 2005. Kalgoorlie did not complete any self-assessments as they were not required to do so as part of their contract with AGPN. West Victoria completed two self-assessments, one for each main locality in the area, at project start and project mid-point. Eurobodalla completed one self-assessment at project start and three at project mid-point (for the three main towns in the area). One self-assessment was completed at project end by each project.

Standards present and not present at project start, project mid-point and project end are summarised in Table 63. Differences in total numbers between the three assessments are explained by the different number of assessments at each time point. Non-responses to a small number of items have not been included.

**Table 63 Palliative care self-assessments**

ITEM	Start	Mid-point	End
P = Present, NP = Not present	P / NP	P / NP	P / NP
<b>Vision and management standards</b>			
We have a vision for excellence in end of life care	7 / 1	10 / 0	7/0
Our service objectives include a focus on end of life care	8 / 0	10 / 0	7/0
Administrative executive staff support implementation of initiatives to improve care at end of life	8 / 0	10 / 0	6/1
Medical staff support implementation of initiatives to improve care at end of life	6 / 2	10 / 0	6/1
Management objectives include a focus on end of life care	6 / 2	10 / 0	6/1
Education resources are designated to support development of competencies and practices in end of life care	5 / 3	9 / 1	6/1
Excellent caregivers (both formal and informal) and caregiving examples are honoured and their stories made visible	4 / 4	9 / 1	7/0
<b>Practice Standards (procedures, policies, care protocol)</b>			
The population we served is defined and communicated	6 / 2	9 / 1	6/1
Confidentiality standards are clearly communicated	7 / 1	10 / 0	7/0
Cultural / religious guidelines are integrated	5 / 2	8 / 2	6/1
Organ / tissue donation guidelines are implemented	1 / 6	4 / 5	2/4
Comfort, care and palliative care standards are implemented. Includes guidelines for pain and symptom management, and hydration / nutrition	5 / 3	9 / 1	5/1
Hospice care is available	4 / 4	3 / 7	3/4
Complementary or integrative therapies are supported	7 / 1	9 / 1	6/1
<b>Spiritual, Religious, and Cultural Standards</b>			



ITEM	Start	Mid-point	End
Support is available 24 hours a day	5 / 3	8 / 2	4/3
Links / communication with community established	7 / 1	10 / 0	7/0
Prayer and other spiritual / religious practices overtly available	5 / 2	10 / 0	7/0
All staff are expected to integrate spiritual / cultural care within practice	8 / 0	10 / 0	6/1
Support for professional caregivers readily available	7 / 1	9 / 1	6/1
<b>Bereavement Support Standards</b>			
Bereavement support groups offered	3 / 5	3 / 6	4/3
Follow-up is available for 100% who have died	6 / 2	7 / 2	5/2
Follow-up contact to address clinical questions initiated by clinicians / primary care providers within 2-4 weeks of death	7 / 1	7 / 2	5/2
Memorial services conducted for staff and families	6 / 2	5 / 5	5/2
Bereavement support 1:1 for families is available	8 / 0	7 / 3	5/2
Bereavement support 1:1 for professionals is available	7 / 1	8 / 2	5/2
<b>Psychosocial and Emotional Standards, including Pastoral Care</b>			
Referral and support is available 24 hours	2 / 6	9 / 1	5/2
Support available for professional caregivers	8 / 0	10 / 0	5/2
Support groups for patient / families easily accessible	4 / 4	5 / 5	4/3
Virtual support groups available (eg. chat groups, telephone conference groups)	2 / 6	5 / 3	5/2
<b>Communication Standards</b>			
Care preference, values, spiritual, emotional, and relationship needs as well as decisions routinely and accurately communicated and honoured	8 / 0	10 / 0	7/0
Doctor communication during the dying process occurs frequently	7 / 1	10 / 0	6/1
Transfer of care occurs with communication of preferences, values, spiritual / emotional, and relationship needs and patient / family care decisions.	8 / 0	10 / 0	6/1
Standards and expectations about excellent end-of-life care routinely communicated to community	6 / 2	9 / 1	6/1
Communication with community spiritual care providers routine as well as specific	4 / 4	7 / 2	6/1
<b>Professional Experiential Education during Orientation and as Continuing Education</b>			
Organisation values and strategic objectives	5 / 2	9 / 1	6/1
Ethics – End of life Care	5 / 2	8 / 1	6/1
Practice standards	5 / 2	9 / 0	6/1
Quality improvement standards	5 / 2	9 / 0	6/1
Communication	5 / 2	9 / 0	6/1
Grief and Bereavement	5 / 2	9 / 0	6/1
Patient / Family supports	5 / 2	9 / 0	6/1
Professional caregiver / staff support	5 / 2	9 / 0	6/1
Spiritual / religious / cultural standards	5 / 2	9 / 0	6/1
Individual performance expectations	5 / 2	9 / 0	6/1
<b>Quality Improvement Standards</b>			
Routine feedback from patients, family caregivers and bereaved family, and community partners is obtained	4 / 3	9 / 1	5/2
Quality priorities include response to above	4 / 3	8 / 2	5/2



ITEM	Start	Mid-point	End
Significant events are assessed for learning and quality improvement	6 / 1	8 / 2	5/2
“Stories” are shared and used to teach about care and to set standards	6 / 1	9 / 1	7/0
Research to continue developing new ways to improve care is developed or findings are applied to practice change initiatives	4 / 3	8 / 2	5/2
Annual objectives and priorities include focus on end of life care	7 / 0	10 / 0	6/1
<b>Staff Support Standards</b>			
There are systems and policies that support bereavement leave for those the person defines as close or family	7 / 0	10 / 0	7/0
There are systems and policies that allow flexibility in work time during illness, caregiving and bereavement	7 / 0	10 / 0	7/0
Palliative care providers are supported in reaching out to fellow providers with practical help	7 / 0	10 / 0	6/1
Acuity and patient assignments provide time to “be with” the patient and family during the process of dying	7 / 0	10 / 0	6/1
Professional caregiver is supported to attend memorial / funeral service of patients.	7 / 0	10 / 0	7/0
<b>Community Network and Partnerships</b>			
Palliative care is available within the community to the extent that patients and their families want it	8 / 0	10 / 0	6/1
Healthcare and church ministry linked in meeting care needs at end of life	8 / 0	10 / 0	6/1
Partnerships with community assist community to meet support needs	7 / 0	10 / 0	7/0
Services are provided that achieve continuity of care within and between community and health care organisations	8 / 0	10 / 0	6/1
Education and information about palliative care is integrated within schools, workplaces, parishes, and other community areas	8 / 0	9 / 1	6/1

At project start some standards were present at all sites:

- Our service objectives include a focus on end of life care.
- Administrative executive staff support implementation of initiatives to improve care at end of life.
- All staff are expected to integrate spiritual / cultural care within practice.
- Bereavement support for families is available.
- Support available for professional caregivers.
- Care preference, values, spiritual, emotional and relationship needs as well as decisions routinely and accurately communicated and honoured.
- Transfer of care occurs with communication of preferences, values, spiritual / emotional and relationship needs and patient / family care decisions.
- Annual objectives and priorities include focus on end of life care.
- The five staff support standards and the five community network and partnership standards.

These standards were still largely met at project mid-point and project end, except for availability of bereavement support for families, which was not present at some sites.

Standards most frequently identified as not present at project start were:

- Organ / tissue donation guidelines are implemented.

- Bereavement support groups offered.
- Referral and support is available 24 hours.
- Virtual support groups available.

Except for bereavement support there was an increased compliance at project mid-point for each of these standards, particularly availability of referral and support 24 hours per day. The assessments at project end also indicated greater availability of referral and support 24 hours per day. The Pilbara project recorded 65% of the total number of standards not present across all projects at project end, which was markedly different from all other projects.

Although the self-assessments at the three points in time are not directly comparable because of differences in the number of completed tools, the results indicate that there was an improvement in compliance for all categories of standards (except for staff standards and community network and partnership standards, where there was no room for improvement). This is illustrated in Table 64. This table has been restricted to the project start and project end point results, which have been calculated both with and without the Pilbara results. As demonstrated elsewhere in our evaluation it is reasonable to consider the Pilbara as an ‘outlier’ project that was not representative of what generally occurred in the RPCP.

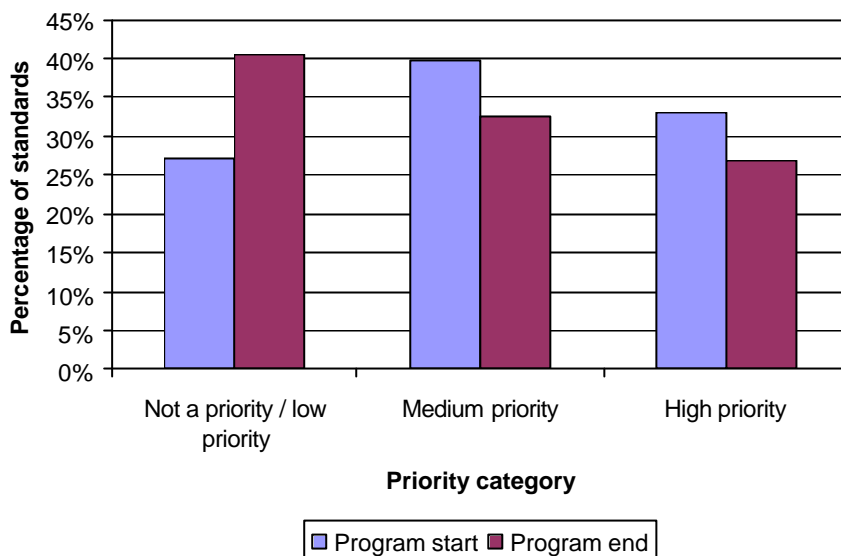
**Table 64 Palliative care self-assessments summary – percentage of standards present**

	All projects except Kalgoorlie		All projects except Kalgoorlie and the Pilbara	
	Program start (%)	Program end (%)	Program start (%)	Program end (%)
Vision and management standards	78.6	91.8	75.5	100.0
Practice Standards (procedures, policies, care protocol)	64.8	71.4	63.8	81.0
Spiritual, Religious, and Cultural Standards	82.1	85.7	79.4	93.3
Bereavement Support Standards	77.1	69.0	76.2	80.6
Psychosocial and Emotional Standards, including Pastoral Care	50.0	57.1	46.4	66.7
Communication Standards	82.5	88.6	80.0	100.0
Professional Experiential Education during Orientation and as Continuing Education	70.0	85.7	65.0	100.0
Quality Improvement Standards	73.8	81.0	72.2	91.7
Staff Support Standards	100.0	94.3	100.0	100.0
Community Network and Partnerships	100.0	88.6	100.0	100.0
Average	77.1	81.9	74.9	92.2

Increased compliance with the standards is supported by the responses that rated each standard according to the degree it was present. On a scale from 0 (not present at all) to 10 (fully implemented and effective) this increased from an average of 5.1 at project start to 6.6 at project end. This change is even more pronounced with the Pilbara project excluded from the results, with an increase from 4.8 to 7.6 across all projects.

Having identified the extent to which each standard is present Tool 3.1 requires a rating of the extent to which the standard is a priority for future action, on a scale from 0 (not at all – no action required) to 10 (undertake as a matter of urgency). The responses were grouped as follows - not a priority / low priority (0-3), medium priority (4-6), high priority (7-10). Comparison between the self-assessments at project start and project end is illustrated in Figure 19, which does not include data for the Pilbara project.

**Figure 19 Project self-assessments – priority at project start and project end**



By the end of the projects a greater percentage of standards were rated as ‘not a priority / low priority’ for future action than at the beginning and a smaller percentage of standards were rated a high priority for future action. This is consistent with the finding about greater compliance with palliative care standards at the end of the projects.

Tool 3.1 was completed very early in the life of each project and requires a good knowledge of local services. Rating some standards is difficult without an excellent understanding of the local situation. With multiple service providers some items are difficult to rate irrespective of local knowledge. This may mean that responses more accurately reflected the standards present at the end of each project than at the beginning. This could have influenced responses either way and either increased or decreased the number of standards rated as ‘present’.

The main value of Tool 3.1 rests with its use within each project as a means of assessing the ‘state of play’ at the start of the project and, potentially, any progress over the life of the project. Across all projects the results indicate greater presence of palliative care standards over the life of the RPCP, with the areas of greatest deficiency being the availability of hospice care, bereavement support groups and support groups for patients and their families.

## 10 Changes in direct care delivery

### 10.1 Multidisciplinary care planning and case conferences

The evaluation team defined multidisciplinary care planning as any activity focussed on improving care planning for individuals by a team of providers, including establishment and organisation of case conferences. As a minimum the team should include one medical, one nursing and one allied health representative and may include the patient and/or their carer.

In practice, it is not always clear what constitutes a case conference and what does not. The RPCP did not have an agreed definition of a case conference. However, within the context of the RPCP, it is reasonable to expect that a case conference would include discussion of an identified patient or patients, involving health professionals caring for that patient and resulting in some documented decisions (which may be a decision to make no changes to clinical management) about the patient's clinical management.

Table 65 provides a summary of how these items were interpreted amongst each of the RPC sites.

**Table 65 Summary of multidisciplinary meetings across sites**

Project	Frequency of Multidisciplinary meetings	GP Involvement	Number of EPC/CDM for Case Conferences	Intention to continue after funded project
Eurobodalla	Monthly in the latter stages of the project	No	n/a	No
South-East Queensland	Monthly	Yes	70	Yes
Mid-North Coast	Weekly	Yes, via teleconference	23	Yes
Adelaide Hills	Weekly	Yes, via teleconference	4	Yes
Eastern Goldfields	Fortnightly	Yes, via teleconference	n/a	Yes
Pilbara	Not held	n/a	n/a	n/a
North West Tasmania	Monthly	Yes	n/a	Yes
West Victoria	One meeting held	Yes	n/a	No

It is apparent that regular multidisciplinary meeting were held on a regular basis in all sites apart from West Victoria and the Pilbara.

There was no need for regular team meetings across the area covered by the Division of General Practice in the Pilbara, primarily because of the small number of patients.

The West Victoria project was only able to conduct one multidisciplinary team meeting that included the patient, carer, GP, practice nurse, palliative care nurse and the palliative care specialist. This is not surprising since their original project plan did not give any commitment to holding multidisciplinary meetings.

The six other sites were successful in implementing a model to hold regular meetings and for five of them these meetings will continue beyond the life of the project (as they have done in Griffith). The most challenging aspect for project coordinators in establishing these team meetings has been the engagement of GPs. The major stumbling block has been the inability to arrange a convenient time and venue to facilitate GP attendance. However, three of the projects met this challenge by hooking GPs up to the meeting via teleconference.

Not all of the meetings progressed to the stage of conducting formal case conferences and only three projects were able to generate EPC/CDM items to reimburse GPs for their involvement. However, it was universally agreed that these meetings were an excellent forum for sharing up-to-date information about patient care and are educational in terms of their potential for professional development.

Perhaps the best examples of how to coordinate regular multidisciplinary meetings can be found in the Mid-North Coast and South-East Queensland.

The Mid-North Coast Project held weekly palliative care team meetings open to all health care providers. This open forum ensured that both generalist and specialist palliative care providers are able to plan their palliative care patient's care in a multi-disciplinary setting. These meetings consistently attracted high levels of health care provider participation suggesting that planning care in this type of setting is valued.

The meetings were regularly attended by the palliative care team, representatives from residential aged care facilities, community health, private hospitals, pastoral care, medical oncology and social work. Also included, as required, have been a geriatrician; cardiologist; dietician; and occupational therapist. There has also been input from a palliative care medical specialist. GPs have participated, mostly via teleconference, and on 23 occasions EPC items were used to reimburse GPs for their time.

In South East Queensland 58 case conferences took place with a total of 78 patients discussed. GP involvement was high with 70 EPC/CDM Medicare items claimed by GP practices.

Both of these models are sustainable and the meetings are planned to continue beyond the life of the program.

## **10.2 Shared service protocols**

The evaluation team defined shared service protocols as policies, procedures or protocols for any aspect of clinical management including admission to the program and referral to, or consultation with, other providers. Shared service protocols include care paths / care pathways.

At the commencement of the program, projects varied in relation to whether this element would be included. Across the projects, one planned not to include any shared service protocols. Three were undecided, one planned to partially include and two planned to fully include shared service protocols.

By the end, all projects were involved to varying degrees in developing and implementing shared service protocols. Those projects where there was an existing palliative care service had some service protocols already in place. Other projects were working on developing a palliative care service and therefore these projects required new protocols. In North West Tasmania, standardised protocols were addressed as part of the state-wide implementation of a uniform model of palliative care for Tasmania.

The different types of shared service protocols used across the projects are outlined below.

### **Service protocols**

The Eurobodalla project based their service protocol on the one developed by the Griffith Area Palliative Care Service. It was adapted by the project officer for the local environment in consultation with the Steering Committee and local service providers. The 48 page protocol covers all aspects of the program such as registering a patient, hospital admission and discharge, after hours service, death at home and communicating.

This was the only project to use the GAPS service protocol as a template.

### **Admission protocols**

Most projects needed to develop admission protocols for referral to the project. Again, this varied depending on what was in place already.

Admission protocols were included in Eurobodalla's service protocol document. Other projects, such as South East Queensland, developed a separate admission protocol document –'RPAC Admission kit'. This kit included an Admission Form, Environmental Assessment Form, Consent Forms and Phase Tool 1.1, plus the University of Wollongong explanations and EPC information for GPs.

East Goldfields developed a specific admission policy to facilitate direct admission of palliative care patients to the local hospital.

### **Clinical guidelines**

The Adelaide Hills project developed a palliative care clinical pathway and resources folder. This document was designed to provide guidance on the different aspects of care required, the management of common symptoms including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. The guidelines were developed through a consultative process and reviewed by a palliative care medical specialist. They were distributed to GPs, RACFs, local hospitals, allied health professionals and community nurses.

South East Queensland developed a General Practitioner quick guide resource kit. This is a local guide for GPs with patients requiring palliative care, which will be posted on the SQDGP website. This project also developed a practical planning checklist for patients and carers to plan for end of life.

A number of the projects used existing guidelines and distributed them to service providers. For example, services providers received a copy of the publication *Therapeutic Guidelines: Palliative Care*.

### **End of Life Pathways**

These were developed by three projects (Eurobodalla, Mid North Coast and South East Queensland).

The Mid North Coast project developed, implemented and evaluated an 'End-of- Life Integrated Care Pathway' in a 48 bed acute medical unit at a local hospital. They used a modified Liverpool End-of-Life (E-o-L) Integrated Clinical Pathway. The audit conducted during 2006 revealed that 66% of all patients who died on this unit had their care managed in accordance with the E-o-L Integrated Care Pathway. The audit reported showing an improvement in the management of symptoms and end-of-life communication with patient and their families.

Following on from the successful trial and outcome of the E-o-L care pathway, as outlined above, the Mid North Coast project has rolled out the pathway to two other sites. Each facility has seconded a lead nurse to manage to implementation. This involves conducting baseline audits, implementing the pathway and re-auditing at the end of the trial.

South East Queensland developed and implemented an E-o-L care pathway at a private hospital and across residential aged care facilities in the region. Education sessions accompanied the implementation of these pathways.



In Eurobodalla an E-o-L clinical pathway was trialed in two local RACFs. The planned objectives had two main focuses: Enhanced End of Life Palliative Care and trialing increased access to medications after hours to support End of Life care. The pilot was undertaken as a quality project, working with the newly established GP Panels Group for that area. This group comprised two Directors of Nursing and one Deputy Directors of Nursing from the RACFs, the community pharmacist and five local GPs. In total of 22 residents at the two aged care facilities commenced on the End of Life Clinical Pathway between January and November 2006. The evaluation results were extremely positive and as a result both pilot sites expressed a wish to continue using the E-o-L clinical pathway.

### Discharge protocols

The South East Queensland project developed and implemented a discharge and risk assessment tool. This tool was based on Queensland Health's tool and improved by adding a risk section.

Overall, the projects implemented this element on an 'as needed' basis across the continuum of care. It appears that end of life pathways might be an effective strategy to recommend for hospitals and residential aged care facilities.

### 10.3 Access line

An access line is a core component of the GAPS model and is described in the expressions of interest material disseminated by the AGPN as:

*A 24 hour on-call service [that] would ensure services are responsive to consumer needs at all times. The service should offer support, advice and management including domiciliary visits, if required. The access number ensures equity and access for the consumer and their family, and should be advertised within the local area.*

Its implementation includes the establishment of the access line, relevant staff training and development of suitable service protocols.

Five of the eight RPC projects already had an existing access line service as described in Table 66.

**Table 66 Existing after-hours services**

Site	Description of existing service
Adelaide Hills	A mobile number shared between two palliative care nurses
Eastern Goldfields	An after-hours on-call roster managed by Silver Chain
Pilbara	Two State-wide 24 hr support lines run by Hollywood Hospital and Silver Chain in Perth
North West Tasmania	Out-of-hours service available to patients registered with the local specialist PCS
West Vic	After hours medical service organised by the West Vic Division of General Practice.

Four of these five projects made no attempts to develop any additional after hours services. However, the West Victoria project enhanced the Division's existing service through the following initiatives:

- 'Registered' palliative care patients' into the current after hours service
- Developed palliative care protocols for the triage nurses to use on the after hours service
- Trained triage nurses working on the existing after hours program
- Faxed triage information from registered patients to the relevant GP

Unfortunately a system was not developed to record the number of calls received by this service. However, anecdotal evidence from local GPs indicated that the existence of the service did reduce the number of after hours calls they received from their palliative care patients. Funding for this enhanced after hours service stopped in June 2006 as it was replaced by a state-wide initiative called 1800 Nurse on Call.

The remaining three services did not have an existing Access Line service and developed an after hours service as described in Table 67.

**Table 67 Access lines developed by RPC projects**

Supported by:	Follow-up action	Number of calls	Sustainable?
<b>Eurobodalla</b>			
On-call staff receive relevant case notes of registered patients  Palliative care training for on-call staff  On-call staff receive a 'flip-chart' containing relevant 'prompts' to assist them in handling the calls	Where relevant an after-hours call-sheet is faxed to the appropriate clinical staff member within 24hrs.	144 calls between Aug 2004 and Aug 2006	Hopefully incorporated into the Divisions budget for chronic disease management
<b>South-East Queensland</b>			
Guidelines and pathways provided for on-call staff	Follow up procedures established	4 calls over a twenty four month period	No, future calls will be directed toward Queensland Health's 13HEALTH, Cancer Helpline and Lifeline.
<b>Mid-North Coast</b>			
Decision support manuals provided to on-call staff  Access to intranet version of PalCIS providing real time clinical information about registered palliative care patients.	Follow up procedures established	55 calls between March 2005 and November 2006	Ongoing negotiations with local AHS for them to maintain the service.

Of the three access lines outlined in the above table, the Mid-North Coast Service was independently evaluated. The results revealed that the majority of calls (78%) were received between 1800 and 2400. The major reasons for accessing the service was for reassurance surrounding medication usage; symptom management and anxiety. In most cases issues identified by the patient and their family could be resolved over the phone with only 2 patients being referred to the Emergency Department in the absence of an outreach palliative care service. On-call staff estimated that the total time for an occasion of service, including documentation and follow-up, was 30 minutes.

In view of the success of this service in Eurobodalla it is hoped that the Access Line will continue as part of the Divisions core business beyond the funding period of the project. The Division estimates that this service costs approximately \$30,000 annually in terms of on-call staff and coordinators wages. It is hopeful that this will be funded within the Division's chronic disease management budget.

Similarly in the Mid-North Coast there is hope that the access line will continue as part of the local area health services core business.



## 10.4 Patient held record

The evaluation team defined patient held medical record as a document kept in the patient's home or by the patient which includes, as a minimum, information on past medical history, current services and current clinical information.

At project commencement, individual sites varied in relation to whether a patient held medical record would be included in their project. Two projects did not include this element in their project. For one of these projects, East Goldfields, a patient-held record already existed in the form of home files maintained by Silver Chain for all its clients.

Another two projects, West Victoria and Eurobodalla, following a recommendation from the National Consultant, revised their project plans to include this initiative. Mid-way through a third project, Pilbara, decided to include a patient held medical record in their work. It was reported that they developed a 'home file' but it was not implemented.

Five projects actually implemented patient held records.

In North West Tasmania, the Palliative Care Service used a 'Community Home File' held by patients to facilitate communication between the patient and members of the PCS. An objective in the project plan was to further develop and enhance the existing patient-held record system. This primarily involved the inclusion of Tool 1.1 in the record and use of a patient-held record by those registered with the project but not with the PCS. The file was also used to collect service utilisation data with patients recording appointments and visits by providers to their home. This worked well with a strong sense of ownership of the file by patients.

Eurobodalla trialed the NSW Health 'My Health Record' or 'Red Book' as a mechanism to record service utilisation and share information between service providers. Accordingly every registered patient received their own 'Red Book' together with a business card which identified that the card carrier was part of the Eurobodalla Palliative Care Service initiative. The distribution of the 'Red Book' to new registered patients was discontinued mid-2005. The patient held medical record was being used more as an information booklet rather than a mechanism to collect data. In addition, two other patient held medical records were also being distributed, one by local GPs and the other by the local pharmacists. Some patients registered in the program had also voiced concerns to the project officer relating to carrying their medical record around with them and the possibility of losing it. In view of these concerns, it was decided not to continue distributing the record.

Western Victoria based their 'communication book' on other similar resources such as the NSW personal health record. An evaluation sheet was distributed but none were returned. However, verbal feedback from the patients indicated they found it very useful when they were travelling inter-state and needed to have a comprehensive record of their medical history.

In South East Queensland, the patient held record was introduced to improve the transfer of patient information between hospitals and general practitioners. The project adapted a patient held record originally developed by GP Connection Toowoomba and was issued to approximately 70 patients. On review, there was not enough information documented in the patient held record to make it a useful patient care tool. The project therefore chose not to continue with the patient held record once the program ended.

In Adelaide Hills, the patient held record was designed to belong with the patient to use as a diary. This diary could be used to record personal reflections, notes or questions to ask doctors. It was not designed to be part of, or replace, the normal medical health record. It was developed in consultation with stakeholder and trialed with six patients. The project also offered a volunteer to assist find and enter the initial information in the diary, as this proved to be a time consuming task. Over 1000 copies of the patient 'diary' have been distributed across South Australia.

Three projects have indicated that patient held records will be sustained in their regions. In two of these projects this has been a new strategy and in the third it is a modification of an existing record.

It appears that no project was able to conduct an evaluation of this element. Formal review of the patient held records would be useful to establish if any aspects of the record assisted in managing care from the patient, the carer and the health provider perspectives.

Until there is more evidence of the impact and outcomes of patient held medical records or diaries, it is difficult to recommend this as a strategy for all rural and remote regions. One project officer recommends that “comprehensive consultation is required before deciding whether to go ahead with a patient held record”.<sup>13</sup> Any new region considering this strategy is advised to clarify the aim of the record and then consult with stakeholders involved in its implementation. There are now five different patient-held medical records or diaries templates developed across five different states. These would be a valuable resource for any region that decided to implement a patient held record.

## 10.5 Other direct care activities

### 10.5.1 Fly-in, fly-out specialists

Three projects developed a visiting fly-in fly-out specialist arrangement. Two of these projects did not have any specialist palliative care service providers prior to the program. One project had an established specialist palliative care team but no medical specialist.

This strategy was not one of the elements of the GAPS model. However, the palliative care service planning framework, recommends that primary care providers have a ‘relationship with designated specialist palliative care service, makes referrals according to level of need, has education to provide care with palliative care (page 21)’.<sup>14</sup>

The fly-in fly-out services effectively provided clinical consultation, local education, support and appropriate advice for service providers involved with palliative care.

Some examples of activities conducted by the palliative care specialist include:

- attending home visits with other team members
- participating in multidisciplinary team meetings and/or case conferences
- undertaking patient reviews (at GP request)
- providing face-to-face education with GPs and other service providers
- conducting case reviews with private hospital nursing staff and with Indigenous Nursing staff.

At the Mid North Coast project, there were 42 specialist palliative care outpatient clinics with 248 palliative care patients being referred for specialist medical review.

The palliative care specialist has provided valuable links between the local area and tertiary level palliation services in Sydney and Brisbane. This has had a couple of benefits for the program. Firstly it reduces the travel burden placed upon local palliative care patients for specialist input into their care. Secondly it has promoted GP engagement in the project by providing opportunities for continued education. For example, in one project this link encouraged GPs to participate in the PEPA program within a tertiary palliative care hospital.

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<sup>13</sup> Rawlings D *Patient held records in a rural palliative care program*. April 2007, Adelaide Hills Division of General Practice, SA.

<sup>14</sup> PCA (2005) *A guide to palliative care service development: a population based approach*

The specialist 'flew in' once a month for two projects and fortnightly for the third. Two projects used the Medical Specialist Outreach Assistance Program (MSOAP) program. In the third project, the local GPs did not support using the MSOAP program, so the project funded this trial.

It appears that two of the projects will be able to sustain this service using ongoing funding from the Medical Specialist Outreach Assistance Program (MSOAP). This funding will be reviewed in 2008. However, the projects believe that a project officer needs to be in place to support the coordination and management of the specialist visits.

### 10.5.2 Link nurses

Three projects established Link Nurse groups. A Link Nurse, as defined by the South East Queensland project, is a representative from an organisation who has a particular interest in palliative care. They act as the link between agencies or organisations and within their own agency or organisation.

For the South East Queensland project, the nurse liaises between management, staff and other link nurses to:

- act as a portal for enquires & information
- attend monthly case conference — give update/report at meetings
- dissemination relevant clinical information
- attend education sessions
- disseminate knowledge to colleagues
- record clinical phases changes (education session will be provided) & data collection
- ensure pathways and referrals are adhered to
- distribute appropriate material
- ensure literature and brochures etc are available to all staff & families
- report and inform relevant services of information on patients changes, discharge and so on.

Across the program there were approximately 10 link nurse positions at Adelaide Hills and 25 Link nurse positions at both the Mid North Coast and South East Queensland.

To assist with recruitment, South East Queensland developed a brochure on Link Nurses.

The groups tend to meet monthly with an education and clinical focus. For example, in South East Queensland, the groups meets monthly for informal breakfast 7- 8am where they can discuss any relevant issues, debrief with other like minded staff and present a case study for discussion. This is followed by a case conference to discuss registered patients in the project. This is reported as a vital component in developing effective communication between services.

All projects developed education plans and implemented programs. These included half and full day clinical education sessions on topics such as opioid conversions and symptom management. At Mid North Coast the Link nurses from RACFs were provided with 40 hours of palliative care education including a 16 hour field placement with the specialist palliative care team.

This group has continued to meet with a representative from 8/10 local RACFs (one is a hostel and the other a nursing home with no interest in joining) and 4/5 local hospitals (with the fifth hospital about to join the group).

The Link Nurse group, Adelaide Hills, worked together to develop a bereavement package for relatives and friends of those who have died in RACFs or local hospitals. The group also assisted with the development of the patient held medical record / diary.

The Adelaide Hills project conducted two surveys of the Link Nurse group members, one in January 2005 and again in September 2006, with most of the members completing both surveys. There were 8 members who responded to the survey in 2005, and 9 responding in 2006.

The results reported by the project coordinator show an improvement in their overall knowledge of palliative care and their confidence in caring for dying patients. All 9 respondents (2006) felt that the link nurse group was a worthwhile experience. One link nurse commented that “it has helped me become aware of the needs for palliative care information and practice to be promoted in our facility”.

All three Link Nurse groups plan to continue to meet after the completion of the program.

A paper has been written outlining the process to establish as link nurse group with case studies from two projects.<sup>15</sup> It is being placed on the AGPN website.

## 11 Management and use of patient information

The original Griffith project adopted several measures of health status including the Palliative Care Phase, the Karnofsky scale, a measure of symptom severity, and the Resource Utilisation Groups Activities of Daily Living (RUG-ADL) scale that provided functional, psychosocial and symptom severity information relating to each phase of illness. These clinical assessment tools were found to be helpful for both the project and for the evaluation.

Clinicians in the Griffith project found that the use of these common assessment tools helped them to develop a common language that facilitated a more objective discussion about patient well-being and helped to track a patient's progression. The tools can also be used as a trigger for more detailed clinical assessment or as an indicator that specialist expertise may be required. The tools are also seen as a good indicator of the level of resources required by patients.

In view of these benefits it was intended that the use of Phase together with its associated assessment tools (Tool 1.1) would not be seen as an evaluation ‘add on’ but as something that clinicians would share with other clinicians and incorporate into their everyday practice.

However, the collection of Tool 1.1 proved to be quite a contentious component of the RPC minimum data set. Almost universally, projects saw Tool 1.1 solely as an evaluation tool and not as an integral component of service delivery. As a result, rather than being collected in ‘real time’ and shared amongst service providers as a ‘common language’, the tool was mostly collected retrospectively only for evaluation purposes.

At the outset many of the RPC projects had high expectations of using Tool 1.1 in a clinically relevant way. Adelaide Hills, Mid-North Coast, Eurobodalla and the Pilbara had all planned to use PalCIS in conjunction with Palm Pilots so that Tool 1.1 data could be entered in ‘real time’. It was also planned to use the Palm Pilots as a mechanism to share information with after hours staff. However, despite the best efforts of the project officers at each site, this never materialised due to technical problems with the palm pilots. Ultimately in Adelaide Hills and Eurobodalla Tool 1.1 data were entered retrospectively into PalCIS for evaluation purposes only. In the Pilbara, no useable Tool 1.1 data were submitted to the NET.

The Mid-North Coast project also had technical issues with Palm Pilots and eventually suspended their use. However, this project was able to share Tool 1.1 amongst clinicians. This was carried out by using two versions of PalCIS. The Master version was made available on the intranet at the local area health service and was accessed by the local palliative care team. This version of

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<sup>15</sup> Rawlings D (2007) *Establishing a palliative care link nurse group in the rural palliative care program*, Adelaide Hills Division of General Practice

PalCIS was also accessed by nurses at a remote site to provide after hours telephone support. This gave them access to real time clinical information about registered patients.

Another version of PalCIS was loaded onto a laptop. This made the data portable and meant that it could be shared with relevant clinicians at regular multidisciplinary team meetings. To facilitate this, data extractions were undertaken on a regular basis to update the laptop version of PalCIS so it contained the complete master list of patients.

At West Victoria, two existing palliative care services signed a service agreement with the local division of general practice to collect Tool 1.1. However, the data collected by both palliative care coordinators were not shared between clinicians. Rather, they were entered retrospectively into a local database system for evaluation purposes only. Despite this, the palliative care coordinator from the Central Grampians Palliative Care Service saw the potential value in collecting Tool 1.1 and absorbed some of its elements into the local community nurses admission kit. It is hoped that, over time, this will be introduced across the whole service.

North West Tasmania and South East Queensland both collected Tool 1.1 on a paper based record. The North West Tasmania project retrospectively entered these data into an Access Database whilst South East Queensland entered the data into PalCIS. Again, this was done at both sites to meet the needs of the evaluation only.

The situation was further complicated by the nature in which the data were collected. In most cases the data were collected by community nurses employed by the local area health service. These nurses were not funded through the RPC program and were required to conduct this extra clinical assessment on their palliative care patients. In many cases, this was in addition to, rather than as a replacement of, their existing information collection. This was not the intention at the onset of the program. But it reflected the structural difficulties of attempting to establish a separate rural palliative care service in the context of existing service and funding systems.

A further issue is that there was no systematic education program for participating clinicians in how to collect and how to use the information that was collected. While some sites gave this issue considerable attention, the training was extremely variable across sites and over time.

In summary, the collection and use of patient information was a problematic issue at all sites for three reasons:

- For many of the community nurses, participation in the RPCP created burdensome additional work on top of existing area health service data requirements.
- The technology employed did not readily allow patient information to be shared in real time.
- There was insufficient investment in education programs for participating clinicians in how to collect and how to use clinical information.

These findings provide important lessons for future programs.



## 12 Sustainability

As part of the Rural Palliative Care Project evaluation, sites complete the sustainability, capacity building and generalisability checklists. These items form part of the Palliative Care Toolkit designed by the Centre for Health Service Development. They are tools 4, 5 and 6 respectively. The tools are completed at three points in time: at the beginning of the project, at mid-point and at the end of the project. The tools are used by site coordinators to assist in their own site evaluation to indicate their progress (they are used only as a guide).

The initial assessment was undertaken on all eight projects in 2004. These assessments were completed by the site coordinators with assistance from the National Coordinator. Discussions of these results appear in the Evaluation of the Rural Palliative Care Program Second Progress Report. Mid-point data was also collected by all eight rural palliative care sites during the period September 2005 to November 2005. End-point data was collected by seven out of the eight sites during the period September 2006 to January 2007.

In certain cases, the site coordinators completed the mid-point assessments with assistance from a National Evaluation Team (NET) member. One project completed the tools in consultation with their site steering committee. This site considered consultation with the steering committee as a useful method of obtaining unanimous responses from several key respondents.

This section outlines the results from the initial, mid-point and end-point data. It identifies and elaborates on any evident differences between the three sets of data. The tables below present the results for each item in the sustainability checklist (Table 68), capacity building checklist (Table 70), and generalisability checklist (Table 72), at baseline (clear rows) and at mid-point and end-point (shaded rows).

### Responses to Sustainability Checklist

The sustainability checklist consists of eleven statements. Statements 1-4 focus on project design and implementation factors. Statements 5-9 are related to factors within the organisation that are known to relate to the survival of a project. Statements 10 and 11 deal with factors in the broader community environment which affect how long projects last. Respondents are asked to rate each statement on a 4 point-scale. Respondents are also asked to comment on the goals of the project once funding ends.

Table 68 details results from the baseline, mid-point and end-point sustainability checklist (Tool 4). It is followed by a comparative analysis and discussion of these results.

**Table 68 Responses to Sustainability Checklist**

No	Item	Time	Yes, fully	Yes, partly	No	Don't know
1	People with a stake in the project - funders, administrators, consumers/beneficiaries, other agencies – have been aware of the project and/or involved in its development	baseline	6	2	0	0
		mid-point	4	4	0	0
		end-point	5	2	1	0
2	The project has shown itself to be effective. Effects are visible and acknowledged	baseline	0	2	2	4
		mid-point	1	6	1	0
		end-point	6	2	0	0
3	The organisation which you intend to host the project in the future has been making some real or in kind support to the project in the past	baseline	2	5	0	1
		mid-point	3	4	0	1
		end-point	5	3	0	0
4	Prospects for the project to acquire or generate some additional funds or resources for the future are good	baseline	1	4	0	3

No	Item	Time	Yes, fully	Yes, partly	No	Don't know
		mid-point	1	5	1	1
		end-point	3	2	2	1
5	The organisation that you intend to host the project in future is mature (developed, stable, resourceful). It is likely to provide a strong organisational base for the project.	baseline	3	1	0	4
		mid-point	3	3	1	1
		end-point	3	4	0	1
6	The mission of the project is compatible with the mission and activities of the intended host organisation	baseline	5	0	0	3
		mid-point	2	5	0	1
		end-point	5	2	0	1
7	Part of the project's essential 'business' is integrated into other aspects of the host organisation eg. in policies, practices, responsibilities etc. That is, the project does not simply exist as an entirely separate entity	baseline	5	1	0	2
		mid-point	3	4	0	1
		end-point	5	2	0	1
8	The project is well supported in the organisation. That is, it is not under threat and there are few rivals in the organisation who could benefit from the closure of the project	baseline	5	1	0	2
		mid-point	0	8	0	0
		end-point	6	0	1	1
9	The intended host organisation has a history of innovation or developing new responses to situations in its environment	baseline	4	1	0	3
		mid-point	0	6	1	1
		end-point	4	3	0	1
10	There is a favourable external environment for the project, that is, the values and mission fit well with community opinion, and the policy environment	baseline	8	0	0	0
		mid-point	5	3	0	0
		end-point	6	1	0	1
11	People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the project should it be threatened	baseline	5	1	0	2
		mid-point	3	5	0	0
		end-point	3	3	1	1

An analysis of both the baseline and mid-point sustainability responses emphasise an overall positive feedback. However, when the mid-point scores were compared to the baseline scores, there was an apparent shift. This shift indicates a reduction in the level of agreement with the statements. For example the collective responses to statements 6 – 9 and 11 shifted from a majority 'yes fully' response during the initial assessment to a majority 'yes partly' response during the mid-point assessment. These statements deal with factors within the organisational setting and broader community that are known to relate to the survival of the project.

Results from the end-point data also indicate an overall positive feedback. When responses were compared for statements 6-8, there was a shift indicating an increased level of agreement with these statements compared to the responses from the mid-point survey.

At baseline, the responses to statement 2 received a majority negative response. Responses from two sites selected a 'no' response while four sites selected a 'don't' know' response. However, mid-point response to statement 2 indicate a majority positive response whereby one site selected a 'yes, fully' response and six sites selected a 'yes, partly' response. The end-point data also show five 'yes, fully' responses and two 'yes, partly' responses. This shows a positive shift in perception from the baseline to a more positive attitude in the mid-point and end-point data regarding the effectiveness of the project.

In comparison, the mid-point results show a negative response to four statements (statements 2, 4, 5, 9). However, for each of these statements, the negative response only represented one out

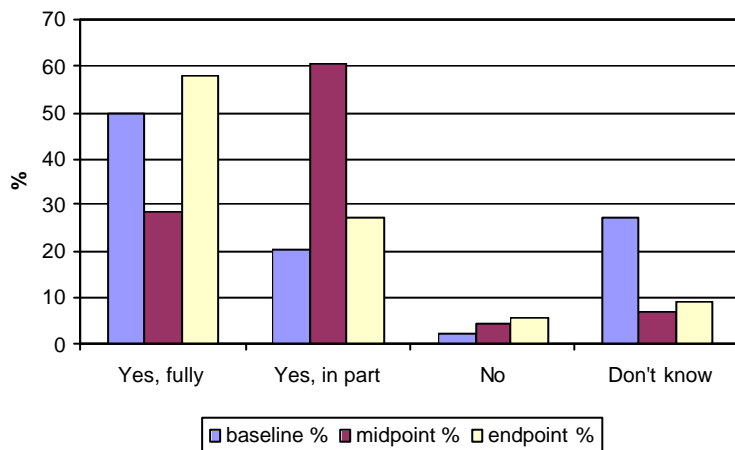
of eight responses. There were four negative responses in the end-point data for statements 1, 8 and 11. For each of these statements the negative response represented one out of 7 responses and in statement 4 where it represented two out of seven responses.

One section of the sustainability checklist asks project coordinators to determine the goals of the projects once funding ceases. This statement was answered by 6 out of the 7 end-point responses. Four sites indicated that by the time the project is over, it would have an impact in the society and possibly be in a position to self sustain. Two other sites indicated that by the time the project ends, they would have found other ways to keep it self sustaining. The remaining two sites indicated that once the project ends it would keep having an impact but not sure as to whether it would be self sustaining.

Overall, responses from the end-point data are more closely aligned with responses from the mid-point data. This indicates a higher level of confidence in regards to the running of the project. It is possible that at the time the baseline data was collected, projects were still in the initial stages and were unable to accurately determine their success.

In Figure 20 we compare the baseline, mid-point and end-point sustainability checklist responses.

**Figure 20 Sustainability Checklist Comparison**



The largest difference between the four categories of responses is evident in the ‘yes, in part’ columns. During baseline assessments, 24% of respondents selected ‘yes, in part’, compared to 63% from the mid-point and 28% in the end-point assessments. There is also a reduction in the number of ‘don’t know’ responses which were initially 31% at baseline and decreased to 8% at mid-point and 9% at end-point. When the ‘yes, fully’ and ‘yes, in part’ responses are combined, we get a total of 67% for the baseline and 87% for the mid-point responses. This indicates a 20% increase in positive responses. However, when the ‘yes, fully’ and ‘yes, in part’ responses are combined and the mid-point and end-point scores compared, we note a 2% decrease in positive responses from 87% during the mid-point and 85% during the end-point assessment.

**Sustainability Percentage Responses by Project**

Table 69 and Figure 21 below depict sustainability percentage responses by project. There were four out of the eight sites for whom more than 70% of responses were ‘Yes, fully’ by the project endpoint and there were seven out of the eight sites for whom more than 70% of responses were either ‘Yes fully’ or ‘Yes, partly’ by the project endpoint. North West Tasmania was the only site that showed a relatively low level of ‘Yes, fully’ and ‘Yes, partly’ responses. This was due to ‘Don’t know’ comprising just over 45% of responses at endpoint.

Both the West Victoria and Mid North Coast projects initially had a very high proportion of ‘Don’t know’ responses, however, 100% and 90% of responses respectively at endpoint were either ‘Yes,



fully' or 'Yes, partly'. Other sites where 100% of responses were 'Yes, fully' or 'Yes, partly' at endpoint included Eurobodalla, South East Queensland and West Victoria.

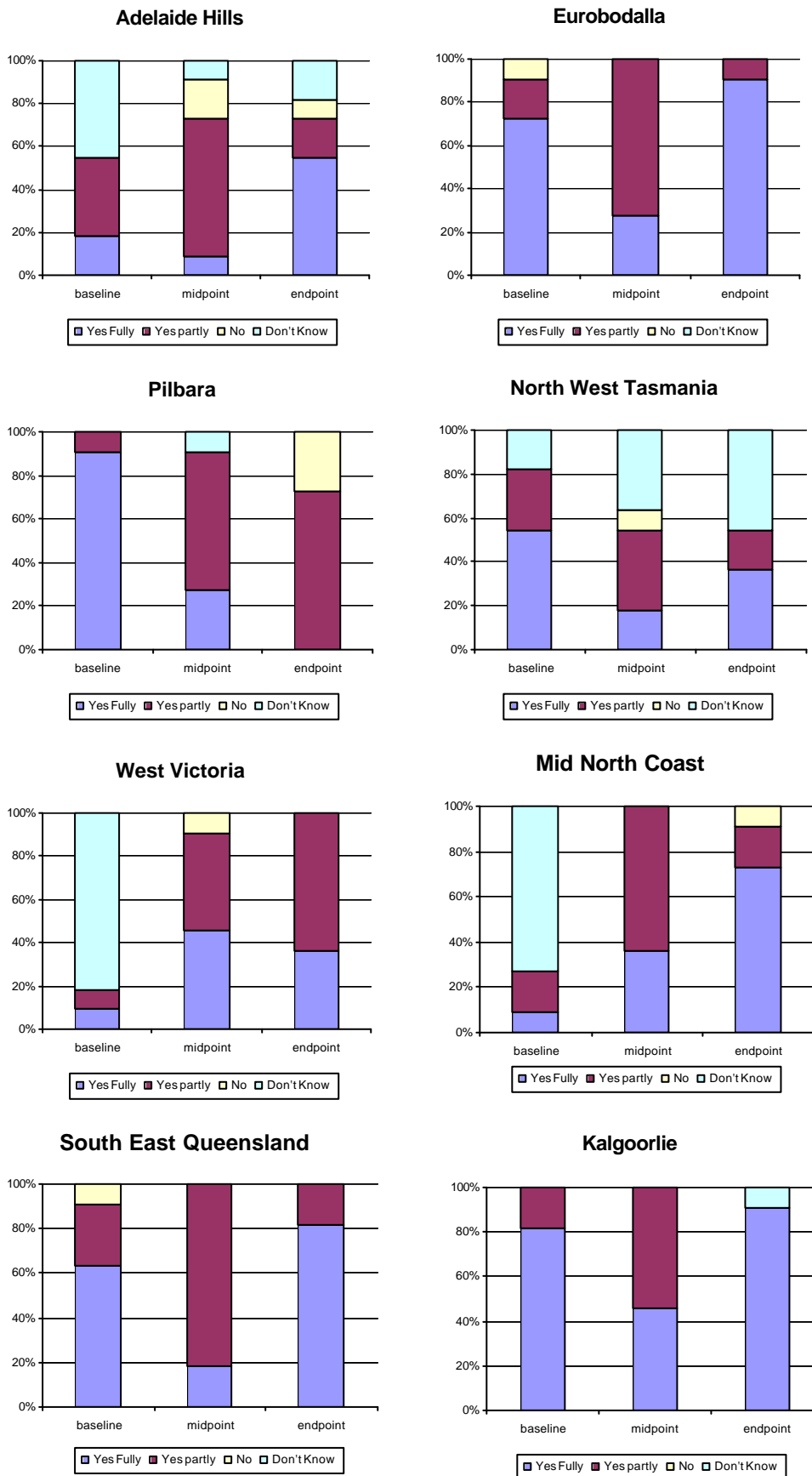
A number sites observed a pattern of 'Yes, fully' responses that were initially high but dropped at midpoint and then rose again at endpoint, most notably Eurobodalla, South East Queensland and Kalgoorlie. North West Tasmania also saw a similar pattern, however, this site did not see a rise to the same extent at endpoint due to the high proportion of 'Don't know' responses.

Pilbara initially had a high number 'Yes, fully' responses but at end point there were no 'Yes, fully' responses at all. The majority of responses were 'Yes, partly' at the end of the project but just over 27% indicated 'No'. The only other site where respondents answered 'No' at end point was the Mid North Coast project but this was only a small proportion of responses.

**Table 69 Sustainability checklist responses – percentage by project**

Project Site	Time	Yes, fully (%)	Yes, partly (%)	No (%)	Don't Know (%)
Adelaide	Baseline	18.2	36.4	0.0	45.5
	Midpoint	9.1	63.6	18.2	9.1
	Endpoint	54.5	18.2	9.1	18.2
Eurobodalla	Baseline	72.7	18.2	9.1	0.0
	Midpoint	27.3	72.7	0.0	0.0
	Endpoint	90.9	9.1	0.0	0.0
Pilbara	Baseline	90.9	9.1	0.0	0.0
	Midpoint	27.3	63.6	0.0	9.1
	Endpoint	0.0	72.7	27.3	0.0
North West Tasmania	Baseline	54.5	27.3	0.0	18.2
	Midpoint	18.2	36.4	9.1	36.4
	Endpoint	36.4	18.2	0.0	45.5
West Victoria	Baseline	9.1	9.1	0.0	81.8
	Midpoint	45.5	45.5	9.1	0.0
	Endpoint	36.4	63.6	0.0	0.0
South East Queensland	Baseline	63.6	27.3	9.1	0.0
	Midpoint	18.2	81.8	0.0	0.0
	Endpoint	81.8	18.2	0.0	0.0
Mid North Coast	Baseline	9.1	18.2	0.0	72.7
	Midpoint	36.4	63.6	0.0	0.0
	Endpoint	72.7	18.2	9.1	0.0
Kalgoorlie	Baseline	81.8	18.2	0.0	0.0
	Midpoint	45.5	54.5	0.0	0.0
	Endpoint	90.9	0.0	0.0	9.1

**Figure 21 Sustainability assessment by site**



## 13 Capacity building

The capacity building checklist consists of eighteen statements. Respondents are asked to rate each statement on a 4 point-scale. Table 70 below details results from the baseline, mid-point and end-point capacity building checklist (tool 5). It is followed by a comparative analysis and discussion of these results.

**Table 70 Responses to Capacity Building Checklist**

No	Item	Time	Yes, fully	Yes, partly	No	Don't know
1	People with a stake in the project – consumers/ beneficiaries, other agencies, health care providers – have been able to contribute to the development of the project.	baseline	4	4	0	0
		mid-point	4	4	0	0
		end-point	7	1	0	0
2	People involved with the project have been able to establish links with other organisations and providers of palliative care in the community.	baseline	7	1	0	0
		mid-point	6	2	0	0
		end-point	7	1	0	0
3	People involved with the project have taken a leadership role in the local community with regard to palliative care.	baseline	6	1	1	0
		mid-point	4	4	0	0
		end-point	6	2	0	0
4	People involved with the project have been able to resolve conflicting interests in the area of palliative care in the community.	baseline	2	1	1	4
		mid-point	2	5	0	1
		end-point	2	4	1	1
5	This project has been able to engage the local media in promoting relevant palliative care issues.	baseline	3	1	3	1
		mid-point	3	5	0	0
		end-point	3	4	1	0
6	The project has involved formal and/or informal training of people whose skills and interests are retained in the project or its immediate environment*	baseline	0	0	6	2
		mid-point	5	3	0	0
		end-point	7	1	0	0
7	This organisation has been able to establish agreed policies or memoranda of understanding with other organisations regarding the provision of palliative care services in this community.	baseline	2	4	2	0
		mid-point	3	4	1	0
		end-point	5	2	1	0
8	This organisation has generated and supported community skills to direct, provide, lead or otherwise contribute to the provision of palliative care services in this community.	baseline	3	4	1	0
		mid-point	3	5	0	0
		end-point	5	3	0	0
9	More organisational resources have been directed to the area of palliative care services in this community	baseline	3	1	2	2
		mid-point	4	3	1	0
		end-point	3	4	1	0
10	There is someone in authority or seniority, other than the director of the project itself, who is an advocate for the project at high levels in the organisation	baseline	7	1	0	0
		mid-point	6	2	0	0
		end-point	7	0	1	0
11	Community coalitions have formed to promote and advocate for palliative care services in this community.	baseline	5	2	1	0
		mid-point	2	6	0	0
		end-point	3	3	2	0
12	Community coalitions and organisations have a shared view of what comprises palliative care services in this community.	baseline	3	4	0	1

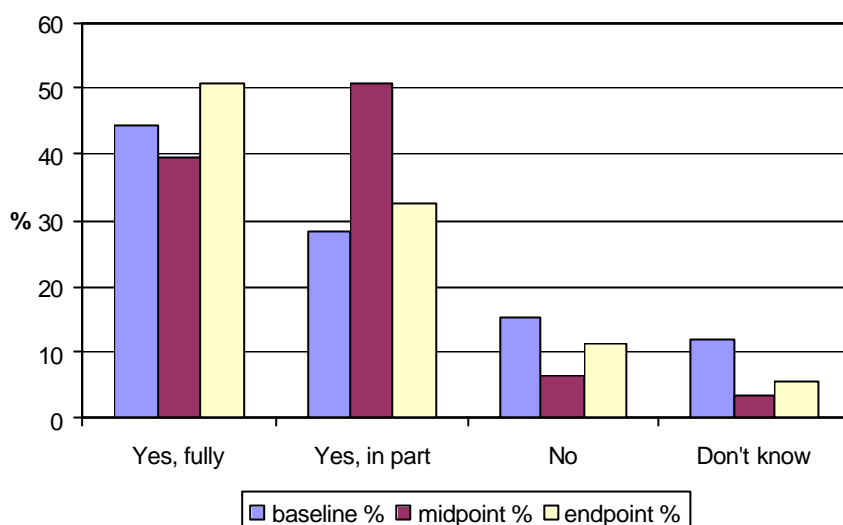
No	Item	Time	Yes, fully	Yes, partly	No	Don't know
		mid-point	3	4	0	1
		end-point	3	3	1	1
13	Key community leaders have engaged in critical appraisal of the need for palliative care services in this community.	baseline	5	3	0	0
		mid-point	3	4	1	0
		end-point	2	4	1	1
14	Community members have taken a leadership role to promote palliative care services in this community.	baseline	2	5	0	1
		mid-point	1	3	3	1
		end-point	1	5	2	0
15	Community events have occurred to acknowledge, promote or provide funds for palliative care services.	baseline	0	3	4	1
		mid-point	3	5	0	0
		end-point	4	3	1	0
16	Community members directly involved in or affected by palliation are actively engaged in the oversight of the development, provision or management of palliative care services in this community.	baseline	3	4	1	0
		mid-point	0	7	1	0
		end-point	1	6	0	1
17	People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the project should it be threatened	baseline	5	2	0	1
		mid-point	3	4	1	0
		end-point	4	1	2	1
18	Community organisations that are similar to the intended host organisation have taken the step of supporting projects somewhat like your project	baseline	4	0	0	4
		mid-point	2	3	1	2
		end-point	3	0	2	3

A comparison between the baseline, mid-point and end-point capacity building checklist responses indicate a reduction in the level of agreement with 3 out of 18 statements moving from a collective response of 'yes, fully' to 'yes, partly'. These include statements 11, 13, and 17. Responses to statement 11 shows that sites coordinators are now slightly less confident that community coalitions and organisations have a shared view of what comprises palliative care services in the area. Overall responses to statement 17 show a reduction in confidence regarding whether people in the community will advocate for and maintain a demand for the existence of the project. The majority of responses to statement 18 show that site coordinators are now slightly less confident that community organisations that are similar to their own organisation have taken steps to support similar projects.

The baseline capacity building checklist indicates two statements receiving a majority negative response (statements 6 and 15). In response to statement 6, six out of eight selected 'no'. However, the mid-point responses to this statement show five out of eight selecting a 'yes, fully', while three out of eight selecting 'yes, partially'. The end-point responses show six out of seven selected "yes, fully" while only one selected "yes, partially". This shows that a positive outcome of the project is that those who have received training through the project are being retained in the project or in its immediate environment. Similarly, a positive shift in the responses to statement 15 (from baseline to the mid-point assessment) shows that community events have occurred to acknowledge, promote or provide funds for palliative care services. However, end-point responses to this question indicate a slight reduction in confidence.

In Figure 22, we compare the baseline, mid-point and endpoint capacity building checklist responses.

**Figure 22 Capacity Building Checklist Comparison**



The largest difference between the four categories of responses is evident in the ‘yes, in part’ columns. During baseline assessments, 30% of respondents selected ‘yes, in part’, compared to 51% from the mid-point assessments. There is also a reduction in the number of ‘don’t know’ responses which were initially 13% at baseline and decreased to 4% at mid-point. During the end-point analysis, the percentage of “don’t know” responses increased to 11%. When the ‘yes, fully’ and ‘yes, in part’ responses are combined, we get a total of 72% for the baseline and 93% for the mid-point and 62% for the end-point responses. This indicates a 21% increase in positive responses from baseline to mid-point and a 31% decrease in positive responses from the mid-point to the end-point assessments.

Table 71 and Figure 23 below depict capacity building percentage responses by project. Those projects that appeared to perform the best in relation to the proportion of ‘Yes, fully’ responses included Kalgoorlie, Eurobodalla, South East Queensland, North West Tasmania and the Mid North Coast.

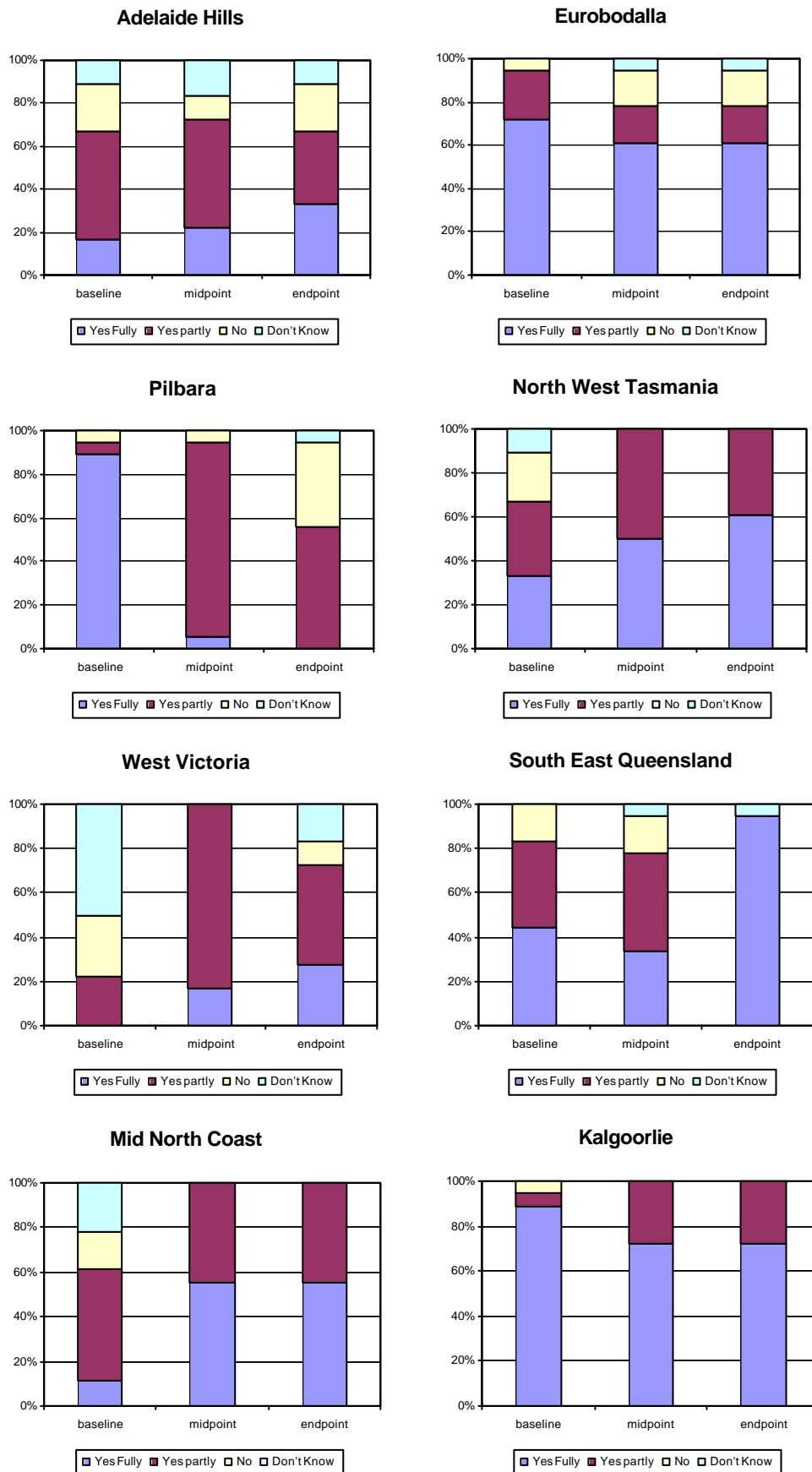
When ‘Yes, fully’ and ‘Yes, partly’ were added these two categories included 100% of responses for Kalgoorlie, North West Tasmania and Mid North Coast at both the project midpoint and endpoint. For Adelaide Hills these two categories combined included more than 80% of responses at all time points.

Those projects that observed the greatest differences over the three time points included the Pilbara and West Victoria. In the Pilbara the proportion of ‘Yes, fully’ responses was almost 90% at baseline but this dropped to only 5.6% at midpoint and 0 at endpoint. At midpoint the ‘Yes, partly’ comprised almost 90% of responses and at endpoint only 55.6% of responses. Almost 40% of responses at endpoint were ‘No’. In West Victoria there were no ‘Yes, fully’ responses initially with 50% of responses being ‘Don’t know’ and almost 28% of responses being ‘No’. At midpoint ‘Yes, fully’ and ‘Yes, partly’ responses made 100% of responses but only 72% at endpoint. This was due to 11% of responses were ‘No’ and almost 17% ‘Don’t know’.

**Table 71 Capacity Building checklist responses – percentage by project**

Project Site	Time	Yes, fully (%)	Yes, partly (%)	No (%)	Don't Know (%)
Adelaide	Baseline	16.7	50.0	22.2	11.1
	Midpoint	22.2	50.0	11.1	16.7
	Endpoint	33.3	33.3	22.2	11.1
Eurobodalla	Baseline	72.2	22.2	5.6	0.0
	Midpoint	61.1	16.7	16.7	5.6
	Endpoint	61.1	16.7	16.7	5.6
Pilbara	Baseline	88.9	5.6	5.6	0.0
	Midpoint	5.6	88.9	5.6	0.0
	Endpoint	0.0	55.6	38.9	5.6
North West Tasmania	Baseline	33.3	33.3	22.2	11.1
	Midpoint	50.0	50.0	0.0	0.0
	Endpoint	61.1	38.9	0.0	0.0
West Victoria	Baseline	0.0	22.2	27.8	50.0
	Midpoint	16.7	83.3	0.0	0.0
	Endpoint	27.8	44.4	11.1	16.7
South East Queensland	Baseline	44.4	38.9	16.7	0.0
	Midpoint	33.3	44.4	16.7	5.6
	Endpoint	94.4	0.0	0.0	5.6
Mid North Coast	Baseline	11.1	50.0	16.7	22.2
	Midpoint	55.6	44.4	0.0	0.0
	Endpoint	55.6	44.4	0.0	0.0
Kalgoorlie	Baseline	88.9	5.6	5.6	0.0
	Midpoint	72.2	27.8	0.0	0.0
	Endpoint	72.2	27.8	0.0	0.0

**Figure 23 Capacity building assessment by site**



## 14 Generalisability

The generalisability checklist consists of eighteen statements. Respondents are asked to rate each statement on a 4 point-scale. Table 72 below details results from the baseline, mid-point and end-point generalisability checklist (tool 6). It is followed by an analysis and discussion of these results.

**Table 72 Responses to Generalisability Checklist**

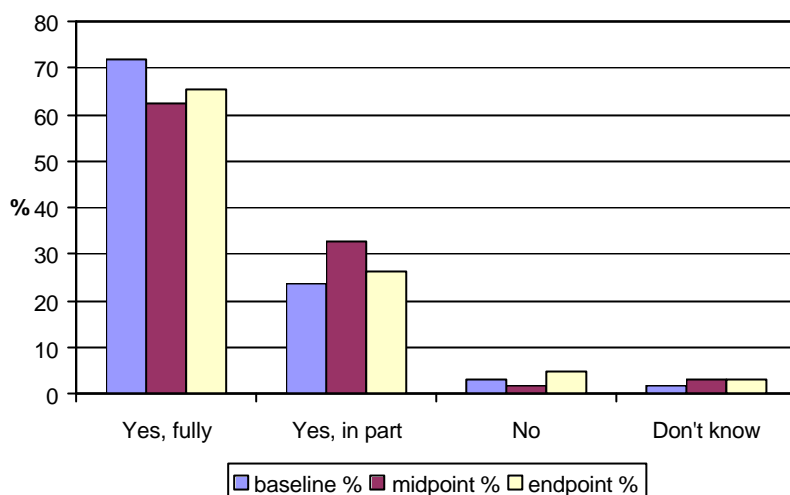
No	Item	Time	Yes, fully	Yes, partly	No	Don't know
1	Our project is designed specifically to meet our own local needs	baseline	7	1	0	0
		mid-point	6	2	0	0
		end-point	6	1	1	0
2	Other regions/services/organisations will learn useful lessons/information from our project	baseline	5	3	0	0
		mid-point	5	3	0	0
		end-point	7	1	0	0
3	It is reasonable to expect that the outcomes of our project could be replicated elsewhere	baseline	6	2	0	0
		mid-point	3	5	0	0
		end-point	4	4	0	0
4	Our project will depend on how sensitive and appropriate it is to our target population	baseline	6	2	0	0
		mid-point	4	3	0	1
		end-point	4	3	0	1
5	Our project is designed to develop capacity (skills and/or knowledge) in palliative care in our region/service/organisation	baseline	7	1	0	0
		mid-point	8	0	0	0
		end-point	6	2	0	0
6	Our project is designed to enable people not directly involved in our project to develop capacity (skills and/or knowledge) in palliative care	baseline	5	1	1	1
		mid-point	6	2	0	0
		end-point	6	2	0	0
7	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	baseline	2	5	1	0
		mid-point	3	4	1	0
		end-point	4	3	1	0
8	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 (*Not available for March 2004)	baseline	8	0	0	0
		mid-point	5	2	0	1
		end-point	5	1	1	1

The baseline, mid-point and endpoint generalisability checklist responses all show a consistent overall positive response. There were six out of eight statements that received a majority 'yes, fully' response during all three assessments. These were statements 1, 2, 4-6 and 8. One statement was rated at a 'yes, partially' during both baseline and mid-point responses (statement 7). This shows that most site coordinators partially agreed that they had a strategy in place to ensure that their experiences and findings were shared with other people who want to develop and improve palliative care.

Only one statement shifted from a majority 'yes, fully' baseline response to a 'yes, partially' mid-point response (statement 3). This meant that halfway through the project, site coordinators were no longer as confident in expecting the outcomes of their projects to be replicated elsewhere. During the end-point assessment, the confidence increased indicated by a majority "yes, fully" response.



**Figure 24 Generalisability Checklist Comparison**



The largest difference between the four categories of responses is evident in the ‘yes, in part’ columns. During baseline assessments, 23% of respondents selected ‘yes, in part’, compared to 33% from the mid-point and 25% during end-point assessments. When the ‘yes, fully’ and ‘yes, in part’ responses are combined, we get a total of 95% for the baseline and 96% for the mid-point responses. This indicates a 1% increase in positive responses and a 5% decrease during the end-point responses. Overall, project coordinators were confident and positive about the generalisability of several aspects within the project.

**Generalisability Assessment by Project**

Table 73 and Figure 25 below depict generalisability percentage responses by project. Most notable are the sites where ‘Yes, fully’ and ‘Yes, partly’ comprised 100% of responses at all time points. These sites included North West Tasmania, South East Queensland, Kalgoorlie and Adelaide Hills. Both North West Tasmania and Adelaide Hills showed consistently high proportions of participants answering ‘Yes, fully’ across all time points. Kalgoorlie showed a drop in ‘Yes, fully’ responses at midpoint and a further drop at endpoint whereas South East Queensland observed a significant drop in ‘Yes, fully’ responses at midpoint and rose again to 100% ‘Yes, fully’ responses at endpoint.

For the Mid North Coast project, 12.5% initially responded ‘No’ to generalisability at baseline but 100% of responses at midpoint and endpoint were either ‘Yes, fully’ or ‘Yes, partly’. Pilbara observed a significant drop in ‘Yes, fully’ responses from 100% at baseline to 62.5% at midpoint and 12.5% at endpoint. In addition 25% of responses were ‘No’ at endpoint.

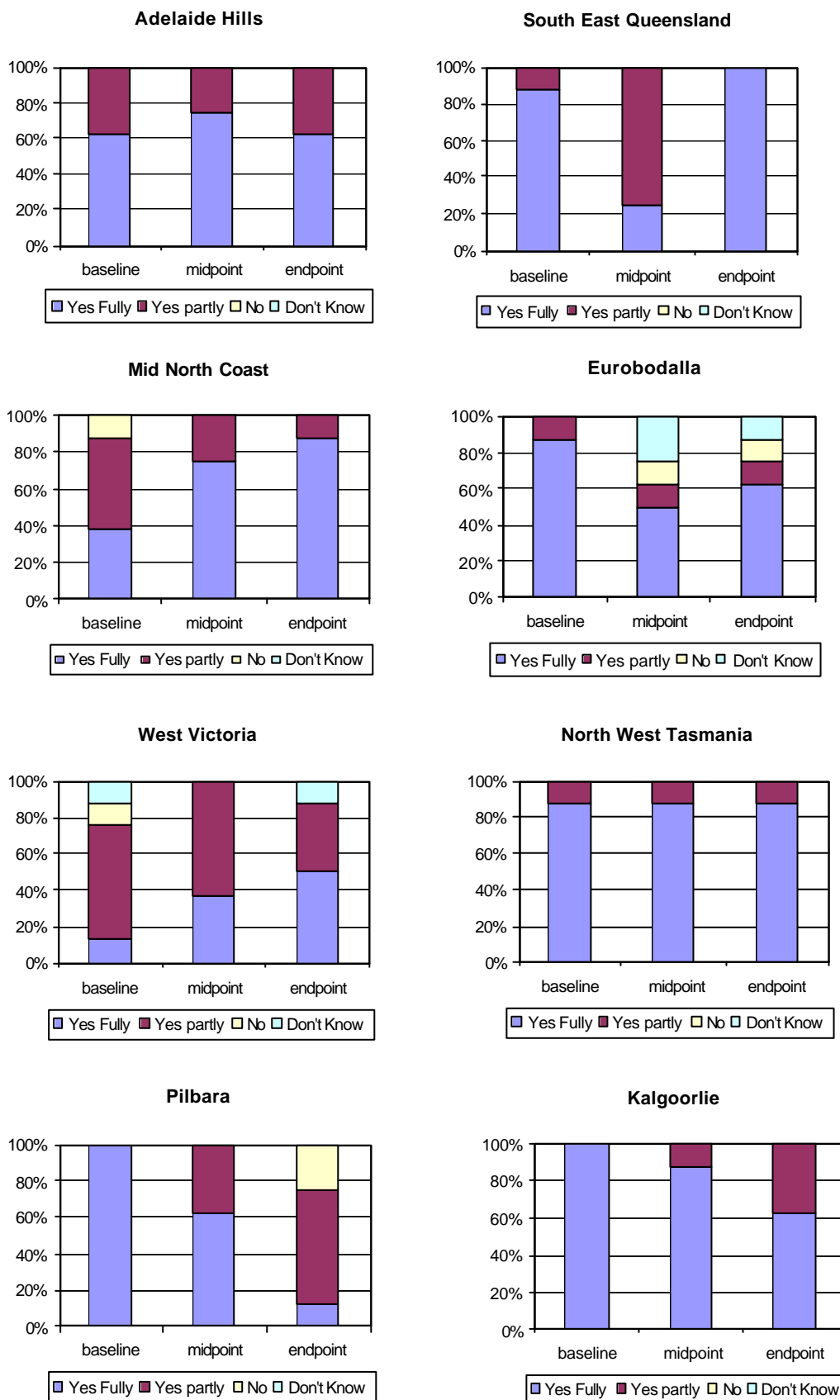
Eurobodalla observed an initially good generalisability assessment at baseline, with 100% of responses being either ‘Yes, fully’ or ‘Yes, partly’. This dropped to just over 60% at midpoint where 25% of responses were ‘Don’t know’. At endpoint ‘Yes, fully’ and ‘Yes, partly’ responses accounted for 75% of responses with the remaining responses divided between ‘No’ and ‘Don’t know’. West Victoria saw the lowest levels of ‘Yes, fully’ responses, however these rose from 12.5% at baseline to 50% at endpoint. At midpoint ‘Yes, fully’ and ‘Yes, partly’ accounted for 100% of responses and 87.5% at endpoint.

**Table 73 Responses to Generalisability Checklist by site**

Project Site	Time	Yes, fully (%)	Yes, partly (%)	No (%)	Don't Know (%)
Adelaide	Baseline	62.5	37.5	0.0	0.0
	Midpoint	75.0	25.0	0.0	0.0
	Endpoint	62.5	37.5	0.0	0.0

Project Site	Time	Yes, fully (%)	Yes, partly (%)	No (%)	Don't Know (%)
Eurobodalla	Baseline	87.5	12.5	0.0	0.0
	Midpoint	50.0	12.5	12.5	25.0
	Endpoint	62.5	12.5	12.5	12.5
Pilbara	Baseline	100.0	0.0	0.0	0.0
	Midpoint	62.5	37.5	0.0	0.0
	Endpoint	12.5	62.5	25.0	0.0
North West Tasmania	Baseline	87.5	12.5	0.0	0.0
	Midpoint	87.5	12.5	0.0	0.0
	Endpoint	87.5	12.5	0.0	0.0
West Victoria	Baseline	12.5	62.5	12.5	12.5
	Midpoint	37.5	62.5	0.0	0.0
	Endpoint	50.0	37.5	0.0	12.5
South East Queensland	Baseline	87.5	12.5	0.0	0.0
	Midpoint	25.0	75.0	0.0	0.0
	Endpoint	100.0	0.0	0.0	0.0
Mid North Coast	Baseline	37.5	50.0	12.5	0.0
	Midpoint	75.0	25.0	0.0	0.0
	Endpoint	87.5	12.5	0.0	0.0
Kalgoorlie	Baseline	100.0	0.0	0.0	0.0
	Midpoint	87.5	12.5	0.0	0.0
	Endpoint	62.5	37.5	0.0	0.0

**Figure 25 Responses to Generalisability Checklist by site**



## 15 Dissemination

This section reports on dissemination activities throughout the life of the project. The six began between February and April in 2004 and ended in December 2006, encompassing a total of 34 months. A wide variety of activities were undertaken by projects including workplace presentations, articles published in newsletters, industry magazines and newspapers, presentations at local, state and national conferences, website postings and radio.

Table 74 outlines the total and average monthly dissemination activities by project during the life of the project while Table 75 outlines the different kinds of activities that were undertaken.

**Table 74 Dissemination activities reported during entire project**

Project	Total activities during project	Average activities per month
Adelaide Hills	100	2.9
Mid North Coast	41	1.2
Eurobodalla	106	3.1
South East Queensland	118	3.4
North West Tasmania	120	3.6
West Victoria	121	3.6
Kalgoorlie	23	0.7
Pilbara	92	2.6
<b>Total</b>	<b>721</b>	<b>2.6</b>

**Table 75 Types of dissemination activities undertaken during the life of the program**

Dissemination activity	Total activities	Percent of activities	Range across projects
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)	241	36.6	1-55
Talk to staff from more than one service or agency in the local area (e.g. talk at an interagency meeting)	187	27.8	0-45
Story in the local newspaper	43	7.7	1-13
Story or article in a local magazine or newsletter (eg, GP news, hospital newsletter, community agency newsletter)	47	4.4	0-8
Story or article in a professional or industry magazine or newsletter	6	3.0	0-6
Presentation or poster at a local conference	13	1.5	0-2
Presentation or poster at a State/Territory conference	8	0.5	0-1
Presentation or poster at a national conference	7	1.2	0-2
Peer-reviewed journal article	0	0.0	
Information provided on a website	14	1.7	0-4
Radio	16	1.9	0-4
Other	139	13.7	0-20
<b>Total</b>	<b>721</b>	<b>100.0</b>	

The most commonly reported types of dissemination activities involved presentations/talks, given to either single or multiple services/agencies. These together comprised nearly 60% of all dissemination activities during the life of the project.

Other activities commonly reported were newspaper and magazine/newsletter stories totalling 13.3%. Nearly twenty percent of dissemination activities were described as 'other'. The nature of these activities was often not specified, but they included project launches, distribution of advertising flyers, information posters/stands in shopping centres and email or fax activities.

Table 76 looks at persons reached and level of follow-up for all dissemination activities.

**Table 76 Persons reached and level of follow-up for selected dissemination activities**

Description	Reach		Follow-up	
	Total activities	Persons reached	Total activities	Follow-ups
Presentation or talk to staff at one service or agency in the local area (eg, talk at a staff meeting, during a hospital grand round)	241	1379	59	2
Talk to staff from more than one service or agency in the local area (eg, talk at an interagency meeting)	187	3291	115	0
Story in the local newspaper	43	239630	27	1
Story or article in a local magazine or newsletter (eg, GP news, hospital newsletter, community agency newsletter)	47	14351	6	0
Story or article in a professional or industry magazine or newsletter	6	17100	6	0
Presentation or poster at a local conference	13	751	23	0
Presentation or poster at a State/Territory conference	8	449	18	0
Presentation or poster at a national conference	7	1245	50	0
Peer-reviewed journal article	0	0	0	0
Information provided on a website	14	13340	2	0
Radio	16	65002	0	0
Other	139	130818	93	0
<b>Total</b>	<b>721</b>	<b>487356</b>	<b>399</b>	<b>3</b>

It is estimated that about half a million people were reached through the various dissemination activities undertaken. It is difficult to measure the exact number of persons reached for some of the activities such as stories in the local newspaper, radio and website use. For these activities, persons reached were provided by the sites as hundreds and sometimes thousands, and based on estimated readership.

The activity that generated the most follow-up during the project was presentations to agencies that had stakeholder interest in the projects. Local newspaper stories, presentations at a conference and 'other' activities also generated some good follow up activity.

The activity that was the least successful during the life of the program was the use of peer reviewed journal articles. However, several projects are in the process of preparing publication of their results via this medium.

## 16 System Level Impacts

Tool 8 is the last tool within a suite of tools in the Palliative Care Toolkit. The tool is used to assess system level impacts and outcomes of the Rural Palliative Care Program (RPCP). RPCP sites completed the tool between October 2006 and January 2007. In most cases (six out of the seven sites) responses to the questions were completed in a group meeting such as a steering committee or agency meeting and consolidated into one response. Eurobodalla and Pilbara each submitted three and four completed tools respectively. Where more than one tool was completed per site, the analysis focused on the form completed by a group of individuals from the organisation rather than the responses from an individual. The only exception exists were only one tool completed by the project office was submitted from Adelaide. Table 77 indicates the number of completed tool 8 from each site.

**Table 77 Number of system level impact assessments completed by site**

Project	Number completed	Type of agency/service
South Burnet (Kingaroy)	1	Project and Primary Care
North West Tasmania	1	Multi-purpose Health Centre
West Victoria	1	Community nursing service
Eurobodalla	3	Community organisation
Mid North Coast	1	Community organisation
Pilbara	4	Community organisation
Adelaide Hills	1	Community nursing service
<b>Total</b>	<b>12</b>	

The tool is divided into four main sections addressing:

- A description of the agency.
- How successful the palliative care project went.
- What the project did for people with special needs.
- Agency, inter-agency and system effects of the project.
- Additional comments section

The following sections provides mainly descriptive and some graphic representation of responses to the tool.

### 16.1 How did the palliative care project go?

All seven sites agreed that the palliative care project changed the way they delivered services in a positive manner. Six sites agreed that the impact on consumers was acceptable while one site thought that it did not have an acceptable impact. Their reason for this was that the changes to direct service delivery to clients/patients did not alter significantly as there was already an established palliative care service prior to the RPCP.

Some of the comments included:

- The RPCP increased patient referrals.
- There was a positive impact on relationship building between service providers.
- The program was extremely successful. Strategies have been implemented to ensure sustainability.

- There was already an existing palliative care service and therefore, the project provided additional fine-tuning.
- One project commented that the patient surveys had a negative impact on patients due to the cumulative impact of other research activities and service requirements.

## 16.2 Impact on people with special needs

Six out of seven projects indicated the project had an impact or outcomes for people from one or a combination of people such as those from culturally and linguistically diverse backgrounds, Aboriginal people, people with dementia, financially disadvantaged people and people living in remote areas. One project did not believe any outcomes assisted these people with special needs. Specific issues relating to these groups that were encountered during the project were:

- Local Aboriginal people were interested in the service but were overwhelmed by other competing health dilemmas.
- Additional structures and support systems for Aboriginal and residential aged care facilities need to be in place.
- The project facilitated the provision of staff with palliative care knowledge to patients with dementia in aged care facilities. These services were not previously available.

## 16.3 Overall impact of the program

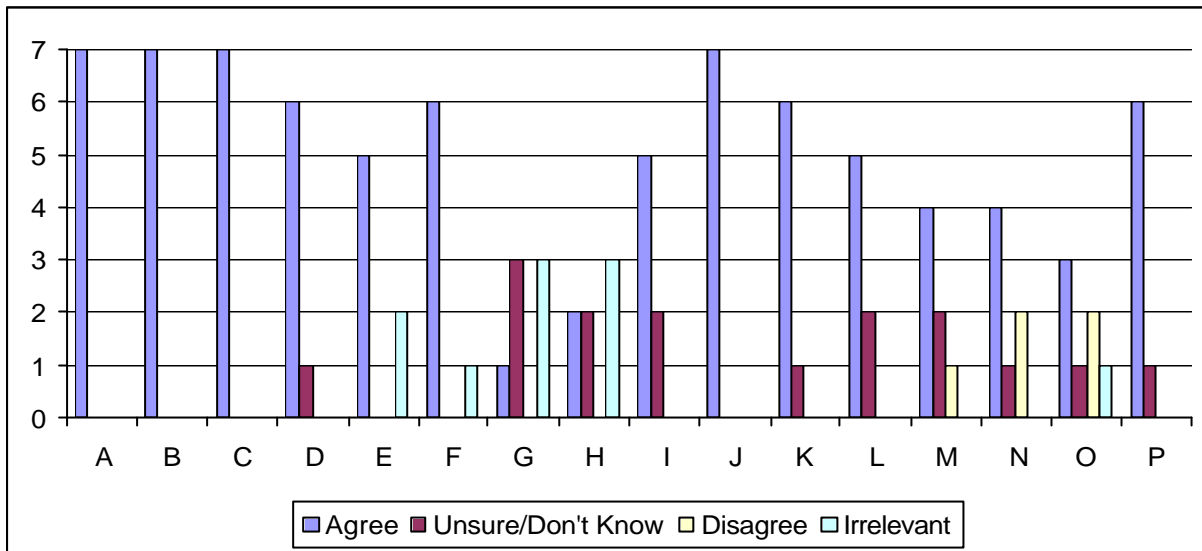
This section reports on the overall impact of the program, including the impact of collaboration within and between agencies involved in palliative care service provision. Responses were received from seven of the eight RPCP sites and are summarised in Figure 26.

This section of Tool 8 contained 16 statements. When the “agree” responses were totalled and compared to those that were “unsure” or “disagreed”, the majority of responses agreed with most statements. Across all items, there was 79.4% (81 out of 102) agreement with the statements while 20.6% (21 out of 102) of items were rated as unsure or disagree. These results indicate that most of the projects viewed the RPCP as positive.

Finally, projects were invited to provide additional comments. Three sites took the opportunity to do so:

- There has been a decrease in aged care referrals as aged care staff are gaining confidence in managing palliative care patients.
- Data collection became a major focus of our project – much more than we had anticipated.
- Employing various aspects of the GAPS model can enhance palliative care services.

**Figure 26 Responses to impact statements**



**STATEMENT**

- A = Different professionals and services now work better as a team to improve the services that people receive.
- B = The project has improved the way that professionals providing palliative care in our area communicate with each other.
- C = The project was effective in improving information sharing between professionals providing palliative care.
- D = The project has resulted in more patients receiving palliative care.
- E = The project has resulted in a more streamlined and efficient referral process for our clients/patients.
- F = The project has resulted in better treatment and support for our clients/patients.
- G = The project has resulted in better volunteer services.
- H = The project has resulted in better support for volunteers.
- I = The project has raised community awareness about palliative care
- J = The project has increased the skills and knowledge of staff working in palliative care.
- K = The project has increased the palliative care skills and knowledge of staff working in other parts of the health system.
- L = The project has increased the palliative care skills and knowledge of staff working in the community care sector.
- M = The project has resulted in better services and support for carers.
- N = The project has improved the availability of bereavement support.
- O = The project has improved the quality of bereavement support services.
- P = We want the changes that the project has achieved to continue.



## **Part Six – Discussion and Conclusions**

## 17 Discussion and conclusions

To varying degrees each of the eight RPCP projects was 'two projects in one', with some strategies undertaken to meet specific local needs and other strategies more closely aligned with the elements being tested as part of the Program. There were significant variations between projects regarding what they set out to achieve at project commencement, with some focusing on direct care more than others. One project in particular (West Victoria) had such a strong focus on education that it bore little resemblance to implementing a system of care based on the original GAPS model.

Others addressed issues unique to their project e.g. purchasing equipment (Pilbara), developing a bequest program (Eastern Goldfields), implementing end-of-life pathways and focusing on residential aged care (Mid North Coast). This was to be expected. However, to a degree, it detracted from the central aim of the Program with the direction of individual projects not always matching the direction of the RPCP. For example, across the different projects, there was little emphasis on elements such as developing shared protocols, common referral and formal agreements between organisations involved in palliative care. This may reflect a lack of understanding of project requirements by some projects at the outset. But it also suggests that it is worth revisiting the elements developed as part of the work in Griffith to refine the mix based on the experience in the RPCP.

This could be undertaken in the context of the results from a recent systematic review of primary health care delivery models in rural and remote Australia that identified essential requirements for an effective and sustainable model. These were identified as workforce organisation and supply; funding; governance, management and leadership; linkages and infrastructure.<sup>16</sup>

From the first site visit to each project, members of the NET found themselves playing a wider support role than simply one of evaluation. Project coordinators varied in their project management skills and the extent to which they required support. Ongoing support and encouragement for this group was essential. Projects faced similar issues and project coordinators valued the networking and sharing of information facilitated by the national workshops. Support for project coordinators, particularly in the area of change management, should be a central feature of any future programs of a similar nature.

There are four main models of palliative care in rural communities:

- the 'traditional' model (diagnosis and management by individual practitioners and referral to other practitioners where necessary)
- coordination of care by a CNC
- coordination of care by a formally established team and
- visiting consultation by 'fly-in, fly-out' specialists who may or may not work with some form of local team.

All four models were represented in the RPCP, with the addition of the situation in the Tasmanian project where there was an established palliative care team with specialist doctors and nurses. Even in those localities where there were no formally established structures, processes and systems dedicated to palliative care, a service was already being provided based on the traditional model of care.

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<sup>16</sup> Wakerman J et al. (2006) *A systematic review of primary health care delivery models in rural and remote Australia 1993-2006*. Australian Primary Health Care Research Institute.

Hence, the Program was more about moving existing service delivery towards a team-based model rather than establishing a service at a truly 'green field' site. This presented many challenges, particularly around the issues of involving GPs in case conferencing and the other aspects of direct care delivery. Those projects working with existing specialist palliative care service providers faced particular difficulties integrating features of the rural model with their systems and processes. Towards the end of the RPCP there was a very mixed picture across the eight projects, with some making real progress and others struggling to make any headway at all.

Each project started with a different level of resources devoted to palliative care (including some elements of the rural palliative model already in place), with considerable differences in the local environment in which each project sought to establish itself. Projects implemented different combinations of the RPCP model elements in different ways.

Implementation occurred in population centres ranging from relatively large communities with established services and good infrastructure to remote communities with no dedicated palliative care service. Some projects effectively established a small number of sub-projects within the one area covered by the local division of general practice. These differences resulted in an interesting series of case studies for improving palliative care in rural and remote communities and supported the decision to use the same data collection tools to facilitate aggregation of data across projects.

Even in those projects where achievements were modest, the lessons learned have the potential to assist others seeking to implement similar strategies in similar circumstances. From an evaluation perspective, understanding why something did not work is as valuable as understanding why something did work.

The work in Griffith indicated that a governing body can be one of the key mechanisms for developing and sustaining a model of palliative care in rural communities and this was confirmed by the RPCP. Each project governing body continued to meet throughout the RPCP, with wide representation from both providers and community representatives. It will be important to see how many of these governing bodies continue beyond the life of the Program.

Although there was relatively little work done to develop formal partnerships between providers, this may have been due in part to the governing bodies providing a forum for collaboration and networking. Arrangements such as memorandums of understanding and shared protocols have a part to play but still require individuals to put them into practice. Social relationships, networks and champions are essential for sustainability and the governing bodies supported this.<sup>17</sup>

The results from the self-assessments undertaken at the beginning and end of the RPCP indicate that there was an improvement in compliance for all but two categories of standards. In those two areas (staff support standards and community network and partnerships) the standard was met and there was no room for improvement. By the end of the RPCP more standards were present and to a greater degree, with a smaller number of standards rated as a high priority for attention.

There is a need for some caution in interpreting these results due to the nature of the self-assessment and the way it was completed (by different people at different points in time). Some of the standards were not specifically addressed by the RPCP as a whole or by individual projects and hence a causal link between improvement and what was done under the banner of the RPCP is somewhat tenuous. That said, the consistency of these results across the categories of standards is a positive finding, irrespective of the cause. The national palliative care standards have been published since the RPCP commenced (and hence post-date the development of the self-assessment tool). There may be some merit in adapting the tool to comply with the national standards for use on an ongoing basis.

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<sup>17</sup> Sibthorpe BM, Glasgow NJ & Wells RW (2005) *Emergent themes in the sustainability of primary health care innovation*. Medical Journal of Australia, 183(10): S77-S80.

Project coordinators were employed by divisions of general practice but all aspects of direct care provision are undertaken either by GPs or staff employed by various public, private or non-government organisations. This presented many challenges, particularly for project coordinators. In some cases there was resentment that funding had been provided to divisions of general practice rather than local health services. Community nurses and GPs, the two key palliative care service providers in rural settings, demonstrated particular reluctance to become involved at several sites. A quote from a recent systematic review of comprehensive primary care models is particularly instructive on this issue:

*There are limitations on the extent to which Divisions can further influence service delivery at a practice or local level, without significant change that involves the rest of the health system. In the absence of commissioning or significant enhancement of their contracting role, their success and effectiveness relies largely on their engagement with and responsiveness to their members.*

*The same applies to Primary Care Partnerships and Primary Health Care Networks, but even more so. Without funding levers, the most that can be expected of these structures is that they improve service coordination, especially across the range of state-funded services. With these limitations, there is a very real question about the extent to which they can engage general practice and extend service coordination across the primary care sector as a whole.<sup>18</sup>*

The results from the RPCP support these findings. As for other health providers, the involvement of allied health staff was problematic and, based on the service utilisation data, only a small component of service delivery. 'Multidisciplinary care' for rural palliative care is essentially about doctors and nurses.

Establishing each of the eight projects took longer than anticipated, particularly in relation to deciding upon and setting in place an acceptable database for the collection of patient-related clinical assessment data. This resulted in delayed recruitment of patients and delays in conducting the first patient and carer surveys, with some projects not commencing enrolment of patients until late 2004 or early 2005. Some projects achieved only low numbers of patient enrolments over the course of the RPCP. The consent process proved to be onerous but the high level of Level 4 consent indicates the degree of confidence placed by patients in their health care providers.

The lack of any consistent pattern for source of referral in the four sites for which such information is available may be due to differences in how services are delivered but may also indicate differences in access to services. As just one example, if one project (Eurobodalla) can have 20% of their referrals coming from residential aged care facilities it indicates that referrals from such facilities at other sites may have been under-represented. Variations in phase of care on referral, the distribution of phases and the length of time spent in each phase also suggest varying access to services although variations in assessment of phase would also have played a part.

The genesis of the RPCP was the work undertaken in Griffith, New South Wales, to develop a model of palliative care for a small rural community. One of the features of that work was the use of various clinical assessment tools as the basis for a common language amongst clinicians.

These tools were incorporated in the RPCP not as an evaluation 'add on', but as a core element of a rural palliative care model. The intention was that they would be implemented in the same way as other elements of the rural model. It was expected that, based on the results from Griffith, clinicians would come to see the tools as useful in their everyday practice.

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<sup>18</sup> McDonald J. et al. (2006) *Systematic review of comprehensive primary health care models*. Australian Primary Health Care Research Institute, p 57.

None of the projects came near to achieving this, with all projects ultimately collecting the clinical assessment data because they had to (for the program evaluation) rather than as an integral component of service delivery. A follow-up evaluation of the Griffith Area Palliative Care Service in 2006 found that use of the clinical assessment tools as a 'common language' was no longer in evidence.<sup>19</sup> This is an important finding for the future of palliative care provision in rural areas, with implications for the Palliative Care Outcomes Collaborative.

The data collection requirements for the national evaluation presented many challenges at each site and necessitated the expenditure of considerable time and energy on the part of project coordinators to resolve the many issues that emerged. In the case of the Pilbara project these proved to be insurmountable, with the result that collection of patient-level data ceased. The use of PalCIS was difficult, either with the system itself or integrating its use with existing information systems. Use of palm pilots presented a number of problems that were not anticipated and the technology was soon abandoned. The Eastern Goldfields was unable to maintain its fledgling collection of Tool 1.1 using PalCIS (which it was not obliged to do as part of the national evaluation).

On the basis of those experiences, it would be easy to conclude that the data collection requirements were too onerous and should be reduced in future programs. However, the purpose of the RPCP was not simply to improve palliative care provision in 8 sites, but to test whether elements of the original GAPS model could be successfully implemented in other rural and remote communities. Evaluating those elements in other settings required the collection of data.

The one exception to this is the use of Tool 1.1 (Patient stage of illness data set). This was by far the most resource intensive tool for sites to implement. However, as already noted, it was not implemented for the purposes of the evaluation but, rather, as a clinical tool and as a core element of the rural palliative care model. Whether or not this tool should be used in future evaluations should be decided based on the purpose.

With the exception of one project (Mid North Coast) the responses to the patient experiences survey were quite modest and hence the analysis of results was largely restricted to patient experiences across the RPCP rather than for individual projects. It is pleasing to note that very few patients responded that they had wasted time on health care or that their financial and personal affairs had not been addressed. In general, patients indicated a high degree of involvement in decisions about their treatment. Approximately two thirds of patients indicated that they had experienced a degree of depression in the preceding three days, indicating an area that may need further work in the future. Carers' experiences show a high degree of agreement that palliative care services are meeting their needs and that appropriate support, information and advice are being provided.

Much of the research into rural palliative care in Australia has focused on the educational needs of those working in rural areas but surveys on the scale of the two in this evaluation are rarely undertaken. The survey confirms the fact that the majority of palliative care providers are nurses. Fewer GPs responded to the second survey compared to the first survey, which is disappointing. This may be due to a lower percentage of GPs asked to complete the survey or a lower percentage responding to the survey. This is particularly the case in West Victoria where there was a very strong emphasis in the project on providing education and yet no GPs responded to either survey.

Responses indicate a high level of 'on the job' training but also a high percentage of providers with some form of short course or formal training in palliative care. This is particularly encouraging given the 'tyranny of distance' faced by rural providers when it comes to education. The percentage of providers with no training at all declined between the first and second surveys and the work by projects to promote educational opportunities no doubt played a part in this.

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<sup>19</sup> Masso M, Fildes D, Quinsey K and Matete S (2006) GAPS revisited: evaluation of the Griffith Area Palliative Care Service 2006. Centre for Health Service Development, University of Wollongong.



Professional development and education was a strong focus for all projects. The subject matter was diverse and education programs well received. The numbers participating were impressive.

Provider confidence in patient/family interactions and clinical management increased for 11 of the 12 items included in the questionnaire between the first and second surveys. Given the tendency for palliative care education to focus on clinical management issues this again suggests that the education organised by projects may have had an impact in this area.

In general, changes in responses between the first and second surveys showed no consistent pattern across most of the items in the questionnaire, making it difficult to draw any firm conclusions about the impact of the RPCP on palliative care providers. In part, this is due to the high level of agreement between respondents on most items, an agreement that is consistent with good practice i.e. the room for improvement is relatively small. The results provide useful material to guide the provision of palliative care education in the future. The items with the highest level of 'unsure/mixed' response were those for 'the most appropriate person to make end-of-life decisions is the patient's primary care provider' and 'as a rule, terminally ill patients prefer not to talk about death and dying'.

A key aspect of the RPCP was bringing together key players in each locality to improve the provision of palliative care. Despite differences in format, representation and approaches this occurred in seven projects with regular clinical meetings (regular meetings did not occur in the Pilbara project). This took the form of multidisciplinary meetings with good nursing representation and quite varied involvement of other health professionals. GP participation tended to be problematic. Some sites used teleconferencing to facilitate GP participation and this worked quite well, while requiring some resources to ensure that it occurred in an efficient way. The number of EPC items claimed is not known but is likely to have been limited.

Although some of the clinical team meetings did not progress to the stage of conducting formal case conferences (and generating claims for EPC items) some developed a 'life of their own' which augurs well for the meetings continuing beyond the life of the RPCP. For example, in NW Tasmania the main focus of the meetings was to bring together GPs and staff from the local specialist palliative care service. In Eurobodalla the catalyst to meet was the monthly visit of the fly-in, fly-out palliative care specialist while in Adelaide, initial reluctance to be involved in multidisciplinary meetings gave way to a position where participants agreed to continue the meetings after project completion. In the Eastern Goldfields, despite unsettling changes to the coordinator position, the clinical meetings continued regardless. Team meetings with GP participation are well established in SE Queensland and the Mid North Coast.

The two sites that made the least progress with multidisciplinary team meetings were the Pilbara and West Victoria project. This is not unexpected, given the reduced focus on direct care strategies in the project plans of both projects at the start of the RPCP.

As already noted, it is not surprising that each project took quite a different approach and implemented different aspects of the core model because each started from a different point. This had been understood when they were selected. The GAPS evaluation report had suggested that there was no reason why the Griffith experience could not be generalised to towns of a similar size as Griffith. However, for quite sensible reasons, it was decided to test the GAPS model in different settings. The selected project sites were diverse in terms of their geographic location, population size, remoteness and existing systems of palliative care delivery. Each differed markedly from Griffith, NSW.

In this context, it is not surprising that each took a different approach to implementing what had been described, based on GAPS, as the core elements of 'the rural palliative care model'.

All of the projects successfully implemented some, but not all, of the core elements. In addition, other strategies, not used in the GAPS model, were developed and implemented.

The key lesson is that, rather than prescribing a rural and remote model of palliative care with set elements, a needs-based planning approach is more appropriate. All the projects demonstrated the need for flexibility in the way that the model elements were selected, developed and implemented. A more sophisticated approach was undertaken by one project. This project reviewed their existing palliative care services against the PCA standards and guidelines, identified service needs and then selected or developed strategies to address these gaps. This approach is recommended for future programs.

At the program level, a key finding is that program governance arrangements need to be structurally aligned so that the program manages both individual projects and the program as a whole. Opportunities were missed because there was no formal structure to ensure that lessons learned by one project were automatically made available to other projects. This reduced the effectiveness of the program overall. As one example, three projects implemented End of Life clinical pathways simultaneously but unbeknown to each other. Coordination of this strategy might have enabled a joint evaluation of the impact of the three projects combined rather than three individual projects.

Change management proved to be more difficult than anticipated. Future staff working on projects should have an understanding of change management issues and understand that support for change management is required at project commencement. Further, auspice agencies need to be clear that change management cannot be simply left to a project officer to achieve. Change management needs to be led by those who are positioned to make a difference, both during the life of the project and after it ends.

A key finding in the evaluation is the critical role of the project coordinators. While agencies at the local level had signed off on their original proposals, it was mostly left to project officers to 'make it happen'.

A range of communication and support strategies were put in place at both the local and national levels to assist them in this process. At the national level, these included strategies put in place by both AGPN and the NET as well as informal networking initiated by various project officers. Some of these strategies did not reach their full potential, as they were not maintained across the course of the program.

The evaluation team completed all of the key evaluation tasks for the program. This included managing the data collection and analysis process, facilitating and evaluating the workshops, and project monitoring across the GAPS model elements. From the perspectives of both the projects and the evaluators, the workshops and the site visits added to the effectiveness of the program

Project monitoring was mainly conducted through the site visits and documentation review. These ranged from 3 to 7 visits per project, with most projects having visits from the same evaluation team member over the three years. In some cases the evaluation team member became part of the intervention. Often just the fact that a team member was actually on site meant that project coordinators had someone to problem solved with, ask to attend meetings or facilitate workshops.

This suggests that future programs might consider using a mixed local and national evaluator model for rural and remote communities, with a local evaluator linked with each project. This local evaluator may provide more on site support and facilitate more local networking than was possible in the RPCP plus assist with local evaluation tasks, such as measure the outcomes of interventions. The role of the national evaluator would thus be one of designing the overall evaluation and synthesising the results of the various local evaluations.

Projects reported that aspects of their projects will be sustained at the end of the program. It seems that certain elements, which differed across projects, will keep going. Time will tell. The program encouraged the projects to concentrate on sustainability from project start to end. This was demonstrated in the way elements were introduced and implemented. However, most



projects expressed concerns about the ability to continue certain elements or strategies without a dedicated resource person to undertake the coordination and development role.

There is no doubt that the program enabled eight rural and remote communities to build capacity around palliative care. This is demonstrated by the project responses to the capacity building assessment. As one example, the projects involved formal and/or informal training of people whose skills and interests will be retained in the local community. As another, the projects generated and supported community skills to direct, provide, lead or otherwise contribute to the provision of palliative care services in the local community. If the lessons learned during the program are disseminated in the sector, the program will also build capacity across the primary care and palliative care sectors more broadly.

Many of the key lessons learned from the projects and the program are generalisable more broadly. Our overall assessment is that selected project and program elements are able to be generalised, but not the model or program as a whole.

The projects were successful in disseminating information about their projects through a variety of activities. At the program level, the main dissemination activity was the RPCP newsletter. It is anticipated that dissemination of the program and project evaluation results will continue to occur after the formal program is over.

The Rural Palliative Care Program had its origins in the 2002 National Palliative Care Strategy. As that document notes, the challenge is to secure the place of palliative care as an integral part of health care across Australia, routinely available within local communities to those people who need it. Care and support for people who are dying and their families needs to be built not only into health care services, but into the fabric of communities and their support networks. Care built around the principles of palliative care needs to be available to anyone who is dying, whatever the cause of death.

Through its three years, the program provided direct care to over 600 patients. But, perhaps more importantly, the program provided an important opportunity for providers working in rural communities to come together and to jointly develop new systems in which to deliver care. Many of the elements that were implemented were highly successful, others less so. That was to be expected, especially given the different contexts in which the projects took place.

Developing and sustaining high quality palliative care is a challenge in any community. It is more so in rural and remote Australia. The RPCP projects demonstrated important gains, but there is an ongoing need to test and evaluate sustainable ways of delivering palliative care in rural and remote settings. The lessons from the RPCP form a solid basis for further work, but there is still much to be done and much to be learned.