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## Care planning sub-program: description of projects funded to improve care planning in palliative care

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## Care planning sub-program: description of projects funded to improve care planning in palliative care

### Abstract

This document is one of three reports for the national evaluation of the Care Planning Sub- Program of the Local Palliative Care Grants Program, a national palliative care program funded by the Australian Government between April 2006 and May 2009.

### Keywords

sub, description, projects, funded, palliative, planning, program, improve, care

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# Care Planning Sub-Program: description of projects funded to improve care planning in palliative care

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July, 2009

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## Introduction

This document is one of three reports for the national evaluation of the Care Planning Sub-Program of the Local Palliative Care Grants Program, a national palliative care program funded by the Australian Government between April 2006 and May 2009. The other two reports are

- *Care Planning Sub-Program: findings from the national evaluation*, which contains the project and program findings of the national evaluation; and
- *Care Planning Sub-Program: report on activities of the national evaluation*, which addresses the deliverables in the evaluation contract.

This report provides a quick-reference guide to each of the 33 Care Planning projects, by addressing the main evaluation questions at the project level, which are:

1. What were the purpose and aims of the project and how did these relate to the sub-program objectives?
2. How was the project planned and implemented?
3. How was the project evaluated and what outcomes were achieved?
4. What aspects of the project will continue (sustainability)?
5. What has been learned from the project (recommendations)?

A table listing the project code, host organisation and project title is found in Appendix 1.

The specific information in each description is a useful background to the main report on the findings of the evaluation, which brings together the lessons from the 33 projects and integrates them to arrive at some general conclusions. It may also be informative for palliative care service providers and others in the health sector who are considering new projects and are looking for details on models and resources that have previously been tried and tested in Australian communities.

### ***Background to the Care Planning Sub-Program***

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

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

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

Tenders were invited in November 2005 for funding of between \$100,000 and approximately \$250,000 for organisations which best demonstrated an approach to improving care planning practices and resources, improving links and collaboration between health care providers and/or improving mechanisms for transition between settings of care. Approximately 138 submissions

were received nationally. From these applications 33 projects were funded, totalling around \$7.5 million over three years. The Centre for Health Service Development (CHSD) was appointed national evaluator of the Care Planning Sub-Program in September 2006.

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

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

Each project was initially classified into program objectives and themes by DoHA, and this classification was checked with the project officer or project manager by the National Evaluation Team (NET) early in the timeframe (at the first site visit) and again at the end (during the exit interview). The projects were indexed according to their themes and the particular objectives of the sub-program they were designed to address, and details of this process can be found in the main report, *Care Planning Sub-Program: findings from the national evaluation*.

### ***Evaluation framework for the sub-program and its projects***

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

The framework for the evaluation is developed at three levels:

Level 1	Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)
Level 2	Impact on, and outcomes for, providers (professionals, volunteers, organisations)
Level 3	Impact on, and outcomes for, the system (structures and processes, networks, relationships)

At each of the three levels, six key evaluation questions are utilised to provide focus, ensure consistency and comparability, and define the scope and depth of the evaluation (see Table 1).

***Table 1 Key evaluation questions for the Care Planning Sub-Program***

<b>Evaluation questions</b>	<b>Evaluation issues</b>
What did you do?	DELIVERY
How did it go?	IMPACT
Can you keep it going?	SUSTAINABILITY
What has been learned?	CAPACITY BUILDING
Are your lessons useful for someone else?	GENERALISABILITY
Who did you tell?	DISSEMINATION

The evaluation framework drew extensively on the CHSD publication, *Evaluation and palliative care: a guide to the evaluation of palliative care services and programs* (Commonwealth of Australia 2004), and on the experiences of the CHSD in carrying out a range of other national

evaluations, in particular, the Caring Communities Program, the Rural Palliative Care Program and Mental Health Integration.

The evaluation framework, process and learning/capacity building focus developed for the national evaluation of the Care Planning Sub-Program is compatible with national palliative care standards and with best-practice directions identified in the palliative care literature.

### ***Data sources for the project summaries***

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

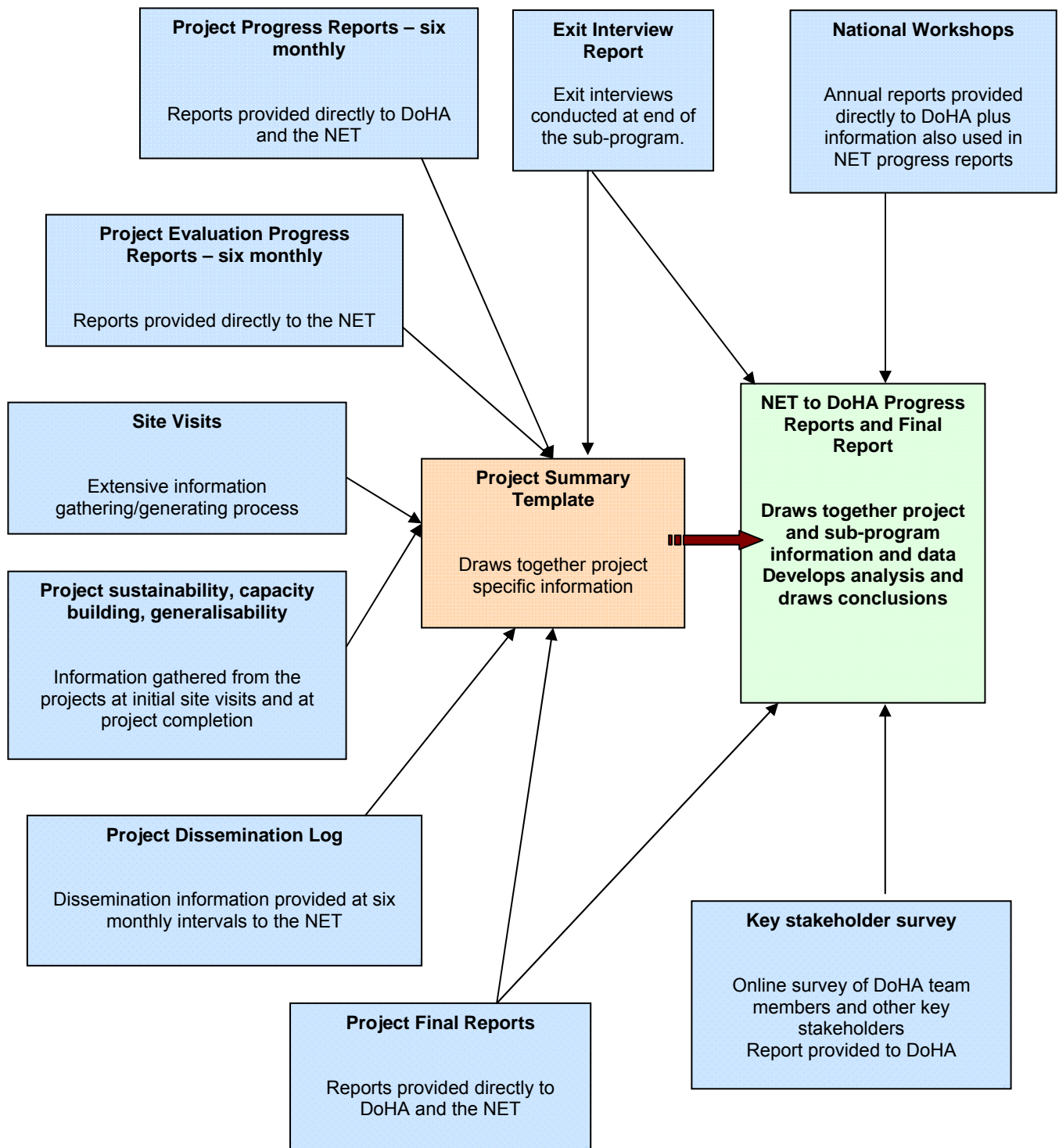
Each project was required, as part of its contract with DoHA, to carry out an evaluation. Some guidance was provided; however, the scope and nature of the evaluation was not specified. Progress and final reporting templates were included in the projects' contracts.

The NET at the CHSD worked closely with project officers, providing assistance where necessary to develop evaluation plans, and advice on sourcing or designing tools and conducting data analysis. Where possible, to maintain continuity of support and gain a deeper understanding of the projects, NET members worked with the same projects for the duration of the sub-program. The NET also developed detailed templates for progress and final reports, which were designed to capture the information required by the evaluation framework.

Nevertheless, it should be noted that the NET had no authority to require a project to develop an evaluation plan or to carry out evaluation activities, or indeed to use the additional reporting templates provided. Most projects did recognise the value of conducting and reporting evaluation activities, but some were prevented from doing so by lack of time or other constraints. Therefore, the project summaries provided here have been written in good faith by members of the NET, based on the information provided by projects through a range of sources, as indicated in Figure 1. In some cases, the information was limited or incomplete.



**Figure 1 Care Planning information flow chart**



## The 33 Projects of the Care Planning Sub-Program

### NSW Project Summaries June 2009

<b>Project title</b>	NSW-1 – Collaboration in trust and care: A transition model of palliative care to residential aged care
<b>Keywords</b>	Local, major city, RACF, specialist palliative care
<b>Host organisation</b>	Calvary Health Care Sydney Ltd
<b>Partner organisations</b>	Calvary Palliative Care Unit: Pacific Heights NH, Sylvania NSW; and Rockdale NH, Banksia, NSW
<b>Project funding</b>	\$190,075.60
<b>Project timeframe</b>	11 May 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop and demonstrate a model achieving an effective and coordinated transition from a specialist, hospital-based palliative care service to a high-care residential aged care facility (RACF).</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To develop a partnership model which will enhance care planning at two partner RACFs and the Calvary Palliative Care Unit.</li> <li>▪ To provide the opportunity for a relationship of trust by the patient and carer as they are transferred from the Calvary Palliative Care Unit to local RACF.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project developed a model of care which includes preparation for and follow-up after transfer from Calvary Hospital to a RACF, including liaison between Calvary Palliative Care Team (CPCT) and RACF staff. The goal was to build a team approach to facilitate continuity of care.</p>
<b>Project planning and development</b>	<p>This project builds on research work undertaken by a senior social worker at Calvary, who was subsequently seconded into the project management role. Relationships between the two partner RACFs, two Divisions of General Practice and Calvary were confirmed through the Memorandums of Understanding (MOU).</p> <p>A reference group was established, comprising senior members of the palliative care service, quality improvement and research, representatives from the partner RACFs and the two local GP Divisions, and a carer representative. The final report notes that the reference group remained active and interested for the life of the project.</p> <p>A project plan and timeline was initially developed by the project officer, and revised with assistance of National Evaluation Team (NET) in March 2007.</p> <p>Education sessions were held for the Calvary palliative care social work team prior to the project, regarding referral to the project. It was decided that potential participants should be referred to the project worker as soon as the decision for transition to RACF was finalised. In addition, nursing staff from partner RACF received education to introduce and promote the project; these sessions were held jointly with the executive director of the RACF. There was frequent liaison with the Calvary community palliative care pastoral care worker and Clinical Nurse Specialist, and consultation forums for general practitioners in their respective DGP during September and October 2006.</p> <p>Ethics approval was received from Calvary Health Care Ethics Committee on 7 June 2006.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project developed a care planning model which focused on transition of palliative care patients from Calvary to partner RACFs. A protocol was developed which outlined the key clinical steps undertaken in the project. This protocol has been widely disseminated in response to frequent requests from other palliative care services.</p> <p>The project included weekly visits to support and review patients who transferred to a local nursing home. Visits were made by members of the Calvary community palliative care team, including the volunteers, the social worker, community nurses, the pastoral care</p>

<b>Project title</b>	<b>NSW-1 – Collaboration in trust and care: A transition model of palliative care to residential aged care</b>
	<p>worker and occasionally a Calvary doctor.</p> <p>Two prognostic tools were adapted for use during the project, with guidelines for their use in identifying patients most suitable for transfer to RACF. A brochure to promote and explain the project was also developed.</p> <p>The project also involved the loan of specialised equipment required by residents in the RACFs, such as air cushions. With the support of the project officer and the Calvary Palliative Care team, partner facilities successfully applied for grants under Round 4 of the Local Palliative Care Grants Program, resulting in the purchase of appropriate equipment, such as syringe drivers. Calvary also donated to the partner facilities a number of used sofa chairs which provide beds for relatives of dying residents to stay overnight at the facilities.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The evaluation plan was designed to measure a range of outcomes at Levels 1 and 2, including perspectives of the transferred residents, their family carers, Calvary staff, RACF staff and management, and GPs. Qualitative and quantitative data were collected. Available standardised tools were not seen as appropriate for this project, resulting in the modification of two prognostic tools.</p> <p>A total of 22 semi-structured interviews were conducted with patients and carers who took part in the project. All interviews were taped and professionally transcribed. Focus groups were also run, involving aged care facility staff as well as Calvary staff during the project, to ascertain how the project was running, and if there were any refinements needed. A series of surveys were completed by RACF staff and management, Calvary staff and GPs closer to the project's conclusion to ascertain their perspectives on how the project went.</p> <p>The evaluation also incorporated one outcome measure which looked at the impact of the project on survival times for people transferred to RACFs.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>A total of 67 patients and their families were assisted by the project, 49 of whom were transferred from Calvary to a RACF, including 22 to partner RACFs. The final report notes that the evaluation shows that the partnership between Calvary and the two aged care facilities improved as a result of the project, and there was a higher standard of palliative care in the RACFs for those transferred residents.</p> <p>An important finding of the project was the improved survival times following transfer from Calvary to a RACF: 50% of those transferred between January 2007 and September 2008 survived at least three months after transfer, an improvement from the baseline research figure of 33%. The final report notes that three months is the minimum time required to adjust to the RACF, according to the Relocation Stress Syndrome (RSS). RSS is the recognized diagnosis of the physiologic and psychosocial disturbances that result from transfer from one environment (home) to another.</p> <p>The evaluation showed that there was a high level of satisfaction with the project on the part of patients and their families. A key aspect was the sense of continuing connection to Calvary, in particular the regular follow-up by the social worker and volunteers after the transfer to the aged care facility.</p> <p>Ten RACF staff participated in a special palliative care course at Calvary, and 30 staff attended one of three workshops run by the project on communication and grief issues. Together with the additional support provided by Calvary staff on their visits to the RACFs, staff exhibited increased skills and confidence in looking after palliative care residents, according to the project final report.</p> <p>At the project's exit interview, it was noted that just over half of the transferred patients were placed in non-partner RACFs. While this involved a lot of extra work for the project officer, with the need to constantly build and maintain relationships, it is possible that staff in these facilities also benefited from the contact and support by Calvary staff (however, this was not formally evaluated).</p> <p>The final report notes an increased responsiveness on the part of Calvary community nurses to the residents' ongoing care, especially in the terminal phase. Furthermore, Calvary hospital staff improved their ability to select those palliative care patients who would do well in nursing homes and also felt much more confident about transferring palliative care patients to nursing homes when they knew they would be closely followed up.</p>

<b>Project title</b>	<b>NSW-1 – Collaboration in trust and care: A transition model of palliative care to residential aged care</b>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>At the outset of the project, a number of strategies relating to sustainability were identified. There are a number of elements which are expected to continue beyond the life of the project, mostly around practices and protocols within Calvary. The project resulted in better use by Calvary doctors of the relevant prognostication tool which improved the ability of staff to select palliative care patients who would do well in the nursing home context. Similarly, staff members from the Calvary community team were more confident in supporting transferred patients.</p> <p>The project set out to enhance understanding and provision of psychosocial and spiritual support to transferred patients, and it was initially intended that pastoral care workers from Calvary could undertake this role. However, due to staffing shortages, this outcome was not fully realised during the project, and there proved greater reliance on the volunteers from Calvary. The project officer noted during the exit interview that the role of volunteers was not foreseen at the outset of the project, but turned out to be quite significant overall. The final report notes that at the end of the project some RACFs had systems in place to provide spiritual support, and Calvary pastoral care services now had the capacity to continue to support transferred residents.</p> <p>One of the main avenues for sustaining the model after the project was initially thought to be improved collaborative care planning by GPs, which would be funded using Medicare Enhanced Primary Care (EPC) items. However, the final report notes that after much discussion amongst the reference group members, it was agreed to abandon this strategy due to 'the burden of extra paperwork required to claim EPC items', and that 'existing care planning methods ... were adequately meeting residents' needs'.</p> <p>Additional funding will be necessary to maintain the project outcomes. During the project, additional funds were sought from Mental Health partnership funding and GP Divisions, but this was not successful. The final report notes that resource implications arise for community palliative care teams which already carry heavy case loads. The project recommends extra dedicated funding for each palliative care service for a 0.2FTE community palliative care nurse and 0.1FTE social worker to provide appropriate support and education in RACFs.</p>
<p><b>Recommendations</b></p>	<p>At the end of the project, a workshop was convened by the project officer, which included local and interstate clinicians, administrators and residential aged care representatives. The National Workshop on Transition from Palliative Care to Residential Aged Care developed the following recommendations:</p> <ol style="list-style-type: none"> <li>1. Pre-Admission Stage <ul style="list-style-type: none"> <li>▪ Pre-admission assessment according to agreed criteria for Palliative Care Unit (PCU). These criteria will vary according to the size and location of the PCU.</li> <li>▪ Assessment of suitability for admission to PCU is conducted by a specialist palliative care health professional.</li> <li>▪ Clarify goals of the transfer to PCU, and reinforce to patients and families that the PCU is "not a long-term facility".</li> </ul> </li> <li>2. Pre-transition to RACF Stage <ul style="list-style-type: none"> <li>▪ Continue message that PCU is "not a long term facility" wherever appropriate.</li> <li>▪ Use prognostic tool (PaP score) on admission and within 2 weeks following admission to PCU.</li> <li>▪ The Clinical Prediction of Survival component of the PaP score is more accurate when done by experienced Palliative Care staff.</li> <li>▪ Decision to transfer to a RACF should take account of patient's likely prognosis, current and likely future symptoms, and a psychosocial assessment of patient's and carer's ability to adapt to the transition to RACF.</li> </ul> </li> <li>3. Aged Care Assessment Team (ACAT) Assessment <ul style="list-style-type: none"> <li>▪ A new category is proposed for Palliative Care patients assessed as</li> </ul> </li> </ol>

Project title	NSW-1 – Collaboration in trust and care: A transition model of palliative care to residential aged care
	<p>requiring RACF level of care. This would give the same flexibility to the resident that a respite admission currently provides, but would be subsidised by the Australian Government at an appropriate rate for a resident with complex palliative care needs according to the ACFI. This status would be time limited to 8-10 weeks and would not be age limited to 65 and over.</p> <ul style="list-style-type: none"> <li>▪ After the resident’s settling in period at the RACF, if they are still alive, they will be re-assessed for permanent status and all the necessary paperwork will then have to be completed.</li> <li>▪ This option will make it easier and more attractive to RACFs to admit palliative patients being transferred to RACFs from PCUs or from hospitals, where the prognosis may be short.</li> <li>▪ This option will also reduce the burden on family carers to complete onerous paperwork for Centrelink and the RACF in the early weeks following transition to a RACF.</li> </ul> <p>4. Options for Care</p> <ul style="list-style-type: none"> <li>▪ RACF beds available on same campus as PCU.</li> <li>▪ Partnership with local RACFs. This partnership needs to be based on likelihood of successful relationship, high level of interest by RACFs and good access to beds as needed. A formal Service Agreement is required between the partners.</li> <li>▪ Increased affordable care options at home for patients requiring high level care. Specially designed Palliative Care EACH packages with no waiting list are required.</li> </ul> <p><i>Note: appropriate longer term care options for younger people are urgently required, as RACFs are not seen as suitable environments to care for these patients</i></p> <p>5. Follow up care in RACFs</p> <p>Specialist Community Palliative Care Teams should provide regular visits to the RACF during the initial 12 weeks after transfer to RACF. The Community Palliative Care team is multidisciplinary and co-ordinates visits according to resident and family carer need. Close liaison between visiting team members and RACF staff ensures continuity of care during the transition period. Liaison with GPs is also required for pain and symptom management issues and to formalise the patients future care plan.</p> <p>The multidisciplinary Community Palliative Care team may include:</p> <ul style="list-style-type: none"> <li>▪ Community Palliative Care Nurse</li> <li>▪ Social worker</li> <li>▪ Volunteer</li> <li>▪ Pastoral care worker</li> <li>▪ Palliative Care Staff Specialist or registrar</li> </ul>



<b>Project title</b>	<b>NSW-2 – Northern Rivers Primary Palliation Response Project</b>
<b>Keywords</b>	Local, regional, community care
<b>Host organisation</b>	Feros Care Ltd
<b>Partner organisations</b>	Nil
<b>Project funding</b>	\$263,858.10 incl. GST
<b>Project timeframe</b>	28 April 2006 to 31 March 2009
<b>Project aims</b>  <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To provide a better service to those patients and their families in the early stages of palliation and ensure their smooth transition-to-home/residential care. This will be accomplished through the appointment of a dedicated regional palliative care case coordinator responsible for the coordination of existing community services within a multidisciplinary and collaborative case management framework.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To provide regionalised palliative care case management.</li> <li>▪ To establish a palliation case management forum and agreed protocols.</li> <li>▪ To facilitate primary care education in palliative care.</li> <li>▪ To establish a 24 hour, 7 day a week palliative care emergency on-call service.</li> <li>▪ To improve the transition process between palliative care settings and overall patient quality of life outcomes.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> This project aimed to provide a flexible, community-based service to support people with palliative care needs. In doing this it sought to improve collaboration between services and support the smooth and appropriate transition between settings of care.</p>
<b>Project planning and development</b>	<p>The project had strong internal support from management, and was seen as an opportunity to extend and complement the range of services provided by the organisation. Support for the project from external stakeholders was slow to develop, due to perceived duplication of effort by existing clinical services. Consequently, the planned stakeholder advisory group was not established, however, once the focus and boundaries of the project became clarified, the project officer was invited to join the regional Palliative Providers Network. This Network provided a context in which to clearly define and locate the service, expanded the client referral base and provided key networking opportunities.</p> <p>Referrals to the project were also initially slow, for similar reasons around perceptions of the project's focus. However, referral patterns changed following the appointment of a new project officer in late 2007 who had strong connections with referral agencies, particularly acute services, in the Tweed region. The project did not require ethics approval.</p>
<b>Delivery</b>  <i>What did the project do, create, change?</i>	<p>With a view to meeting its aims the project:</p> <ul style="list-style-type: none"> <li>▪ Developed a case management assessment procedures pack based on feedback from specialist providers for use with all new referrals. This ensured a consistent approach to assessment.</li> <li>▪ Revised current software (Care Manager) to manage patient information allowing for integration and facilitating easy tracking of patients.</li> <li>▪ Developed a Referral Feedback Form which is faxed to referrers of all patients.</li> <li>▪ Developed Resource Packs targeted at primary care providers to deliver best practice care interventions. These packs were developed in consultation with an international palliative care researcher/educator.</li> <li>▪ Conducted five workshop education sessions convened by an international expert during palliative care week.</li> <li>▪ Set up a 1300 number for all incoming calls during business hours and after hours. The 1300 number is provided to all patients on their home file. It is also available in the service brochure and in large print on fridge magnets.</li> </ul> <p>The project also developed, published and distributed a local Palliative Care Resource</p>

Project title	NSW-2 – Northern Rivers Primary Palliation Response Project
	<p>Guide. This resource was designed for general practitioners, community care providers, members of the public and hospital discharge planners in accessing appropriate regional services in a timely fashion.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Level 1: The project developed a Palliative Care Client Experiences survey tool, a Palliative Carer Experiences tool and a Quality of Life Survey.</p> <p>Level 2: A service provider survey was developed to determine the responsiveness and awareness of palliative care needs in the community. Palliative care stage of illness data was also collected and patient outcomes reviewed following discharge with respect to goals of care.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The focus of the project was the provision of case management for people with palliative care needs. The initial target group was anticipated to be people in the early (non complex) stages of palliative diagnosis, who could be assisted with the planning and decision-making for future care needs. The aim was to establish a service which complements the existing services provided by the organisation, which had a range of community care services and respite services, as well as residential aged care. The referral patterns determined the course of the project, however, and the majority of clients tended to be those in the later stages of their illness.</p> <p>In total, the project assisted 105 clients, with an overall estimated impact on 250 people once family and carers were taken into account. Clients received between 0.5 and 2 hours a week of palliative care assessment, coordination and planning services by the project, and a further 2.5 hours assistance depending on their needs. The final report notes that the needs of people referred were of an immediate nature, e.g. home care assistance, personal care assistance and accessing equipment. The exit interview revealed that Feros Care were able to provide services within 24 hours of referral, which resulted in reduced stress levels for the client, their family and carer. Once these immediate needs were addressed, discussions could commence regarding planning for future care needs, however, no details are provided about the tools and processes used for decision-making, or outcomes of these discussions for clients.</p> <p>A range of survey tools were used to measure client experiences and quality of life. No data is provided regarding the overall number or outcomes of the surveys, however, the final report does note that all patients surveyed revealed a high degree of trust and satisfaction with the service.</p> <p>A case planning and assessment procedure pack was produced, which ensured the consistent approach to assessment and development of individualised service delivery plans for clients.</p> <p>The project promoted a 1300 number which was available 24 hours a day, seven days per week. This facility was promoted amongst clients and their families, as well as the broader health and care service sectors. The final report does not include details about the number of calls received, or the nature of those calls, although it does note that the 1300 number and provision of after-hours information will be maintained after the project's completion.</p> <p>The 1300 number also served to be a resource for service providers. To support this service, the project developed a contact list of after-hours providers and supports available across the region which was intended to be available to all services. The final report notes, however, that other providers preferred to maintain their own established after hours set-ups.</p> <p>During 2008 the organisation contracted the services of Brigid Purcell, from Huddersfield University in the UK, to present a series of five education workshops across the region, and also review the Feros Care education tools. It is not clear from the final report what the overall number or nature of the audience was for these workshops, however, the report does note that feedback regarding the content was very positive.</p> <p>The main beneficiaries of the education provided under the project appeared to be Feros Care staff. The exit interview notes that Feros staff capacity was built through palliative care education and awareness, and also assisted in building the organisation's reputation for having a clinical focus, in addition to aged care.</p> <p>There were initial difficulties establishing the service and receiving referrals, primarily due to perceived duplication of effort by existing clinical services. Much effort was made to clarify the role and boundaries of the project, and over time these relationships improved, with the</p>

Project title	NSW-2 – Northern Rivers Primary Palliation Response Project
	<p>project officer invited to participate in the regional palliative providers' network. This resulted in improved referrals to the service, especially in the Tweed area where the project officer had existing strong links with acute services. Referrals were received from a wide range of sources, including local hospitals, general practitioners and social workers. A phone survey of fourteen service providers, including palliative care services, at the conclusion of the project indicated a high level of confidence in utilising and recommending the service.</p> <p>New referral protocols and feedback mechanisms were introduced as part of the project to ensure a consistent approach to providing care, and other providers were included in the reassessment processes. In addition, a protocol was introduced which ensured that at the time of their referral, all clients were registered with the specialist regional palliative care service based at St Vincent's Hospital in Lismore.</p> <p>A number of resources were produced by the project. A service brochure and information pack for providers and the general public was developed, and 200 copies distributed across the region. A referral pad was also developed in consultation with general practitioners, and a local palliative care services resource guide, 200 copies of which were also distributed across the region, to general practitioners, hospitals and specialists. The final report noted that these took some time to develop, however were readily accepted and welcomed by the referring target group.</p> <p>The project had initially expected to target people early on in their diagnosis of requiring a palliative approach to care, and it was anticipated that this target group could be readily identified and be supported with quite a distinct model of care. However, attracting appropriate referrals proved difficult, for a number of reasons. The model that resulted, therefore, had a greater focus on facilitating internal referrals for services which were of a very practical nature, e.g. personal care, domestic assistance and equipment.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The project initially anticipated that the project would be able to be continued as it would have developed quite a distinct model of care for a niche client group – those with early palliative care needs. It was expected that Feros Care as well as the broader service community would have enhanced skills resulting from the education and support provided during the project, and the development of the resource kit, new tools and educational resources.</p> <p>By the project end, the focus of the project had shifted to case management and coordination of services for palliative care clients, predominantly those living in the Tweed area. Funding from the Home and Community Care (HACC) program will be used to continue this role, including ongoing participation in the palliative care network. The resources developed by the project will continue to be distributed, e.g. Palliative Care Resource Guide and referral pads, and the 1300 number and after-hours information will be maintained.</p>
<p><b>Recommendations</b></p>	<p>The recommendation provided by the project is as follows.</p> <ol style="list-style-type: none"> <li>1. The establishment phase of 'new' projects requires extended start up time as opposed to projects that are extensions of existing programs.</li> </ol>



<b>Project title</b>	<b>NSW-3 – Hunter Palliative Aged Care Collaborative Framework</b>
<b>Keywords</b>	Local, major city, RACF
<b>Host organisation</b>	The Trustees of the Roman Catholic Church for the Diocese of Maitland-Newcastle ( <i>Catholic Care of the Aged</i> )
<b>Partner organisations</b>	Hunter Palliative Aged Care Collaborative Network
<b>Project funding</b>	\$265,984.40 incl. GST
<b>Project timeframe</b>	May 2006 to May 2009
<b>Project aims</b>  <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop, evaluate and implement a Palliative Aged Care Collaborative Framework to support organisations in their care planning goals for a palliative approach, including the development of a toolkit and a clinical pathway.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Develop a Collaborative Framework and Care Planning Model.</li> <li>▪ To establish a 'Community of Practice' website to promote cross sectoral collaboration on best practice, care planning and evaluation of the palliative approach.</li> <li>▪ To establish and promote a consultancy and support service to support the care planning process within facilities involved in the project.</li> <li>▪ Establish support structures and networks for staff, volunteers and families.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project aimed to develop a framework for collaboration between the individual, family and carers, service providers (St Joseph's aged care facility), general practitioners, hospitals and allied health services around the palliative care needs of the individual resident.</p>
<b>Project planning and development</b>	<p>The project was regarded by the organisation as an extension of a project which received funding in Round 1 of the Local Palliative Care Grants Program. That project developed training in palliative care for the Hunter Aged, Disability and Palliative Care Network (HADPCN), which includes 55 services in the Hunter region of NSW. The overall governance arrangement for the project was extended to oversee the collaborative framework project, and included representatives from the Catholic Care for the Aged, Hunter New England Area Health Service, Newcastle University School of Nursing, General Practice division, and other relevant aged care providers. The group operated in an advisory, rather than steering, capacity, as the project was predominantly driven by the project manager. The final report notes that the committee met only three times however stakeholder involvement in the project was maintained through HADPCN.</p> <p>There was no clear project or evaluation plan developed for the whole of the project; some elements were documented, but the project appeared to be predominantly driven according to the agenda set by the project manager. The project experienced some initial difficulties recruiting and retaining staff, and monitoring progress of the project became complicated when the project manager changed jobs to a more senior position elsewhere in the organisation.</p> <p>The project manager reported that no ethics application was required and, as the project was being implemented predominantly within the one organisation, there were no formal agreements required with other services.</p>
<b>Delivery</b>  <i>What did the project do, create, change?</i>	<p>The first objective of the project was to research and develop a collaborative framework model for providing palliative care to residents of aged care facilities. The model included decision-making tools, and a format for working with residents, their families and care staff to develop advance care directives (ACDs). The framework was implemented initially within one large nursing home at the St Joseph's Aged Care site, and included education and training of staff, as well as high level coordination and practical support by the project manager. A video was developed to support the implementation of the ACDs, including interviews with residents, their families and care workers discussing their experiences of developing and utilising the directives.</p> <p>The project arose out of discussions within a broader network arrangement – the Hunter Aged and Disabled Palliative Care Network – and although the project was based at St Joseph's, the aim was always to extend the learnings and resources to that broader network. This was achieved through the development of a specific website, which includes</p>

Project title	NSW-3 – Hunter Palliative Aged Care Collaborative Framework
	<p>elements of the model as well as appropriate resources, links and contact details for further support.</p> <p>A series of education and training initiatives were implemented to support the delivery of the framework with a focus on developing care plans which are responsive to individual life choices of the care recipient. The project also developed resources and facilitated access to training on coping strategies, networking, loss and grief, time management and self care. A number of community education forums were held across Hunter Manning Region targeting general community, church and retirement groups, providing information on both clinical and pastoral issues associated with caring for a person with palliative needs. Presentations on the key aspects of providing a palliative approach in aged care were provided to a series of professional dinner forums, general practitioner workshops and state and national conferences.</p> <p>Support for residents and families was provided through the development of resources and templates for relevant decision-making processes, such as ACDs. A pamphlet on coping skills was developed and widely distributed, and the ‘Seasons for Growth’ courses promoted and delivered. This course assists participants manage and understand the effects of significant change, loss and grief in their lives, and is convened by the Catholic Diocese of Maitland-Newcastle. A volunteer program was also developed. The “Companions in Care” program recruited and trained volunteers with a primary focus on providing pastoral support to residents and families in latter stages of disease processes, but prior to terminal phase. These resources are also available on the website.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Project evaluation was not included in the budget, and no formal evaluation plan was developed. The project manager explored the use of the existing evaluation tools, however felt they were too focused on palliative care, and not appropriate for residential aged care. Consequently, it appears that evaluation of the project was undertaken in an opportunistic manner.</p> <p>One table of data is included in the final report, providing details of one aged care facility in terms of resident deaths, transfers to hospital, and uptake of ACDs. This was informative.</p> <p>From the final report, it appears that feedback from users and the HADPCN was used as a means to evaluate and refine the resources and processes developed by the project.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The project aimed to develop a collaborative framework to providing palliative care which meets the needs of residents and their families. One of the components of that framework was the ACP, which staff were provided training and support to develop in conjunction with residents and their families. The final report contains statistics from one residential aged care facility (RACF) that was part of the project, which demonstrates there was a successful uptake of ACPs and a commensurate decrease in the number of people being transferred to hospital to die.</p> <p>The 132 bed facility had only three residents with ACPs at the start of the project in 2006, and by the end this had risen to 119 residents with ACPs. The number of people with ACPs who died in 2006 was 2 (out of 81 total deaths during the year); 34 in 2007 (out of 72); and 45 in 2008 (out of 56).</p> <p>Support for families was provided through the development of a pamphlet on coping skills, and the promotion of the course ‘Seasons for Growth’, which was delivered by the local Catholic Diocese. The final report notes that the pamphlet was well received and utilised, and decision making in families was identified as being well supported, but provides no details on the overall number of residents or family members impacted by these aspects of the project.</p> <p>The focus of project activities for staff and providers was around the delivery of education and training, and mentoring. The final report notes that over 180 staff from within Catholic Care for the Aged (CCA) undertook the national palliative care competency training either as part of an entry level traineeship or as a stand alone module delivered over six weeks with workplace assessment imbedded into the model. Over 35 staff from external facilities undertook the national competency from the community services training package. It is not clear from the report whether these figures represent those trained under this funding round, or as part of the previous project funded under Round 1 of the Local Palliative Care Grants Program.</p> <p>The report noted that the aged care facilities involved in the project did not experience any</p>

Project title	NSW-3 – Hunter Palliative Aged Care Collaborative Framework
	<p>staffing problems and agency nursing staff did not have had to be recruited in the time since the project commenced. This was put down to the education provided, which increased the capacity and capability of care staff. Similarly, the report goes on to say, there have been a reduced number of complaints and patients are reporting greater satisfaction with their care.</p> <p>The final report does not include data on the evaluation of the training, however it notes that the training was a success as it was delivered with an expectation of workplace learning and assessment, and the learning materials had been developed with a major emphasis on advanced care planning discussion techniques and skills to ensure competence and confidence were maximised in the task of talking to people about planning for the future.</p> <p>The report notes some difficulty engaging registered nurses and general practitioners in the project, noting their resistance was due to the project seen to be imposing on their clinical areas. The report goes on to say that the extent of training within CCA facilitated a culture shift and change in philosophy of care that was needed to change practice, as care staff became more informed and registered nurses and general practitioners became more engaged.</p> <p>The care planning tools and framework were the subject of a program by the Aged Care Channel in 2008. The final report estimates the reach of the program to be approximately 5000 residential aged care staff.</p> <p>A volunteer program “Companions in Care” was developed to assist in the provision of pastoral support to residents and families in latter stages of disease process but prior to terminal phase. The final report notes that there are likely to be associated benefits from the volunteers promoting a palliative approach beyond the aged care facilities, as they engage with their wider community networks.</p> <p>A website was developed as part of the project in consultation with HADPCN and other stakeholders. The site includes tools and resources which support a palliative approach in aged care, as well as linkages to other relevant sites. The resources can be accessed at: <a href="http://pc.catholiccare.org.au/">http://pc.catholiccare.org.au/</a>.</p> <p>The table of data provided in the final report suggests that there has been an improvement in the number of residents being transferred to hospital and dying, with a reduction from eight in 2006, to one in 2008. The report suggests that collaborative care planning and discussions enabled families, general practitioners, registered nurses and care workers to feel empowered in decision making around hospital transfer and other treatments that the person themselves may have wanted.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The final report notes that the project provided an important change management within the Catholic Care for the Aged (CCA). Systems and processes are now in place to support the palliative approach, senior management have been engaged in the process, and staff at all levels have incorporated the philosophy of care so the organisation is better able to meet the needs of people who require palliative care. The introduction of the complex care category in the new Aged Care Funding Instrument, which includes care for people with palliative needs, provides the added incentive for the organisation to continue to implement the palliative approach.</p> <p>Catholic Care for the Aged has also committed to maintaining and updating the website developed as part of the project.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. Additional funding is required if the palliative approach is to be sustained; every facility needs at a minimum a clinical nurse consultant, if not a nurse practitioner, as general practitioners do not have the time or the skill base to lead in this area and care workers are not empowered to do so.</li> <li>2. There is a high need for state funded acute beds within RACFs; this would support people with dementia in acute phases of illness much better than hospital transfer and also assist emergency departments which do not have the environments or resources to care for people with dementia.</li> <li>3. Additional resources should be provided to train, support and recruit volunteers to be companions in care for palliative care; bereavement and pastoral support services are not identified in funding instruments and are resource intensive.</li> </ol>

<b>Project title</b>	<b>NSW-4 – Northern New England Palliative Care Planning Project</b>
<b>Keywords</b>	Local, regional, RACF
<b>Host organisation</b>	H.N. McLean Memorial Retirement Village Pty Ltd
<b>Partner organisations</b>	Nil
<b>Project funding</b>	\$218,878.00 incl. GST
<b>Project timeframe</b>	21 April 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a model for palliative care targeting potential residential care residents and those who would prefer to stay at home, and improve services for palliative care patients in the proposed service area by enhancing palliative care planning and access.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Enhance services through improved care planning for palliative care patients in the target groups of residential care residents and those who prefer to stay at home during the palliative care phase was a major aim of the project. This would ensure that: <ul style="list-style-type: none"> <li>- older people's health and well-being was optimised in their chosen place of care,</li> <li>- transitions across the community, acute and aged care sectors were smooth,</li> <li>- carers were supported in their role.</li> </ul> </li> <li>▪ Provide support to health professionals and aged care providers in the acute, community and aged care settings in their care planning role with palliative clients through a multidisciplinary and co-ordinated approach to provision of palliative care planning services.</li> <li>▪ Increase knowledge of palliative care by providing extensive education for health professionals and developing and promoting service linkages across the area.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The focus was to up-skill relevant staff members, support smooth transitions between services and inform the community of the relevant services available. The funding was utilised to develop a multidisciplinary approach to care planning, including the development of a comprehensive holistic palliative care planning tool to be utilised by all care stakeholders and the development of a user friendly local "Palliative Care Planning Resource Guide" to assist service providers, patients and families to access services throughout the Palliative Care journey.</p>
<b>Project planning and development</b>	<p>A Palliative Care Planning Coordinator was employed as project manager, and to develop tools and resources and provide the linkages across sectors.</p> <p>The project was considered to be a quality improvement project and did not require ethics clearance. Memorandums of Understanding (MOU) were used as a mechanism to gain the support of all stakeholders in the implementation of flexible models of service delivery that would meet the needs of the target group of the project in their local community. It would also support the improved collaboration between services involved in providing care and supporting the smooth and appropriate transition between settings of care i.e. residential aged care facilities (RACFs), the person's home and inpatient facilities. Not all stakeholders signed the MOU, however most of the non-signing organisations continued to engage with and support the project activities.</p> <p>Key stakeholders were informed of the project's progress through their participation on the steering committee. Terms of reference were established; however, participation by members was sporadic, due to distance, busy workloads and juggling of other priorities. The wider community, including residents and their families, were informed through the development of resources such as the palliative care brochure and local resource guide.</p> <p>The initial, overly ambitious project plan was refined and strategies devised to address the broad geographic spread. This included limiting the initial trial area, with view to piloting resources, refining them, and then making them available for broader roll-out across project region. In principle, every aspect of the project was based upon the Palliative Care Guidelines for Residential Aged Care.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	Care Planning Guidance Tool – the <i>IF and THEN Model</i> . The CPGT, as it became known, was developed in consultation with stakeholders, and incorporated the Australian Palliative Care Guidelines. The CPGT included appropriate guidelines, advanced care planning and an end-of-life care pathway. The CPGT acted as prompt for care planners – for example, a

Project title	NSW-4 – Northern New England Palliative Care Planning Project
	<p>question is posed, and <i>IF</i> the answer is yes, <i>THEN</i> the action is completed; <i>IF</i> the answer is NO, <i>THEN</i> the issue is turned into an action item on the care plan. Each chapter and topic within the CPGT was explicitly aligned to the Guidelines to a Palliative Approach in Residential Aged Care (2006). The tool was developed and trialled for use within the HN McLean Retirement Village, and disseminated for use to the majority of service providers across the region in early 2008.</p> <p>Development of Pain Management Resources. A collaborative literature review with the Gwydir Shire Palliative Partnerships Project (NSW-5) was undertaken following the findings of an audit of patient files, which revealed major deficits in the documentation of pain assessment, staff reporting of pain, recognition of behaviours linked to pain and inadequate staff response to reports of pain. Together the two projects developed a training package on pain management of older people with complex needs, comprising a DVD entitled <i>The Impeccable Assessment of Pain</i> and Certificate IV training materials. The DVD has been endorsed by Professors Peter Ravenscroft and Jenny Abbey. The training package and DVD have been endorsed by the Barwon Division of General Practice for all staff providing care to the elderly, and have been recommended for training to medical officers regarding the holistic and objective assessment of pain. One hundred copies of the training package have been developed and 300 copies of the DVD.</p> <p>Education and training. Palliative care capacity was built through the recruitment, training, mentoring and support of a palliative care volunteer workforce and by the provision of education across the health workforce. Competency based education for workers in RACFs was adapted from Aged Care Certificates III and IV – CHCPA01A/02A ‘Plan for, provide and deliver care services using a palliative approach – building competency and capacity in organisations in care provision’.</p> <p>The project produced a brochure outlining Palliative Care Planning Coordination Services, and a comprehensive local resource guide. The project officer also took part in discussions with older persons resulting in the development of personal advance care plans.</p> <p>The geographic scope of the project was very large, comprising a rural and remote region of approximately 12,500 square kilometres in the Northern New England and North West regions of NSW. There are approximately 550 places in ten aged care facilities across the region, and a further 50 in the four Multi Purpose Services (MPS), as well as 200 community care packages and an unknown number of Department of Veterans’ Affairs (DVA) funded services. Consequently, the report notes there are high numbers of staff delivering care in the community and aged care facilities for people who will be, at some time in the foreseeable future, requiring end of life care or care delivered within the parameters of a palliative approach. The final report notes that education delivery has occurred in all but one of the communities within the project area, targeting primarily staff working in aged care, community care and the primary health care sectors.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Evaluation was not costed into the original budget and the evaluation plan was kept relatively straightforward as a result. All evaluation audits, surveys and questionnaires were designed by the project officer to be utilised before and after various activities related to the project. A basic questionnaire was used to gauge key stakeholder knowledge, understanding and expectations of the project at its outset, and completion. Stakeholders included health, aged care, community care representatives from across the Northern New England area, as well as consumers (two), a minister of religion, and an Aboriginal Health worker. The final report notes that not all questionnaires were returned, however from those which were returned, it was possible to infer that the project had a number of benefits for each of the target groups.</p> <p>Level 1: A randomised audit of 10% of residents’ records in three aged care facilities was undertaken to establish base-line data related to the presence or absence of notation about various aspects of care. This was undertaken as a pre-implementation strategy for the Care Planning Guidance Tool (CPGT). The audit looked at the nursing notes and medication charts of residents and patients, as well as notes and medication history on admission and from the three months prior. Documentation on the following Aged Care Accreditation Standards were sought: 2.8 pain management, 2.9 palliative care, 2.10 nutrition and hydration, 2.15 mouth care, 2.11 skin care, 3.4 emotional/family support, 3.6 privacy and dignity, 3.8 cultural and spiritual life, 3.9 choice and decision making, as well as advance care planning. The audit notes revealed an actual or potential high degree of compromise being experienced by care recipients in relation to pain management, including the recognition of pain, assessment of pain, and timely and adequate response to pain. In response to these findings, the two projects (NSW-4 and NSW-5) worked collaboratively to</p>



Project title	NSW-4 – Northern New England Palliative Care Planning Project
	<p>address these issues, including the development of a DVD and training resources, and an education program. However, the additional work resulting from the initial findings compromised the ability of the project officer to undertake the post-implementation audit of files within the time period of the project as was initially envisaged. The final report notes that the host organisation intends to undertake this post-audit to assess any impact on pain management, however results were not available at the time of reporting.</p> <p>An evaluation of the end of life care was also undertaken by evaluating three deceased residents' notes from the HN McLean Village for the previous month.</p> <p>From the final stakeholder questionnaire, it was inferred that residents received an improved level of care, resulting from the increased capacity of staff to provide person centred care, their ability to participate in advance care planning and their access to information in decision making.</p> <p>Level 2: Recipients of education were provided with questionnaires to assess the pre-educational level of knowledge, and the changes in the knowledge immediately post session. In addition, a follow-up questionnaire was provided to a random 20% of participants three months after the training to gauge retention of information. The results from this latter audit revealed a retention rate of approximately 85-90%.</p> <p>Evaluation of the training pertaining to 'Developing Champions in Advance Care Planning', delivered over a two year period to 80 participants, showed that this was also successful. The final report notes that respondents demonstrated an increase in knowledge about ACP, and willingness to undertake ACP with residents.</p> <p>Following the Care Planning Guidance Tool pre-implementation audit, cited above, a survey was developed asking staff to rate their knowledge and confidence related to pain assessment in older people with cognitive impairment. This was distributed to staff across five aged care facilities, and drew responses from 62 staff. Initial file audit findings were confirmed, revealing that staff lacked knowledge and confidence to recognise and undertake pain assessment in cognitively impaired residents. These findings were used to develop a DVD and training package on '<i>The Impeccable Assessment of Pain</i>'. The training package was presented to 60 participants across the three communities of Bingara, Warialda and Inverell. Evaluation using a post-education survey form showed 48 rated the training as excellent, ten rated it very good, and two rated it moderately good.</p> <p>The recruitment and training of palliative care volunteers was evaluated using the evaluation forms included in the Palliative Care Volunteer Training Manual (Palliative Care Victoria). Two training programs were conducted, comprising thirty people in total, who received 30 hours of training each. Evaluations forms were completed after each training session, and upon completion of the overall training program. The findings of the overall evaluation of the first training program were used to inform the format and presentation style of the second session. The final report includes comments from participants which indicate a positive response to the content, format and presentation of the training.</p> <p>From the final stakeholder questionnaire, it was inferred that aged care staff, GPs and practice nurses in the community had benefited from the project, particularly in terms of having improved education, awareness and access to information about symptom management, end of life care and advanced care planning.</p> <p>Level 3: The impact of the project on the system was evaluated through the stakeholder knowledge questionnaire which was taken at the start, and conclusion, of the project, and also data regarding hospital transfers.</p> <p>The embedding of advance care planning processes within the HN McLean Village has also impacted on the local health services, with a significant reduction in the number of residents being transferred by the end of the project. An audit of medical records at the Inverell Hospital which had been conducted prior to the project, revealed that 20 residents from the HN McLean Village had been admitted to acute care, however on review of the nursing and medical notes it was apparent that only three of these admissions required acute interventions or transfer to a tertiary hospital. A later audit undertaken in late 2008, following the provision of education and support regarding pain management, and the education to staff, GPs and the general community regarding and advance care planning, revealed that there were only five residents transferred for acute needs over a similar three month period, i.e. representing an overall decrease of 75%. The reasons for transfer</p>

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	<p>include suspected fractures resulting from a fall (three out of the five) and acute episode of illness (two).</p> <p>The findings of the final stakeholder questionnaire inferred a number of systemic improvements. At the HN McLean Village, policies and procedures regarding advance care planning were now embedded into practice. This includes not only utilising the appropriate documentation, but also facilitation of staff to act on the end of life wishes of residents. The project has also enhanced the general community's knowledge about palliative care services, through the development of resources and educational opportunities provided. The networking opportunities and improved communication between services has also been facilitated by the participation of stakeholders on the steering committee.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The final report notes that there have been a number of improvements for consumers (community and residents of aged care facilities) resulting from this project. These relate primarily to increased access to information relating to palliative care, advance care planning, service provision and availability, and greater participation in activity relating to advance care planning, end of life care, and improved pain management. The major aspects of the project which have facilitated these outcomes are the Care Planning Guidance Tool, the advance care planning (ACP) section of which has been well utilised within RACFs and the broader community: the final report estimates that over 100 persons locally as well as across the project region having an ACP; and, the Impeccable Assessment of Pain DVD and Training package. The Pain resources were developed following an audit of a sample of residents' files which revealed that the identification and management of pain was not well attended to, and the project worked collaboratively with NSW-5 to develop these resources.</p> <p>The project estimates there has been a reduction in transfers of residents of HN McLean Village to Inverell Hospital of around 75% as a result of the activities of this project. This is based on the findings of an audit of medical records at the local Inverell Hospital which was undertaken prior to the project commencing, and a subsequent audit later on in the project's timeframe, which revealed only five transfers for acute needs over a three month period, compared to 20 previously.</p> <p>The overall impact of the project on clients and residents, however, is difficult to gauge. The final report notes that the Care Planning Guidance Tool is now used in a number of facilities across the Northern New England region, and referred to during care planning activities when staff prepare a new care plan or when they review existing care documentation.</p> <p>The education and training delivered by the project targeted staff and volunteers working in aged care, as well as some community disability service workers, across the region. The report notes that education was offered 'in place' to each facility, as well as through centrally located, area-wide forums. The final report also notes that the uptake has been 'comprehensive with a broad representation across the care continuum' and that there has been an increased capacity and competence gained through access to and participation in the education, with feedback from some facility managers that the effects of the training resulted in changes in care practices, documentation and timely response to behaviours that may indicate the presence of pain.</p> <p>Results from surveys of residents' families and carers reveal that they feel more confident that their loved ones now receive a higher quality of care in the RACF setting. This is supported by the results from the post-implementation audit of patient records which, the final report notes, shows that they have resulted in changes in practice.</p> <p>The resources developed for pain management appear to be highly regarded and well utilised. In addition to feedback from educational participants, there has been interest in the resources by general practitioners. The Barwon Division of General Practice has expressed interest in purchasing copies of the training package for all aged care facilities within its region, as well as purchasing over 100 copies of the DVD to distribute to the hospitals and doctors across the area.</p> <p>Thirty individuals participated in the palliative care volunteer training offered by this project. The training comprised 30 hours of education and training, equipping them to work within the HN McLean Village and the community care sector. The final report notes that feedback from volunteers, staff and family reported the following:</p> <ul style="list-style-type: none"> <li>▪ Staff are comforted and reassured by the knowledge that care recipients' holistic needs are more likely to be met;</li> </ul>

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	<ul style="list-style-type: none"> <li>▪ Families feel able to talk and unburden with the volunteers;</li> <li>▪ Care recipients have a personal visitor each week they can talk to or be with; and.</li> <li>▪ Volunteers report that their lives are enriched through personal interactions with the residents.</li> </ul> <p>At the organisational and system level (Level 3), the project has achieved a number of changes. The Care Planning Guidance Tool has been incorporated into the practices within HN McLean Village, and underpins the development of care planning processes. Consequently, the presence of definitive information about care recipients' preferences for health care and medical treatment options through the provision of advance care plans has resulted in changes in patterns of admissions and transfers to acute care from aged care facilities. Importantly, the project has also resulted in the development of strong links and networks that has facilitated better inter-agency conversations, consultation and collaboration. However, the scope and large geographic area of the project limited its capacity to develop and maintain strong links with and involvement from other organisations.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The Care Planning Guidance Tool has been incorporated into the practices within HN McLean Village, and underpins the care planning processes within it. This will remain ongoing. However, the final report notes that the greatest aspect of sustainability relates to the increased capacity of aged care staff to care for older people with palliative care needs resulting from the comprehensive education program that has been delivered for the duration of the project. The professionally produced training package 'The Impeccable Assessment of Pain', has also contributed to this increased capacity. This will be self-sustaining, with all proceeds from sales to other organisations being put toward producing further packages for ongoing dissemination.</p> <p>In addition, the momentum of the project will be maintained through the strong professional links that have been established by the project, including links with the local palliative care network and Barwon Division of General Practice. The HN McLean Village is exploring options to establish a small support team for the ongoing recruitment, training and support of volunteers.</p>
<p><b>Recommendations</b></p>	<p>The following recommendations written at completion of the three year project for consideration are directed toward the funding body and those organisations contemplating undertaking a similar project for a similar period of time (3 years).</p> <ol style="list-style-type: none"> <li>1. Closer scrutiny of the actual application is invited to be undertaken to ensure that the aims and objectives of the auspice body will actually be achievable within the funding amount applied for. Whilst it may be advantageous to fund more for less, this does not always result in the best or desired outcomes for the funding body, auspice body, the implementing organisation or the community in which the activity takes place.</li> <li>2. All organisations contemplating a similar undertaking, i.e. a 3-year project, are invited to consider the possible rise in costs over the project's lifetime. Additional funding may be required to take into account CPI impacts.</li> <li>3. Projects occurring in close proximity to each other could be invited to work in collaboration and partnership where possible, as this may have benefits previously unimagined, that may result in exponential increases to the outcomes of both projects.</li> <li>4. Project officers, particularly first timers, are often very skilled in many areas, but may not have the total proficiency required to meet all expectations. Resources could be developed and made available, such as an associated website, addressing some of the skills and tasks that need to be undertaken, such as report writing, convening and chairing meetings and undertaking literature reviews during the project.</li> <li>5. Closer scrutiny of details such as those relating to the size of the potential project area and number of associated providers, key stakeholders and disparate organisations involved is invited by both potential submission-makers and the funding body to assess capacity to accomplish the stated aims and objectives within budget and the timeframe set so as to be assured of successful outcomes and satisfactory collaboration and consultation between and with associated organisations.</li> <li>6. Prior to final selection, an opportunity could be offered to prospective projects, to revise aspects of aims and objectives and funding projections to ensure that these remain appropriate and achievable.</li> </ol>



<b>Project title</b>	<b>NSW-4 – Northern New England Palliative Care Planning Project</b>
	<ol style="list-style-type: none"><li data-bbox="448 241 1417 300">7. Opportunity and capacity to extend a project for a further three to six months to fully imbed resources and evaluate the outcomes would be beneficial.</li><li data-bbox="448 327 1417 439">8. The most important recommendation relates to future activity that builds on all the previous activity undertaken. The status quo is as follows: there is a flurry of activity and then, nothing. Whilst the resources remain and can be used, there is no longer a driver in the seat to propel the activity further along.</li><li data-bbox="448 465 1417 600">9. Change is challenging at any time: however, change in an environment such as aged care where it seems change is constantly impacting on all aspects of an organisation, any new resource needs a champion to continue to imbed and install and establish it from new to accepted to full utilisation; for resources to be viewed and acknowledged as part of the accepted processes.</li></ol>

<b>Project title</b>	<b>NSW-5 – Bingara and Warialda Palliative Care Planning Project</b>
<b>Keywords</b>	Local, regional, RACF, community care, acute care, primary care
<b>Host organisation</b>	Hunter New England Area Health Service
<b>Partner organisations</b>	Bingara and Warialda Multipurpose Services
<b>Project funding</b>	\$274,747.82 incl. GST
<b>Project timeframe</b>	3 May 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To improve the capacity of local staff to respond to palliative care needs as appropriate; to improve engagement and active participation of clients and carers in care planning processes; and to develop and implement the necessary processes and systems to ensure effective delivery of palliative care in the Gwydir Shire.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Develop local guidelines and formalised procedures that give clarity, direction and consistency on role delineation and care planning practices.</li> <li>▪ Train staff, building their confidence and ability to respond promptly and appropriately to the needs of the client, their carers, family member or palliative care service provider.</li> <li>▪ Support and educate carers so they are aware of and able to access available palliative care services when required.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> This project aimed to support a smooth transition between services and improve collaboration between services. Also, through education, it sought to enhance the skills of local health professionals in dealing with palliative care clients, improve their capacity to identify and respond to clients' and their families' changing levels of need.</p>
<b>Project planning and development</b>	<p>Key stakeholders were invited to join and establish a project advisory committee, which was scheduled to meet every three months. However, engagement was compromised by the limited availability and travel requirements of members. The project officer was recruited in September 2006 and worked at both the Bingara and Warialda hospital sites. The project officer reported to the Bingara Hospital management, while the cost centre for the project was the Warialda Hospital. Both hospitals were scheduled to transition into newly built Multi-Purpose Services during the life of the project, and this impacted significantly on the planning and implementation of the project. The rationale for the project was to develop strategies to support the primary and secondary palliative care services in these local communities.</p> <p>A gap analysis was undertaken based on the National Palliative Care Standards and the Australian Council of Health Standards (ACHS) EQUIP 4 standards. Draft <i>Local Guidelines for Service Delivery</i> were prepared and formed the basis of interim Memoranda of Understanding (MOU) between the key stakeholders in the local area, who agreed to participate in the development and trialling of care planning tools. These were replaced at the end of the project with more binding, long-standing MOU regarding ongoing implementation.</p> <p>The project was not required to seek approval by ethics committee, as it was considered by the HNEAHS Ethics Committee to be a quality assurance project.</p> <p>The initial project plan was very broad and ambitious, and included duplication of existing resources (e.g. literature review on best practice, where Palliative Care Australia [PCA] standards encompass best practice). The project officer refined the project and evaluation plans, to feature goals which were more realistic and relevant for the local context. A contract variation to this effect was granted in July 2007.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>A major outcome of the project was the development of the Palliative Care Planning Package, which comprised the following three components:</p> <p>Home-Based Record of Care Folder: The project initially set out to develop a patient-held record (PHR), following a review of care plans used by palliative care services and agencies. After consultation with stakeholders, the PHR was extended to include assessment, carer resources and communication tools, which aimed to improve the level of coordination between services while supporting smooth and appropriate transition between</p>

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	<p>settings of care. The resulting Home-Based Record of Care Folder also included details on the client's medication and history, service coordination plans, visit register and communication log, referral and consent form and discharge planning information.</p> <p>Patient Diary: Patients were provided with a diary in which they could record their own personal perspectives on issues associated with their care.</p> <p>Carers Resource Box: This was a pastel-coloured box with a photo of a tranquil rural scene on it, containing a number of practical and pamper products, many of which were sourced from local businesses, as well as information pamphlets and resources from key agencies such as Carers NSW, Home Hospice and PCA. The Carer Box was a purposeful intervention to engage carers, and to provide information that could be accessed at a time suitable to them. The boxes were based on a similar concept developed by the Rural and Remote Palliative Care Planning Model Project (NSW-8). One hundred boxes were produced, for distribution during the project, and following the project's completion.</p> <p>A second focus of the project was the provision of training and education to health and non-health staff. An education program was developed based on feedback from staff who were surveyed regarding their perceived training needs. Subjects identified as important education topics for staff included advance care planning; end of life ethics; pain management; symptom management; skin and wound care; and for carers: grief and loss; bereavement support; carers' resources; and self care. A total of 297 occasions of training were undertaken during the project. Resources developed and utilised include the DVD <i>The Impeccable Assessment of Pain</i> developed jointly by this project and the Northern New England Care Planning project (NSW-4), and the NNE project's <i>Care Planning Guidance Tool – IF and THEN Model</i>. The project also facilitated, for the first time, clinical supervision in palliative care to staff working in the Bingara and Warialda Multi-Purpose Services, which remains ongoing.</p> <p>The project developed pain management resources, based on a collaborative literature review with the NNE project (NSW-4). This review was undertaken following the findings of an audit of patient files, which revealed major deficits in the documentation of pain assessment, staff reporting of pain, recognition of behaviours linked to pain and inadequate staff response to reports of pain. Together the two projects developed a training package on pain management of older people with complex needs, comprising a DVD entitled <i>The Impeccable Assessment of Pain</i> and Certificate IV training materials. The DVD has been endorsed by Professors Peter Ravenscroft and Jenny Abbey. The training package and DVD have been endorsed by the Barwon Division of General Practice for all staff providing care to the elderly, and have been recommended for training to medical officers regarding the holistic and objective assessment of pain. One hundred copies of the training package and 300 copies of the DVD have been published.</p> <p>The project facilitated negotiations with the Home Hospice organisation to improve the capacity of staff to respond to the needs of carers. Early in the project, a community information pamphlet was written in order to inform community members about the project and about the palliative approach to care. A total of 200 pamphlets were distributed throughout Bingara and Warialda, and the document was also uploaded onto the Area Health Service website.</p> <p>Local guidelines were developed in order to provide consistent care planning processes, which adhere to best practice principles, across services in the local area. Guidelines were developed in consultation with the management committee, trialled and evaluated. The final guidelines formed the basis of the interim MOU between hospitals, medical centres, hostels and key community services in the area. The project built on the 'Care Planning Guidance tool – IF and THEN' model developed by the nearby Northern New England Palliative Care Planning Project (NSW 4).</p> <p>A local services directory providing an overview of local service availability was drafted and distributed to GPs to give to clients following a diagnosis of life-limiting illness.</p> <p>A major aspect of the project was its collaborative approach with the NNE Care Planning Project (NSW-4) based at Inverell, and its community development focus. The close relationship with the NNE project was in part due to the fact that the NSW-5 project was incorporated within the larger geographic area covered by NSW-4. The project officers sought to work together to ensure consistent development and implementation of resources across both projects. The project officers were members of each other's project advisory</p>

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	<p>committees, and collaborated on the provision of education; research on staff capacity regarding pain assessment and management, the production of the DVD <i>The Impeccable Assessment of Pain</i> and the training package CHCAC12C – <i>Provide services to an older person with complex needs related to the presence of pain</i>. They worked together on conference presentations and trialling of resources. In addition, the project has worked in partnership with local community to enlist support to project activities, including the local Men’s Shed collating and binding the Patient Diaries, the local Roxy Theatre hosting two education forums and the launch of the DVD, and the Bingara Vision 2020 website uploading the community information pamphlet.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>All project activities were evaluated, and findings reflected into the project plan in an ongoing manner. The key issue for this project was the relatively small numbers of palliative care clients and their carers in the local communities of Bingara and Warialda, and therefore findings regarding the resources developed for these groups were primarily anecdotal and qualitative.</p> <p>Level 1: Evaluation tool 4.1 from the Centre for Health Service Development (CHSD) Evaluation Toolkit was modified so that carers could be included in the sample up to two years after bereavement. This tool was used to ascertain consumer needs at the outset of the project. The purpose of the survey was to obtain baseline data and to identify gaps in resources and support at the time, especially regarding self-care. An audit was undertaken of 20% of client files in Bingara and Warialda aged care to review whether pain management tools were being used effectively. Results indicated lack of documentation of effective and adequate pain assessment and management for many residents.</p> <p>Level 2: Evaluation Tool 2.1 from (CHSD) evaluation toolkit was used to survey 14 staff from across the two communities, to identify what they perceived to be their training needs; staff members were surveyed again using the same tool after training to determine its effectiveness.</p> <p>At Level 3: The main evaluation activities focused on feedback to the interim MOU, and the development of the Local Guidelines for Service Delivery, which formed the basis of the enduring MOU at the completion of the project. Feedback from stakeholders was limited as only three people responded to the end-of-project survey (20 were approached). The survey was intended to collect opinions about the effectiveness of the interim MOU in maximising continuity and establishing high practice standards. This feedback was generally positive. The limited response to this survey reflects the limited engagement of key stakeholders throughout the project. For example, only a third of stakeholders approached for feedback on the service needs gap analysis responded to this request and therefore had input into the subsequent development of the Local Guidelines for Service Delivery. That said, however, the fact that the Guidelines were endorsed and made the subject of an enduring MOU at the completion of the project suggests that they effectively met the needs of the various stakeholders.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>Many of the evaluation activities were formative, with the results fed back into the development of the project’s tools and resources. For example, the outcomes of the carer survey (Tool 4.1 of the CHSD Toolkit) were used to develop an education program for carers, covering topics such as grief and loss; bereavement support; carer resources; and self care.</p> <p>Following the outcome of the staff survey (Tool 2.1), an education program was developed for staff, covering topics such as advanced care planning; end of life; pain management; symptom management; skin and wound care; loss and grief; communication and anxiety; self care; and, interpersonal skills. At the completion of 2007 staff training program survey results revealed that the large majority reported improvement in confidence and skill as a result of the education: 23% mild, 46% moderate and 16% very large improvement. There were 297 occasions of staff training during the project. In addition, the project supported two staff completing their Palliative Care Certificate; two staff completing the Certificate IV ‘Plan and provide care services using a palliative approach’; and four week-long clinical placements for staff.</p> <p>The audit of clients’ files demonstrated a lack of documentation of effective and adequate pain assessment and management for many aged care residents, leading to the development of the pain management DVD and training package in collaboration with the NNE Care Planning project (NSW-4) as described above.</p>

Project title	NSW-5 – Bingara and Warialda Palliative Care Planning Project
	<p>The small populations of Bingara and Warialda, together with the trial period commencing so late in the project's timeframe, resulted in only five clients being provided with the <i>Palliative Care Planning Package</i>. This small sample was not large enough to have adequate power for statistical analysis to evaluate the efficacy of the Package as a flexible model of service delivery.</p> <p>Consequently, qualitative data obtained through interviews with clinicians provided the basis for a case study to show the potential effectiveness of this tool in the care planning of a palliative client from a remote rural area. The case study suggests that the approaches and resources developed were relevant and useful for carers and for staff, and assisted in providing enhanced palliative care to clients. Historically service delivery has been viewed as being ad-hoc and reactive, whereas with the implementation of the Package, service delivery has adopted a more planned, holistic and pro-active approach. The Package has enabled more involvement in care planning for the carers and family of clients with life-limiting conditions.</p> <p>Communication between service providers has also been enhanced through the use of the tools that have been developed as part of the <i>Palliative Care Planning Package</i>, i.e. visit register and communication log. This has been particularly important for people living in cross-border areas, if they are not known to local providers or if they receive their primary care from GPs across the border in Queensland.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>Ensuring the sustainability of the project's outcomes will require the ongoing commitment of key staff members within the local area. Registered Nurses were identified to be Change Champions at both Bingara and Warialda MPSs to continue driving the change process, and the project report notes there is enthusiasm for an effective approach to holistic planning of care. However, ongoing leadership from senior staff, such as clinical nurse specialists, consultants and managers is required to ensure that newly developed resources and practices are embedded into everyday use.</p> <p>A number of resources have been developed during this project, and mechanisms are in place to ensure the viability of at least some into the future. For example, there is agreement from the Department of Health and Ageing that the DVD and associated training package can be sold at a price commensurate with the ongoing reproduction and distribution costs. Others, such as the <i>Palliative Care Planning Package</i> with its three components, have limited production runs, and while there is currently sufficient to last, potentially, for a couple of more years, they will need to be updated, re-printed and re-packaged at some time in the future. However, the engagement of the local services in the development and production of elements of the Package, such as the local Men's Shed and cotton manufacturer, suggests that local commitment is likely to be readily harnessed if a driver is provided.</p> <p>A series of community and professional briefings with the Home Hospice Program coordinator has been organised in Bingara, Warialda and Inverell for the period 12–14 May 2009, in order to gauge the level of community support and commitment to the future expansion of mentor training in this area.</p>
<p><b>Recommendations</b></p>	<p>The project has made a series of recommendations at the end of the report, most of which refer to the project establishment, management and evaluation. These issues were particularly pertinent to the project officer who was a clinician, and did not have prior project management experience.</p> <p>Recommendations include:</p> <ol style="list-style-type: none"> <li>1. Consultation with clinicians prior to establishing projects, to ensure objectives are 'part of a realistic quality improvement framework' and 'not overly ambitious'.</li> <li>2. Additional training in evaluation by the national evaluation team at outset of project, and timely follow-up with site visits.</li> <li>3. Encourage collaboration between projects – in terms of geographic location as well as content.</li> <li>4. Projects should not run concurrently with major organisational transitions.</li> <li>5. Identification of 'change champions' at each site to facilitate trialling and implementing new tools and resources.</li> </ol>

<b>Project title</b>	<b>NSW-5 – Bingara and Warialda Palliative Care Planning Project</b>
	<ol style="list-style-type: none"><li>6. Engagement of independent experts and consultants to provide evaluation of project performance.</li><li>7. Funding for travel and dissemination should be included in budget at outset of project.</li><li>8. Assistance and advice with dissemination activities.</li><li>9. Feedback on report writing, in terms of quality and content; and examples of final reports to provide insight into the kind of language use, format and inclusions of a final report.</li></ol>



<b>Project title</b>	<b>NSW-6 – Catholic Healthcare – Palliative Care Plan Development</b>
<b>Keywords</b>	Local, regional, RACF
<b>Host organisation</b>	Catholic Healthcare Ltd (CHC)
<b>Partner organisations</b>	Nil
<b>Project funding</b>	\$263,670.00 incl. GST
<b>Project timeframe</b>	31 December 2006 to March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To have all services of Catholic Healthcare implement a system-wide approach to a best practice model of care planning for palliative care patients. The model will involve all stakeholders including carers, families and health professionals. It will embrace a range of services from family care, community care and residential aged care.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To provide palliative care education packages to the local aged and allied health care sector to promote a palliative approach in their various workplaces.</li> <li>▪ To implement multidisciplinary team (MDT) meetings for the care planning of residents with palliative needs.</li> <li>▪ To promote advance care planning (ACP) as a routine inclusion to the admission process and scheduled MDT meetings to contribute to smooth transitions in care.</li> <li>▪ To implement an end of life care pathway to promote evidence-based practice and quality management of clients who have entered the terminal phase of illness.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project had a focus on a multidisciplinary approach to client care and a smooth transition between services using care planning.</p>
<b>Project planning and development</b>	<p>The project was guided by a Project Advisory Group, which met four times a year and was used as a review mechanism for elements of the project. A project and evaluation plan were developed, which formed the basis of activities for the project. Early in the project, Catholic Healthcare underwent a restructure and doubled in size, resulting in less than anticipated engagement by senior management, whose focus was on other organisational priorities at the time. Consequently, there were some delays in review and approval of elements, in particular the planned conference and educational activities, which caused some changes in timing to the overall project activities. Ultimately, however, all elements anticipated at the outset of the project were undertaken.</p> <p>Ethics approval was not required for the project.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project was designed to address the <i>National Palliative Care Standards (2005)</i>, and the <i>Guidelines for a palliative approach in residential aged care – enhanced version (2006)</i> funded by the Department of Health and Ageing. In particular, the model developed by the project addressed the need to increase the capacity of aged care providers to deliver quality, evidence-based palliative care through the following four major strategies:</p> <ul style="list-style-type: none"> <li>▪ Education was the keystone of this project. This was provided through two 16-hour education packages directed at nursing and care staff. The education packages were run twice during the project period. A two-day conference was held in Sydney in November 2008 for Catholic Healthcare aged care providers, titled, 'Terms, Tools and Teams – a palliative approach in residential aged care'.</li> <li>▪ Case conferences or MDT meetings were central to the care planning component of the project. The existing case conference process established in the organisation's aged care facilities was reviewed, refined, and trialled with a greater focus upon a palliative approach. A MDT toolkit was also developed to provide guidance in planning and facilitating case conferences in participating facilities.</li> <li>▪ Advance care planning (ACP) was introduced in the education programs and via several education seminars and workshops.</li> <li>▪ End of life care was supported by the development of an end of life care pathway to facilitate and promote evidence-based practice and quality management of clients in the terminal phase. End of life care was also included in the delivery of the 16-hour palliative care education.</li> </ul> <p>Several resources were also developed by the project including a palliative care clinical assessment summary form to enable all symptoms and their severity rating to be recorded</p>

Project title	NSW-6 – Catholic Healthcare – Palliative Care Plan Development
	<p>on one page and management strategies identified on the reverse side. A pamphlet focusing on a palliative approach and another focusing on the dying process were also developed.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The project used a variety of methods to evaluate its activities.</p> <p>The education package was evaluated using Tool 2.1 of the Centre for Health Service Development (CHSD) Evaluation Toolkit. This was provided to all participants prior to their attendance, and immediately following the education. This data was supplemented with results from a series of focus groups which were conducted toward the end of the project, which looked at education issues as well as other aspects regarding the implementation of a palliative approach.</p> <p>The model of care was developed using a plan, study, do, act (PSDA) cycle. This provided valuable information to the project officer during the course of the project, which in turn was used to refine the project elements.</p> <p>Auditing of client notes was also conducted, in order to ascertain the effectiveness of the end of life care pathway which was implemented. File notes were audited at two points during the project, before and after the education and introduction of the end of life care pathway.</p> <p>The overall impact of the project was assessed using a series of four focus groups towards the end of the project, involving 18 participants from a variety of staffing positions within the organisation. The focus groups provided feedback on what they considered were the positive and negative aspects of the introduction of a palliative approach to aged care, multi-disciplinary team meetings, advance care plans, education, and end of life care.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The introduction of a palliative approach to care and the associated activities to support this has resulted in significant benefits for clients and their families.</p> <p>The project introduced multidisciplinary team meetings to the organisation, and contributed to the development of the Mid North Coast Division of General Practice MDT Toolkit (2006), which provided guidance in planning and facilitating case conference meetings. A total of 93 MDT meetings were implemented for the care planning of residents across the three participating facilities. These were attended by 461 participants including 65 GPs, 238 nurses and allied health care providers and 158 residents and family members. The focus groups revealed that staff felt that the MDT meetings / case conferences were very family focused, and the process encouraged families to talk amongst themselves so they are better prepared for the death of their family member. Staff also felt the introduction of advance care planning was positive for residents and families, as this empowered residents to have a say in, and ownership of, their care. In addition, residents and their families had increased interaction with staff, and a better anticipation of deterioration in resident's condition. Staff also commented that family members appreciated the 'Understanding Dying' brochure.</p> <p>These perceptions were supported by the audit of file notes, 20 of which were undertaken prior to the introduction of the palliative approach and end of life care pathway, and 30 afterwards. The audits showed there was significant improvement in evidence-based assessment and associated prescribing of medications, particularly related to pain management. For example, analgesia prescribed at 72 hours prior to death was 40% in the pre-test data, compared to 76% in the post-test data. Similarly, PRN (as required) medication for breakthrough pain was recorded at 35% in the pre-test data, compared to 73.3% in the post-test data. End of life care pathway was not used at all in the pre-test data, and in 36.6% post-test.</p> <p>The data demonstrated that communication with families was also improved, showing greater evidence of family and general practitioner awareness that the resident was dying. This was supported by the focus group findings, which showed staff felt more confident in providing end of life care and communicating at end of life.</p> <p>The major impact on staff and service providers was through the education packages delivered, and the ongoing support provided to the participants by the project officer. Fifty five residential aged care staff participated in 16 hours of education over a four-week period. The education was based on that developed by the Mid North Coast Division of General Practice with funding from the Rural Palliative Care Program (2004-2006), and delivered collaboratively with the Mid North Coast Integrated Network Palliative Care</p>



Project title	NSW-6 – Catholic Healthcare – Palliative Care Plan Development
	<p>Project (NSW-7), also funded under the Care Planning Sub Program. The training was completed by 33 registered nurses (who went on to become palliative care link nurses in their respective facilities), and 22 enrolled nurses and care staff. Participants came from aged care nursing and care staff as well as local hospitals, and private and public community care services.</p> <p>The evaluation demonstrated that the education had a positive impact on staff. Enrolled nurses and care staff revealed an improved confidence in:</p> <ul style="list-style-type: none"> <li>▪ Answering questions on the dying process (5 out of 19 prior to the education and 16 afterwards)</li> <li>▪ Reacting to reports of pain from patients (6 able to perform confidently pre, and 16 post)</li> <li>▪ Reacting and coping with limited patient decision making capacity (6 confident to perform with minimal or no consultation pre, and 15 post).</li> </ul> <p>This was supported in feedback provided during the focus groups, in which staff agreed that, due to the education, providing palliative care was now more structured, there was better recognition of the phases of care and use of assessment tools, and improved ability to identify symptoms and provide evidence when someone required pain or symptom management.</p> <p>The introduction of multidisciplinary team meetings was also seen as a positive measure for providers, as well as residents. The main benefits arose from the ability to coordinate care, and relationship building between key stakeholders which arose and facilitated improved communication outside the MDT context. The project was highly successful in getting general practitioners to participate, with 24 out of a possible 28 local GPs; and used a very focused approach to engaging with GPs in the MDT meetings. This included maintaining a strict meeting schedule, offering teleconference facility to include GPs, prioritising GP issues, and using Medicare case conferencing items to remunerate GPs. The MDT meetings faced a number of challenges, mostly around co-ordinating meeting times, physical resources such as teleconference facility, and engagement of senior staff as care staff were unable to leave the workplace to participate. This proved a disappointment for some junior staff, who indicated in the focus group that they would have liked to participate in the MDT meetings.</p> <p>The MDT meetings also provided the opportunity for discussions regarding advance care planning, resulting in strategies being put in place for 93 residents with palliative care needs to facilitate smooth transitions in care.</p> <p>A further initiative directed at care staff was the palliative care conference titled, 'Terms, Tools and Teams – a palliative approach in residential aged care', which targeted Catholic Healthcare aged care providers. Held in Sydney on 25-26 November 2008, the conference attracted 94 staff, representing its 39 aged care services. The conference showcased the activities of the project, and also included 14 guest speakers. A direct consequence of the conference was a greater level of interest by senior management within the organisation in the initiatives of the project, and the project officer was invited to participate in the organisation's Special Interest Group to develop a palliative approach in all Catholic Healthcare's aged care services.</p> <p>As the project neared completion, it became apparent that there was significant underspends in the initial budget, in part because the cost of implementing the initiatives within the organisation was not as much as had been anticipated. Permission was received from the Department of Health and Ageing to use the funds for the development of four web-based palliative care learning packages, based on the education package provided under the project, to be included on the Mid North Coast NSW Institute of TAFE website 'HEALNet'. The four packages developed provided an introduction to a palliative approach in aged care, information regarding MDT meetings and pain and symptom assessment, and end of life care, and are accessible to nurses and care staff everywhere via the internet. No formal evaluation of this initiative had been conducted at the time of reporting.</p> <p>The project has had an impact on organisational systems and processes, which will be sustained into the future. The multidisciplinary teams and the MDT toolkit have been adopted for local use and presented to Catholic Healthcare for consideration for inclusion in the broader organisation-wide procedures documents. ACP is now routinely discussed at the time of admission of new residents to local facilities, and ACP documents are included in the front of resident notes, to enable easy access to documents for transfer to other</p>

<b>Project title</b>	<b>NSW-6 – Catholic Healthcare – Palliative Care Plan Development</b>
	<p>facilities and facilitating smooth transitions in care. Catholic Healthcare now includes the NSW Health Advance Care Planning documents on their intranet website, as well as Catholic Health Australia's Advance Care Planning documents and Code of Ethical Standards.</p> <p>The project also highlighted a number of factors which need to be considered at a systemic level to assist in the continued implementation of a palliative approach. These include the provision of education within work time, rather than in staff's own time, in recognition that palliative care is core business for aged care; and the inclusion of handover time to improve communication about resident's conditions between staff changing shifts.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>A number of aspects of the project will be continued at the local and broader organisational levels.</p> <p>At the local level, MDT meetings will continue, and the MDT toolkit will continue to inform proceedings. Discussions regarding advance care planning are now initiated at the time of admission of a new resident, and the assessment documents developed, education program and end of life pathways have also been integrated into local practice.</p> <p>At the beginning of the project it was hoped that engaging key and relevant staff members in the working group would guarantee the sustainability of the care planning process. However, due to a major organisational restructure and growth, engagement by senior decision-makers in the organisation was not always possible, hindering the uptake of various aspects of the project. That said, however, at a broader organisational level there has been a commitment to consider the MDT model and toolkit for inclusion in the organisation's procedures documents, and the organisation has adopted a policy of ensuring all ACP notes are included in the front of residents notes for easy access and to facilitate smooth transitions in care. Catholic Healthcare also has included the NSW Health Advance Care Planning documents on its intranet website, as well as Catholic Health Australia's Advance Care Planning documents and Code of Ethical Standards.</p> <p>The education provided under the project will continue, being delivered at the local level, and being made available more generally by their development into a web-based learning package and available on the Mid North Coast NSW Institute of TAFE website 'HEALNet'.</p> <p>As a result of the success of the 'Terms, Tools and Teams – a palliative approach in residential aged care' conference held in November 2008 for all Catholic Healthcare's aged care services, the project officer now actively participates in the Special Interest Group to help develop a palliative approach in all Catholic Health Australia's aged care services.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project regarding the project processes are listed as follows.</p> <ol style="list-style-type: none"> <li>1. The model developed by this project recognises that many residential aged care clients have palliative needs, and that a palliative approach should be introduced long before they have entered the terminal phase of their illness.</li> <li>2. The initiatives of the project are robust and flexible enough to be rolled out more widely in residential aged care facilities and also have relevance to the community aged care sector.</li> </ol>

<b>Project title</b>	<b>NSW-7 – Mid North Coast Integrated Network Palliative Care Project</b>
<b>Keywords</b>	Local, regional, primary care, RACF, community care, acute care
<b>Host organisation</b>	Mid North Coast Division (NSW) of GP
<b>Partner organisations</b>	North Coast Area Health Service; Ramsay Health Care – Baringa Private Hospital; Catholic Health Care Services Ltd; Coffs Harbour Nursing Centre; Coffs Harbour Home Nursing Service
<b>Project funding</b>	\$263,340 incl. GST
<b>Project timeframe</b>	May 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop and test an integrated network approach to triage intake, referral and care planning processes for patients with palliative care needs living in the Coffs Harbour and Bellingen local government areas of NSW.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To support health care providers across the care continuum to provide evidence based palliative care in a coordinated manner.</li> <li>▪ To utilise the weekly multi-disciplinary palliative care planning meeting to develop individualised care plans to improve patient and carer outcomes and to provide general health care providers with palliative care learning opportunities.</li> <li>▪ To support the smooth and appropriate transition of palliative care patients between settings of care, including to develop standardised network transfer protocols.</li> <li>▪ To establish formalised network agreements between project partners to ensure that there are processes in place to promote the efficient and effective use of limited palliative care.</li> <li>▪ To explore the possibility of project partners making a financial contribution so that this initiative if deemed to meet local need can be sustained beyond the life of the funding.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project aimed to use a multidisciplinary approach, i.e. GPs, Clinical Nurse Consultants and Specialists, Residential Aged Care Facility (RACF) staff, community nurses (public and private) to develop care planning, which promotes smooth transitions between care settings.</p>
<b>Project planning and development</b>	<p>The Mid North Coast Division of General Practice (DGP) signed Memoranda of Understanding (MOU) with all project partners regarding their participation in the project.</p> <p>A Critical Reference Group (CRG) was established in June 2006, including representatives of project partners, to provide governance. The CRG met on average quarterly, for the duration of the project.</p> <p>The initial project plan was ambitious, and was considered unrealistic in terms of the time and resources available for the project. Following discussions with the National Evaluation Team (NET) and Department of Health and Ageing (DoHA), a number of refinements were made. The main areas of change included limiting the scope of the project's promotion of common tools and processes, with a resultant focus on standardised palliative care assessment tools and a common language (instead of the proposed clinical and key performance indicators), and the development of a centralised palliative care triage and referral advice system (instead of a centralised intake system). The original objective of escorted transfer of patients between home and hospital was also deleted, primarily due to the occupational health and safety and insurance implications of the proposal.</p> <p>Ethics approval was not required for this project.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project had three main areas of activity, around which a number of resources and processes were developed. These included: multidisciplinary team (MDT) meetings; a palliative care triage and referral service; and education for nurses, general practitioners and allied health professionals.</p> <p>The project funding allowed for the continuation of the coordination of MDT meetings, which had commenced in 2004 with funding under the Mid North Coast Rural Palliative Care Project (RPCP, 2003-6). The MDT meetings were initially held weekly, then fortnightly following a review in May 2008. Participants included relevant health and allied health professionals and service providers, and clients and their families were also invited to participate. The meetings had an action learning approach, which enabled participants to</p>

Project title	NSW-7 – Mid North Coast Integrated Network Palliative Care Project
	<p>engage in learning opportunities about palliative care planning issues. The project collaborated with another Care Planning Project in the region, NSW-6, run by Catholic Healthcare in the organisation of MDT meetings related to its clients.</p> <p>The original plan for the palliative care triage and referral advice service was to have a centralised palliative care intake system for the region. However, following discussions with the NET and DoHA, it was agreed that a more modest approach was more achievable within the constraints and context of the project, resulting in the development of a triage and referral advice service. The service was developed to manage calls, provide advice, and facilitate referrals. Health care providers from general practice, aged, hospital and community care settings were able to contact the project co-ordinator, an experienced palliative care nurse, directly if they required palliative care information or advice.</p> <p>Education was provided to support the delivery of evidence-based palliative care and build primary provider capacity. A significant component of the project, this was delivered through training programs, in-service sessions and workshops, at no cost to participants and largely in collaboration with partner organisations and expert providers. The majority of education was focused on the nursing workforce, and GPs and allied health care providers were invited to MDT workshops. A number of education and training sessions were run in conjunction with the Catholic Healthcare Care Planning project (NSW-6), particularly where there were overlaps in terms of audiences and subject matter (e.g. nurses working in aged care, assessment, pain management and organising MDTs).</p> <p>A Smooth Transition Working Group was established to develop standardised network transfer protocols for palliative care clients in the region, as well as those returning from metropolitan areas following treatment. This aspect of the project aimed to facilitate the smooth transition of palliative care recipients involving no interruption of planned care, including the development of transfer guidelines, and accelerated admission process, provision of escorted transfer, and planned admission and discharge guidelines which included a network approach to manage and place palliative care patients.</p> <p>A number of resources were developed to facilitate the smooth transition of palliative care clients between service settings. One of the main products was a flow chart which outlined the palliative care admission process at the Coffs Harbour Hospital. This was presented as a laminated desktop tool. A resource was developed for palliative care patients in the general community. The palliative care patient card is a two-way communication mechanism, providing basic information for the patient and health care provider. Another aspect of this element of the project was the development of the Yellow Envelope, a readily identifiable folder which contained key information about a client's assessed needs and treatment strategies. The Residential Aged Care Facilities Multidisciplinary Team Meetings Toolkit was also revised as part of this project.</p> <p>The project aimed to build on and enhance existing service networks through its education sessions and newsletter. For example, information about the Commonwealth Respite and Carelink Centre was included in education sessions (8); GP newsletters (circulation 175) and the project's own Palliative Care Projects Newsletter (circulation 500+). In a similar vein, the project was able to assist with the loan of Graseby Syringe Drivers to RACFs in the region. This was particularly important following a decision by the local palliative care service to withdraw this service. Consequently, the Coffs Harbour Nursing Service, a private nursing service which was active on the Critical Reference Group, agreed to loan its syringe driver, better enabling RACFs to care for residents during their terminal phase.</p> <p>Other activities undertaken by the project included:</p> <ul style="list-style-type: none"> <li>▪ Provision of additional funding for an after-hours telephone support service (AHTSS) which was implemented as part of the forerunner for this project, the Rural Palliative Care Project. Funding was provided to support the service for six months. The service provides a 1300 number for palliative care service patients and carers to access advice and support from 5pm to 8am, seven-days per week. It is run out of the Dorrigo Multipurpose Service.</li> <li>▪ Collection and entering of Palliative Care Outcomes Collaboration (PCOC) data from the Coffs Harbour Palliative Care Service.</li> </ul>
<b>Evaluation methods</b>  <i>How was the</i>	<p>The project undertook a number of process evaluation activities, predominantly surveys and questionnaires designed by the project coordinator in conjunction with the NET, to measure stakeholder experiences of the key activities such as MDT meetings, triage and transition.</p>

Project title	NSW-7 – Mid North Coast Integrated Network Palliative Care Project
<i>project evaluated?</i>	<p>The online tool 'Survey Monkey' was used to administer an overall "Project Survey" in December 2008. This tool was used to enable stakeholders to provide feedback on the project, and also acted as a means for dissemination of project information.</p> <p>Specific questionnaires were developed to evaluate the MDT meetings and palliative care patient card. Surveys were also used to evaluate education programs and workshops.</p> <p>Data were collected regarding MDT client numbers and outcomes, as well as provider participation. Similarly, referral patterns and outcomes of the triage and referral advice service were also recorded.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The project appears to have made a significant impact on the systems and processes used to provide palliative care for people in the region. As there is no central register of all palliative care patients in the region, it is difficult to estimate the number of patients who have been affected by the project. It is estimated that a significant number of the aged care residents in the region (total 880 within 13 RACFs) will have benefited or will benefit in the future, either directly or indirectly, from staff involvement in the palliative care education, and in the GP participation in the MDT meetings.</p> <p>Ninety-five MDT meetings were conducted during the period of the project, involving case conferences for 172 patients, including 150 patient reviews. The project final report notes that MDT meetings are now embedded into local practice, with the core group of participants including the palliative care CNC and social worker, CHHC chaplain, link nurses as available, the MDT coordinator and until October 2008 a GP advocate. Membership has been enhanced since October 2008, by routine involvement of a palliative care physician (via teleconference). While patients and their carers were made aware that they were welcome to participate in the MDT meetings, by the end of the project none had done so.</p> <p>Of most interest is the high level of GP participation in the MDT meetings. Over the 30-month period of the project, the participation by patients' own GPs at case conferences increased steadily. There were 215 occasions of involvement by GPs, 128 of which involved the patient's own GP, accounting for 122 EPC items. At the end of the project, patients' own GPs were involved in 92.5% of MDT meetings, with an average 74% over the life of the project. The project used a strategy of GP advocates – those GPs with an interest in palliative care who would chair the MDT meetings, and this is believed to have a significant influence on the broader GP sector, with up to 75% of the region's GP practices participating in the MDT meetings (21 out of 28 practices).</p> <p>The evaluation of the MDT meetings included the distribution of a questionnaire regarding the case conferences. Forty questionnaires were distributed to a range of stakeholders, with a 75% response rate, predominantly from nurses (15 out of 30) and GPs (9). Three out of five stakeholders reported that they felt outcomes had improved for patients and carers as a result of the case conferences (with 50% indicating moderate to great improvement). Physical symptoms and psychosocial issues were felt to have been adequately addressed, however there was a mixed response regarding spiritual issues and advance care planning. Most felt carer issues were adequately discussed.</p> <p>The health and service providers also benefited from the MDT meetings, with a large majority of respondents (86%) indicating they felt more informed about the patient, and were better able to address their needs (73%). Similarly, there was improved communication between providers about patients (76%) and almost all agreed that planning for their patients' future needs had improved (97%).</p> <p>The MDT meetings utilised an action learning approach, which included the sharing of specific skills and knowledge by the provider participants. Consequently, participants reported an increase in knowledge about palliative care and confidence in providing that care, particularly around medication, management of symptoms, disease courses and trajectories, and the efficacy of particular treatments such as radiotherapy.</p> <p>The triage and referral advice component of the project provided 589 episodes of information and/or advice to providers, comprising 148 calls received and 441 made by the project coordinator. Most calls received were from residential aged care services (57), GPs (28), community care providers (25), inpatient and allied health services (18 and 17 respectively). The requests received were mainly for triage and referral matters, with almost half the calls resulting in the provision of information and support, and a similar number again requiring referral to the palliative care service, MDT or medical review. While</p>



Project title	NSW-7 – Mid North Coast Integrated Network Palliative Care Project
	<p>the overall number of calls received by the service was not high (average of six per month during November 2006 to December 2008), it is likely that these would otherwise have fallen to the local specialist palliative care team, in particular the clinical nurse consultant, to respond. In that sense, the triage and referral advice service enabled those clinicians to remain focused on their clinical roles, and not be diverted by calls for information and referral.</p> <p>The education program was a significant component of this project, with 73 sessions being delivered, reaching 785 participants. Much of the education was provided in collaboration with the DoHA funded Spiritual Care (Round 2 LPCGP) and NSW-6 Catholic Healthcare (Round 3 LPCGP) projects, and also involving the palliative care CNC to ensure quality and relevant clinical education.</p> <p>A core element of the training was a 16-hour palliative care link nurse education program, targeting Registered Nurses, many of whom worked in aged care. The training was delivered in sessions of four hours each, over a four week period, involving 37 participants initially, with 33 completing the full course. These 'champions' of palliative care built on those previously trained under the previous RPCP initiative, bringing to a total of 64 'champions' in the region, 57 of whom were believed to be still involved in different care settings across the region by the time the project finished. The successive projects have resulted in link nurses in the local Coffs Harbour Hospital Campus emergency department, medical ward and Aboriginal and generalist community nursing. Additional link nurses were educated for community nursing services (private and public), the private hospital and RACF. Sixteen of the link nurses also attended a one-day observational placement with the Palliative Care Service and attended an MDT meeting, in addition to the training. A similar training program was also conducted for Enrolled Nurses and Assistants in Nursing, again of 16-hours duration over a four week period, resulting in 22 completing the training (out of 24 who started).</p> <p>The project also conducted a "Pain Campaign", reaching 15 RNs and ENs from aged care, community and hospital settings, to act as "pain campaigners". The final report notes that the impact of the training has led to one RACF, which only has an RN 'on call' after business hours, now having staff with the confidence and skills to regularly use Graseby Syringe Drivers for pain management in the terminal phase care of residents.</p> <p>Education was also provided on Palliative Care Assessments. Seventeen sessions were provided, reaching 202 participants, to support the use of evidence-based tools. The Coffs Harbour Palliative Care Service became a contributor to the Palliative Care Outcomes Collaboration (PCOC) in 2006, and the training supported the PCOC data collection. Associated with this, a palliative care assessment form was developed and trialled in the medical ward of the hospital. A chart audit revealed that the average of pain scores documented almost doubled, from 39% to 66% as a result.</p> <p>In addition to the formal training provided, the MDT meetings (including in-service programs, workshops and action learning) has played an important role in improving the palliative care competencies and confidence of primary care providers. The project final report notes that anecdotally, this has resulted in an increase in palliative care delivery and case management by primary care services, reducing the burden on the specialist palliative care service, supporting a population base approach.</p> <p>Approximately 130 palliative care admission flowcharts were distributed widely to GPs, Baringa Private Hospital and Coffs Harbour Nursing Service, RACFs and NCAHS including wards, palliative care services and community nurses. The evaluation of this aspect of the project showed that 61% of respondents had seen the flowchart, with almost all of these (95%) indicating that it had clarified the patient journey process. The 'yellow envelope' proved to be an effective tool for communication about aged care residents on transfer to and from local hospitals.</p> <p>A total of 390 patient cards were distributed across the region. Feedback from users indicate that the card had been somewhat successful, but not overwhelmingly, with 57% survey respondents indicating it had assisted in informing patients and carers about treatment aspects; and half of respondents indicating that it assisted health staff to readily identify palliative patients, and improved information sharing for health providers.</p>

Project title	NSW-7 – Mid North Coast Integrated Network Palliative Care Project
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>Consideration of the sustainability of project outcomes was integral to the overall project planning from the outset, and included in the project plan. In the exit interview, the project officer noted the importance of having evidence-based outcomes and good partnerships, and of building on the work of the RPCP which had gone before.</p> <p>By the end of the project, agreement had been reached by the project partners (Mid North Coast Division of General Practice, Coffs Harbour Nursing Service, Baringa Private Hospital and North Coast Area Health Service) to collectively fund a Palliative Care MDT Coordinator, one day a week, for 12 months. The project final report notes that MDT meetings are now embedded into local practice, with the core group of participants including the palliative care CNC and social worker, CHHC chaplain, link nurses as available, the MDT coordinator and a GP advocate.</p> <p>The triage and referral advice function has not been sustained, as the MDT coordinator role includes regular contact with providers and health services.</p> <p>The regional Palliative Care Advisory Group (PAG), which includes partners from a range of stakeholders across the region, has committed to develop a collaborative palliative care education plan, to be available to multidisciplinary providers across care settings.</p>
<p><b>Recommendations</b></p>	<p>The recommendations provided by the project regarding the project processes are listed as follows:</p> <ol style="list-style-type: none"> <li>1. The region requires access to a palliative care physician who can provide face-to-face consultations. Limited access by phone and the reduction to currently non-existent palliative care physician outreach visits under MSOAP (Medical Specialist Outreach Assistance Program) has negatively impacted on the management of complex palliative care patient issues and availability of appropriate education and support, especially for medical and specialist palliative care staff.</li> <li>2. MDT coordination requires ongoing funding. Partner contributions will enable continued coordination of the MDT meetings until March 2010, but beyond this ongoing funding is required to sustain and further develop this successful and essential component of the project.</li> </ol>

<b>Project title</b>	<b>NSW-8 – Rural and Remote Palliative Care Planning Model</b>
<b>Keywords</b>	Local, regional, remote, community care, primary care
<b>Host organisation</b>	Intereach Inc. NSW (formerly Regional Social Development Group)
<b>Partner organisations</b>	Riverina Division of General Practice and Primary Health Care (RDGP)
<b>Project funding</b>	\$246,961.00 incl. GST
<b>Project timeframe</b>	3 May 2006 to 31 January 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop an evidence-based model of care planning for people requiring palliative care in rural and remote communities.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Using an action research approach, trial a model of flexible and responsive care planning which evaluates processes, assessment tools, communication pathways, information provision and carer support for each patient, their families and care giver/s.</li> <li>▪ Improve collaboration between services involved in providing care.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project aimed to design a model of intake, assessment, case management and referral that provided time efficient integration into full range of services for palliative clients and their carers in regional NSW. The outcome was a flexible model of service delivery that sought to meet the needs of each palliative patient in their local community, and enhanced collaboration between service providers.</p>
<b>Project planning and development</b>	<p>Ethics approval for the project was granted by the Ethics Sub-Committee of the Intereach Board. A stipulation of approval was the provision of the names of counselling and psychology services across the region to be made available for patients, their families or care giver/s that participated in the evaluation process.</p> <p>The NSW-8 Rural and Remote Palliative Care Planning Model project was a close companion to the NSW-9 Rural Community Palliative Care Packages and Education project, auspiced by the Riverina Division of General Practice and Primary Health Care (RDGP), also based in Wagga Wagga, NSW. The focus of this project (NSW-8) was to research a model of flexible and responsive packages of care for people with palliative care needs, and to implement and evaluate that model. An action research model was adopted, and the project officer was the case manager for those palliative care clients referred to the RDGP project (NSW-9). The close relationship between the two projects was cemented with a Memoranda of Understanding (MOU) which was signed by the RDGP and the senior management of the Riverina Murray Commonwealth Respite and Carelink Service (CRCC), which is auspiced by Intereach. The MOU outlined the relationship between the two projects, which involved the CRCC providing case management and flexible brokerage of services for RDGP referrals of people who required palliative care, their carers and family members.</p> <p>Due to anticipated duplication of key stakeholders and similarities between the two projects, there was a common steering committee for the two projects, which was chaired by the chief executive of the RDGP (NSW-9) project. Additional members were recruited to participate on a number of working parties which considered the implementation of the case management model, referral and intake process, assessment forms and consent, patient held notes/home notes, communication protocols and pathways, and role delineation.</p> <p>Project and evaluation plans were developed in conjunction with key stakeholders.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The close parallels and working relationship between this project and the NSW-9 project conducted by the RDGP has made the delineation between activities of the projects difficult to discern. The key aspects of this project, however, focussed on the research and development of a model of care, which was tested using the referrals provided through the RDGP (NSW-9) project. The project commenced with a literature review to examine patient experiences and service provision issues in palliative care, specific to rural communities, best practice strategies and interventions. Based on this information, the project developed a flexible, specialist case management and care planning model that incorporated a range of best practice tools and interventions. The PallCare Packages, as they became known, operated on a similar principle as the ComPacks services provided by Community Options in NSW, and provided the following range of strategies or interventions:</p>



Project title	NSW-8 – Rural and Remote Palliative Care Planning Model
	<p>Specialist social work case management was provided to patients and their families and care giver/s. Initially, this additional service was not well received by the existing community nurses and specialist palliative care nurses. The final report notes, however, that as the benefits of the role became clearer there was greater acceptance and collaboration by the local health services.</p> <p>Common intake, assessment and consent processes were developed that incorporate the unit of care being the patient, the family and care giver/s. The project utilised an action research and quality improvement approach to identify the elements of existing processes and forms that were appropriate for a range of service providers and meet both the patient and care giver/s needs. As a result, a common assessment form, as well as an appropriate referral and care plan update/feedback form was developed.</p> <p>Flexible brokerage of equipment and services was provided according to patient and carer need. Two tiers were developed. The low care package offered over toilet support, four wheel walker frame with seat, shower chair with supports, bed stick and lambswool rugs. The high care package contained the addition of an electric bed, wooltech overlay or pressure air mattress, bedside commode, and incontinence protection products. A Carers Pack was also developed, comprised of a range of practical resources such as samples of lip balm, hand cream, body and alcohol washes and incontinence products, as well as information and support resources such as a copy of the Red Cross' Carers Book, a relaxation CD and stress ball.</p> <p>Development of partnerships between key service providers and stakeholders in each community was considered critical, however the process of building trust and rapport proved a considerable challenge for the project officer. The final report notes that effective communication strategies are essential for clear understanding and collaboration from key stakeholders, and requires an investment of time and effort to achieve.</p> <p>Multidisciplinary care planning and case management was provided with the aim of delivering the best possible outcomes for patients, their families and carer giver/s across the rural communities. The final report notes, however, that this proved difficult to achieve due in part to the poor communication processes across most of the rural communities and poor buy-in from project partners, in particular the Area Health Service, resulting in poor collaboration and ineffective partnerships.</p> <p>Continuity of care and seamless referral processes was addressed through the appointment of a case manager (the project officer) who was the point of contact for referrals to the project with the intention to liaise with families, local health and community care providers. The case manager developed communication pathways in each community, participated in discussions with individual patients, their families and carers and provided this information to the members of their local team, and participated in 'continuum of care' meetings in some communities.</p> <p>Psychosocial support for the patient, carer and family, including grief and loss / bereavement information and support, was also provided by the case manager. The discussions with patients, families and carers centred on personal goals and hopes for their future, and how their care reflected this. The final report notes that many carers indicated that they greatly appreciated the support provided and wished that it had been more readily available whilst the patient had been alive and for longer periods after.</p> <p>Home notes were also trialled in a number of communities to improve communication between service providers, an issue particularly problematic in geographically isolated areas, where service providers rarely physically coincided with each other. The final report notes that while this was not well utilised by some community nurses and Area Health staff, many patients found them useful for their own information and communication with their GP and the case manager.</p> <p>Carer support and information was made available 24-hours, seven days a week through the CRCC phone support. This built on the triage, intake and referral service delivered by the CRCC, which was developed to underpin the case management service. In some instances the CRCC was able to 'top up' regular HACC services so that an appropriate amount of care was provided to the patient in order to provide respite for the carer. Carers referred to the CRCC were able to receive immediate, brokered personal care and domestic services for short term assistance until the local community service provider was able to</p>

Project title	NSW-8 – Rural and Remote Palliative Care Planning Model
	<p>conduct their assessment and provide an ongoing service.</p> <p>A number of professional support, education and supervision activities were conducted as part of the project. The final report notes that several education sessions were offered to community nurses and practice nurses across the region through the RDGP education program. However, participation by Area Health Service staff was limited, as they needed to attend in their own time and at their own cost. Carer education workshops were also conducted in Cootamundra, Ungarie, and West Wyalong and included many current and bereaved carers, volunteers from CanAssist and palliative care volunteers and Home Care Service providers. Palliative Care Australia Certificate III and IV courses were delivered to community service providers in the region, and education for nurses was provided in Albury. Other online Palliative Care education was sourced, as well as a comprehensive resource library developed for use by RDGP staff, the case manager, CRCC staff and social work students across the region. Two social work students from the La Trobe University (Wagga Wagga) had placements with the project, conducting research into after-hours support required and provided for palliative patients.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>An initial baseline survey was conducted to measure awareness, satisfaction, level of support, and priorities for care planning. The survey findings provided the key aspects of an effective model of care planning relevant for rural and remote communities. Following the completion of the trial of the model, bereaved carers' perspectives were sought through a series of formal semi-structured interviews and focus groups at six weeks and three months post death of the patient. Service providers' perspectives were sought through an on-line questionnaire, as well as interviews, looking at referral and assessment pathways, communication protocols and collaboration. These evaluation strategies were incorporated into the quality improvement process and PDSA cycles being implemented throughout the life of the project.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>Due to the close relationship between this project and that of the RDGP (NSW-9), the distinct impacts and outcomes of each project are difficult to discern. The key focus of this project was to research a model of flexible and responsive packages of care for people with palliative care needs, and to implement and evaluate that model. An action research model was adopted, and the project officer was the case manager for those palliative care clients referred to the RDGP project.</p> <p>In total, the project/s delivered flexible and individualised packages of care and support to 150 patients/clients across the rural and remote communities of the Riverina, and a further 200 primary care giver/s were provided with supportive care and access to services. Approximately 80% of all carers referred to the project were provided with a Carers Pack, which included products and resources tailored to their particular needs. The final report noted that the Carers Pack proved to be positively commented on by carers. The model was replicated in the NSW-5 project, tailored to local circumstances, and received similar positive evaluation findings.</p> <p>In addition to the case management, brokerage and support provided to patients, families and care giver/s, the project provided education to a range of stakeholders. The final report notes that evaluations of the nurse education and from the community service providers indicated that ongoing education is considered essential to their professional development and provision of integrated palliative care. These health professionals identified a number of priority education topics, including psychosocial support, advance care planning, 'delivering bad news', as well as symptom management and pain control. The report also notes that a small number of community and carer education sessions were conducted and were also very successful; however time and funding constraints prevented this being provided to other rural and remote communities.</p> <p>The final report indicates that PallCare Packages has elements that all stakeholders, at all levels, agreed made a difference for patients, their families and care giver/s. While the report did not include detailed evaluation findings, it notes that there were a number of key success factors, including:</p> <p>Earlier referral to palliative care services of patients, their families and carers was achieved due to enhanced relationships between the Cancer Care coordinator, oncology social worker and the regional manager for the Home and Community Care Program (HACC). In addition, communication between the cancer care coordinators and local service providers was improved.</p> <p>The triage facility resulted in palliative care clients being able to be seen by practice nurses</p>

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	<p>sooner, or early appointments were made to the general practitioner if necessary.</p> <p>Care plans developed by the case manager facilitated improved communication between all members of the care team. Furthermore, this assisted general practitioners to claim the relevant Medicare items such as Enhanced Primary Care for their contribution to the care plan, GP Management Plans and Team Care Arrangements.</p> <p>Greater recognition amongst health and support services of the role of carers in supporting the person requiring palliative care. The final report notes that initiatives developed as part of the model, such as the Carer Pack, access to CCRC after hours support, and grief and loss support, were greatly appreciated. Several carers (4%) were identified early as being at risk of complicated grief and seen by their general practitioner under the GP Mental Health program and subsequently referred to a psychologist. GPs indicated that they also felt the project was beneficial, with patients, their families and carers reporting positive outcomes.</p> <p>The involvement of the Commonwealth Respite and Carelink Centre as the key triage, assessment and referral mechanism resulted in heightened awareness of its services within rural communities.</p> <p>Clarification of a specialised social work case management model, based upon research and trials. The report notes the evaluations indicated it was an effective element in the provision of holistic palliative care to clients in rural and remote communities. The project officer was also involved in the activities of the NSW Social Workers palliative care special interest group regarding the development of key performance indicators (KPIs) for psychosocial interventions, and theoretical underpinnings for social work practice in palliative care.</p> <p>Development of linkages between services and the local rural university. Two social work placements from La Trobe University (Wagga Wagga) assisted with research for the project, and the report suggests these have provided the opportunity for ongoing social work and nursing student placements in palliative care.</p> <p>Conceptualisation of the model as a 'package of care' assisted in it being accepted by other clinical providers involved in the provision of palliative care. The report notes that coining the term 'PallCare Packages' took away the misconception there was duplication of roles with the case manager and established clinicians.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The two projects have developed, implemented and evaluated a model of care which targets palliative care clients in rural and remote regions. In 2008, the RDGP was successful in securing additional funding from the Australian General Practice Network to continue to implement the PallCare Packages across the Riverina, NSW. The common assessment form, as well as an appropriate referral and care plan update/feedback form developed by the projects, will continue to be used as part of this new initiative. In addition, the project officer for this project will work closely with the new project to ensure learnings from the overall project are incorporated into the new project.</p> <p>The education and training provided by the project is also expected to have an ongoing impact within the region, and consideration is being given to the project officer developing the auspicing body to become a registered training organisation to continue to make palliative care education available across the region.</p> <p>The model has the capacity to be embedded more broadly, through its proximity conceptually to the ComPacks services delivered by Community Options in NSW, and the involvement of the CCRC. Prior to the project's completion, discussions had occurred between the project officer and representatives of the Carers Support Section in the NSW office of the Department of Health and Ageing, to appraise them of the model and its outcomes, and the potential for enhancing CCRC more broadly with skills and capacity in supporting palliative care clients and carers.</p>
<p><b>Recommendations</b></p>	<p>The recommendations provided by the project regarding the project processes are listed as follows:</p> <p>At the organisational level:</p> <ol style="list-style-type: none"> <li>1. Implementation of PallCare Packages across all rural regions, however it is suggested that initially three broad geographical regions would be extensively trialled.</li> </ol>

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	<ol style="list-style-type: none"> <li>2. That a peak body be funded as an external organisation to provide governance and management of PallCare Packages and monitor the implementation of the model across rural regions of Australia. This model is similar to the establishment of ComPacks.</li> <li>3. That Rural Palliative Care Collaborative Networks be established with the peak body as lead agency, to facilitate cross sectoral communication, professional development and planning. This would ensure that regional and rural palliative care programs were integrated across all clinical levels of care (specialist and primary health care) and the community service sector.</li> <li>4. That this peak body collaborates with the Palliative Care Outcomes Collaboration (PCOC) in the dissemination and collection of palliative care data and the development of and education in the use of community based data tools.</li> <li>5. That the Palliative Care Social Work Interest Groups and Palliative Care Australia develop Social Work standards for palliative care similar to the National Association of Social Workers in America. This would allow for the development of a specialised social work role, underpinned by specialised standards of practice in providing psychosocial care in palliative care and end of life care.</li> <li>6. That the Medicare Allied Health initiatives be broadened to include a category for rebatable items for specialist social workers and psychologists providing palliative psychosocial care and end of life care.</li> </ol> <p>At the provider level:</p> <ol style="list-style-type: none"> <li>7. That the PallCare Packages, through effective governance by the peak body, develop effective collaboration with service providers in each local community, and identify gaps in service delivery to patients, their families and care givers requiring palliative care.</li> <li>8. That a phenomenological rural research project be funded to elicit the lived experience of patients, their family members and care giver's experience of the transition from curative care to palliative care. This will provide valuable insights into the specific psychosocial supports and interventions that are considered useful, identify language barriers and communication strategies to enhance and improve these people's experience and understanding of palliative care and end of life care.</li> <li>9. That all patients with a terminal illness be identified early in their disease trajectory and that a palliative approach to care planning and supports be available that considers the psychosocial aspects of living with a terminal illness.</li> <li>10. That consistency be developed in defining a person requiring or referred to palliative care across all chronic disease trajectories, and that both the clinical health care team and community service providers share a common language. This will greatly reduce confusion for patients, their families and care givers, and provide consistency and equity of access to high quality palliative care across all rural and remote regions.</li> </ol>

<b>Project title</b>	<b>NSW-9 – Rural Community Palliative Care Packages and Education</b>
<b>Keywords</b>	Local, regional, remote, community care, primary care
<b>Host organisation</b>	Riverina Division of General Practice and Primary Health (RDGP&PH) Ltd
<b>Partner organisations</b>	Greater Southern Area Health Service (GSAHS) and Intereach Inc (formerly the Riverina Social Development Group)
<b>Project funding</b>	\$275, 000 inc. GST
<b>Project timeframe</b>	May 2006 to May 2008
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a palliative care package model for rural and Aboriginal target populations supported by an education strategy, under a two-phased approach.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Improve collaboration between services to improve effectiveness and maximise the use of resources.</li> <li>▪ Develop an effective population based approach to assessment and care planning for rural and Aboriginal target populations incorporating community based care, case management and collaboration between service agencies.</li> <li>▪ Develop a flexible model of community based palliative care packages. Trial case management approach to service coordination to improve service effectiveness.</li> <li>▪ Apply the principles of Quality Management over the two years of the project.</li> <li>▪ Develop education and information strategies for health professionals to access palliative care training and inform primary health care professionals. Develop population based information packs to support patients, primary carers and family members within the target populations.</li> <li>▪ Document and report on the model so that it might be implemented on a wider scale.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project sought to improve access to palliative care for people in rural communities, provide a holistic approach through the “palliative care package”, improve coordination and collaboration in care provision and enhance staff skills within the palliative care context. The project was supported by an education and community awareness strategy to inform primary health care professionals and agencies, patients and families about palliative care options during the time with life limiting illness.</p>
<b>Project planning and development</b>	<p>The project management were advised by the Director of Clinical Governance Unit at the Greater Southern Area Health Service (GSAHS) that ethics approval was not required.</p> <p>The NSW-9 Rural Community Palliative Care Packages and Education worked in close partnership with the NSW-8 Rural and Remote Palliative Care Planning Model, which was auspiced by Intereach Inc, also based in Wagga Wagga, NSW. A Memorandum of Understanding was signed by the two organisations, which outlined the relationship between the projects. The Riverina Murray Commonwealth Respite and Carelink Centre (CRCC) (auspiced by Intereach) provided case management and flexible brokerage of services for people requiring palliative care who were referred to the NSW-9 RDGP&amp;PH project, their carers and family members. Memoranda were also signed with the GSAHS and the Riverina Medical and Dental Aboriginal Corporation (RM&amp;DAC).</p> <p>A steering committee was established to oversee both the NSW-8 and NSW-9 projects, and included senior representation of a broad range of stakeholder groups, including primary, community and aged care services, indigenous services; consumers, and the Area Health Service. The committee was chaired by the RDGP&amp;PH Chief Executive Officer.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project sought to develop and implement a “palliative care package” to patients and their carers across the Riverina area of NSW, as well as education and communication strategies to inform the target population, health care professionals and service providers of its focus. An action research methodology was utilised - Plan Do Study Act (PDSA) cycles – to enable learnings and outcomes to be incorporated into the development of the project as it progressed.</p> <p>A case management multidisciplinary model was developed with the aim of enhancing partnerships between service providers that traditionally had not worked together in palliative care. The PallCare Packages, as they became known, included the following components:</p>



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	<p>Case Management: The case management model used in this project focused on providing support to both the care recipient (patient) and the carer, utilising a strengths based, family centred, solution focused approach. The case management was contracted to the partner organisation Intereach, and was undertaken by the social worker employed as the project officer for the NSW-8 Care Planning project.</p> <p>Multidisciplinary case coordination: Multidisciplinary teams (MDTs) were established to coordinate care for clients in most cases, to avoid duplication or confusion around role delineations which had arisen at the start of the project. The case manager drew together the team, which generally included the client's general practitioner, community nurse and/or primary health care nurse, community care provider and carer/s, and others as required to meet the context and needs of the client. Multidisciplinary care plans were developed, utilising the Medicare MBS Multidisciplinary Care Planning Form, which allowed the GP to contribute to the care plan and claim on the Medicare items.</p> <p>Carer information and support: The project supported carers in a number of practical ways, as well as through the provision of information and resources. The key aspect to this was the use of the CCRC as the main referral and entry point for the case management service. This enabled access to the 24 hour seven day per week carer support and emergency respite offered under that Commonwealth program. Carers also had access to CareLink that provided them with well resourced information regarding services and support across all regions, as well as eligibility criteria and assessments.</p> <p>A number of pamphlets and resources were produced, including the "Caring at Home" booklet, based on the South Australian book and tailored to the local context. The booklet included relevant service and support information to clients and their families and carers and discussed the issues that may arise when a person has a life limiting illness.</p> <p>Patient held records: These were termed 'home notes' during the project, and were developed in consultation with the Division, GSAHS and Intereach. The idea for home notes arose from recommendations of previous projects funded under the Local Palliative Care Grants Program, the GAPS project and Adelaide Hills Rural Palliative Care project.</p> <p>Flexible brokerage of equipment and services: Included in the funding for this project was the capacity to purchase palliative care equipment. Following consideration by the steering committee, it was agreed that it would be more pragmatic to hire the equipment, as it allowed patients and carers to have individual packages developed that address their particular needs, circumstances, and stages of illness.</p> <p>Coordination of carer respite and home and domestic assistance and referral to support services: This element of the project further enabled a tailoring of services to meet the client and their carer/s' needs. Funding was available for brokerage of additional domestic assistance and personal care, if it was not possible to be provided by the relevant Home and Community Care (HACC) or community nursing service. In addition, funding was provided to purchase of nutritional supplements where these were recommended by dietitians and speech pathologists. In addition, funding was available for additional nursing support after hours that may not otherwise have been made available through the usual service channels.</p> <p>Referral to support services: By using a case management approach, which included a holistic approach to care, the project was able to link clients in to a range of services which they may not otherwise been aware of. The use of the CCRC was also a deliberate mechanism to ensure that carers received access to information about and referral to appropriate support services as required.</p> <p>A number of education and training opportunities were provided to support the provision of palliative care across the region: The majority of these were targeted at clinicians and service providers working in primary, acute and community care contexts. Training was also provided for volunteers in two localities, which aimed to assist them support terminally ill patients and carers at home.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The main objectives of evaluation were to:</p> <ul style="list-style-type: none"> <li>▪ Determine whether true partnerships and collaboration between stakeholder organisations were achieved and involved key primary health care services including hospitals, GPs, specialist palliative care, respite care, Aboriginal medical services, residential aged care and community based aged care;</li> <li>▪ Determine whether the education and community awareness strategy informed primary</li> </ul>



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	<p>health care professionals and agencies, patients and families about palliative care options during the time with life limiting illness;</p> <ul style="list-style-type: none"> <li>▪ Determine if the flexible model of care packages and brokerage of equipment and services actually assisted patients and carers and facilitated the movement of patients whose needs move between the three levels of care; primary, intermediate, and during the time with life limiting illness.</li> </ul> <p>A variety of evaluation strategies were undertaken with patients, carers, GPs, community nurses, primary health care nurses and the steering committee. Evaluating the impact of the project on clients and carers/family members occurred using a mix of surveys, as well as a limited number of file audits. The education and training activities were evaluated using surveys distributed at the conclusion of each session.</p> <p>The final report notes that the project implemented an action research methodology which allowed review of process and impact evaluation as the project developed. As such, many of the procedures, resources and 'way of doing things' changed from inception to end of project and reflect the application of quality review principles.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The project was funded to provide palliative care packages to a maximum of 48 patients and their carers, however the total number supported was almost double this, with 71 clients and 156 carers receiving support. The increase was able to be met mainly due to the ability of the contracted agencies (Intereach and CCRC) to absorb some brokerage through their existing programs.</p> <p>Despite being identified as primary target groups for the project in the initial project documentation, only three Aboriginal clients and families were supported by the palliative care packages. The final report notes that the Aboriginal population proved a very difficult community to engage with through the project, even though there were representatives of the RM&amp;DAC and Wirdajuri Home Care on the steering committee.</p> <p>Similarly, aged care facilities were also identified as a key target group for the project. The final report notes that only four facilities were supported with case management and information during the project, the reason being that palliative care is seen as part of their core business. Palliative care discussions were held regularly at the Aged Care Collaborative Committee meeting facilitated bi-monthly by the Division project officer, and each facility was issued with a copy of the <i>Guidelines for a Palliative Approach in Residential Aged Care Facilities</i>.</p> <p>The final report notes that overall, clients referred to and admitted to the palliative care package program were identified earlier in their palliative care journey and were provided with equipment and a care package including case management, which utilised social work interventions around end of life care, psychosocial support and counselling</p> <p>An audit of files and patient held notes revealed that advance care planning (ACP) was mentioned regularly, mostly in reference to discussions around the topic. However, this did not translate into the development of formal ACPs, with only one completed and one partially completed. The audit also revealed some variation amongst the type of information recorded in regards to patient medication, but does not specify the details or implications.</p> <p>The evaluations from carers participating in the project indicated overall satisfaction with both the case management and flexible brokerage. Many could identify aspects of case management interventions such as end of life pathways, care planning, counselling, and bereavement care and indicated that these were appreciated and valued in their caring role.</p> <p>The project received mixed response from services providers. Although key stakeholders were represented on the steering committee, this did not result in translation throughout their wider organisations. This was especially the case with the GSAHS, which was quite resistant to the project at the local level and did not readily participate in the multidisciplinary case management and care planning activities, or communication mechanisms such as the home notes.</p> <p>Even though the program had been running for two years, community nurses who participated in the evaluation focus groups could not identify, without prompting, the main components of the program. When prompted, however, they prioritised equipment and case management as the most important components of the palliative care packages. They acknowledged the benefits of the brokerage as it allowed flexibility in managing clients' needs and provided access to services which were otherwise unavailable.</p>

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	<p>Despite having signed an MOU and being a member of the steering committee, the GSAHS did not appear to engage well with the project. The final report speculates that this was because those involved in these activities did not have direct line of influence or responsibility with the clinicians providing the services to the individuals receiving the palliative care packages. Consequently, there was limited participation in the multidisciplinary aspects and communication strategies of the project.</p> <p>The major outcome of this project was the articulation of a model of care for community dwelling clients who require palliative care. The PallCare Packages model (as it became known) include the following elements:</p> <p>1. Case Management: The evaluation indicates that the case management role provided a valuable adjunct to palliative care in the rural communities, and enhanced communication between clinicians and providers involved in providing care for an individual with palliative needs and their carers. Carers ranked the case management aspect as the most important component of the entire palliative care package. However, some community nurses and carers indicated that there was some confusion in relation to roles and responsibilities of the case manager, and found terminology confusing in some instances.</p> <p>An audit of the project case management files established the most commonly required support supplied by the project was the personal work and end of life care discussions. Equipment was also important, with 58% of clients requiring items such as electric beds, mattresses, walking sticks, bed sticks, sheepskins, toilet commodes, wheel chairs and incontinent aids. Respite, domestic assistance and personal care services were required by 40% of the clients.</p> <p>2. Multidisciplinary case coordination: A fundamental aspect of the case management role is the development of care plans which incorporate the numerous clinical and service provision supports required by the client and their carer. However, participation in the process of developing the plan, the MDT meetings, was impacted on due to a number of factors, primarily related to distance. The traditional MDT model utilises scheduled meeting times in a common location, however this was not always possible when staff and services covered a wide geographic region such as in the Riverina. Similarly, palliative care clients and carers also found it difficult to attend. Consequently, a communication protocol involving email and telephone follow-up was developed to facilitate improved engagement and communication exchange between the different stakeholders.</p> <p>The care plans developed were forwarded on to the relevant providers and clinicians involved in the care of the palliative client. Initially, there was limited feedback to the case manager, however engagement improved when personal contact was made and individual discussions held regarding individual client care plans.</p> <p>Overall, there was a wide range of disciplines involved in the care planning for clients and carers of this project. The audit of case files and home notes indicate that this involved representatives of the following services: community nursing, occupational therapy, physiotherapy, Aged Care Assessment Team, dietician, speech pathology, general practitioner and clinical nurse consultant, as well as family member and/or carer and the case manager.</p> <p>3. Carer information and support: Evaluations from carers and community nurses indicated this information and support was a key factor in empowering the carers in their caring role. In particular, the report notes that carers commented on the 24 hour seven day per week access, saying that this 'made them feel well supported'.</p> <p>The types of support provided to the carers was evidenced in the audit of home notes, and included: encouragement of inclusion of the carer in decision making; emotional family support; strategies for care suggested; discussion of future care/advanced directive; carer respite; support on physical aspects of caring; bereavement support; carer strain support; and provision of information.</p> <p>4. Patient home records: Initially all clients and carers were provided with the patient home record, or home notes, as they became known. However, the engagement by other service providers and clinical staff</p>

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	<p>such as community nurses and general practitioners was relatively low, with only 10% of home notes having entries by these groups. The final report suggests that this reflected difficulties within the GSAHS in particular, which impacted on information and education being disseminated to the local clinicians and nurses in the rural communities.</p> <p>A further complication was the introduction by the GSAHS of its own personal home record half way through the project, which incorporated many elements of the project’s home notes. For example, each version included pain charts. Interestingly, the audit of files and home notes found that the pain charts contained within the GSAHS personal home records were all completed, whereas none were completed in the project’s home notes. The report surmises that this could be attributed to the lack of education, training and support provided by GSAHS early in the project implementation phase around the use of home notes.</p> <p>5. Flexible brokerage of equipment and services: The hiring of equipment proved to be a very cost efficient and effective service for palliative care clients. This was the most commonly required support with 58% of cases referred to the program requiring equipment such as electric beds, mattresses, walking sticks, bed sticks, sheepskins, toilet commodes, wheel chairs and incontinent aids. The decision by the steering committee to hire, rather than purchase equipment outright, was validated by the ability of the contracted medical equipment provider to provide the ‘packages’ of equipment at reasonable rates. The provider also coordinated delivery and pick up of the equipment in all rural communities across the project area within a 24-48 hour time frame.</p> <p>Brokerage of respite, domestic assistance and personal care was also provided to approximately a third of all clients. The final report notes that evaluations from carers indicated that the brokered services enabled them to provide the care they desired in the place of their choosing for as long as possible.</p> <p>6. Coordination of carer respite; home and domestic assistance; additional nursing support after hours; and referral to support services: In addition to the brokerage of services, referral to and coordination of services was a central part of the case management role. The final report notes that carer stress and uncertainty regarding care were the most frequently reasons for requests of assistance. Emergency care plans were also developed with many clients and carers, and in the majority of cases these were also communicated to the clinical teams.</p> <p>The project also facilitated the purchasing of additional nursing support after hours; however evaluations suggest conflicting views as to the adequacy of this support. Community nurses and primary health care nurses indicated this was still not adequate throughout the project timeframe. The final report includes a comment from a community nurse in a remote location, which concludes with the view that limited resources and appropriately skilled staff available in rural locations makes it difficult to ensure access to 24-hour support.</p> <p>Carers, however, had different perspectives, with the final report including positive feedback about the access and support provided by the CCRC and case manager in particular after hours. One carer is quoted as saying, “I used the service at the CCRC and I rang the case manager a lot. This was particularly useful on the night that my husband died.”</p> <p>A number of education and training opportunities were provided and resources developed to underpin the PallCare Packages model. The project officer for the RDGP&amp;PH conducted 65 group and individual presentations throughout the Riverina region during the project, targeting general practices, aged care providers, community health and community nurses. Allied health professionals and community groups such as the Cancer Assistance Society and the Country Women’s Association also received presentations and resources regarding the project. The final report notes that this was very positively received, and a number of groups requested additional training to be provided.</p> <p>Formal training programs were also sourced and their delivery facilitated and promoted to the broader clinical and service network in the region. Examples include working with the Wagga Wagga TAFE to include palliative care issues in the training provided for Home and Community Care (HACC) services, identifying Certificate IV competency training for primary care providers, and the promotion of Certificates III and IV in Palliative Care courses offered by the Albury Mercy Hospital, a registered training organisation.</p>

Project title	NSW-9 – Rural Community Palliative Care Packages and Education
	<p>Opportunities to participate in the Program of Experience in Palliative Care (PEPA) were also facilitated; however these were limited by the lack of appropriate speakers. However, one rural general practitioner did attend a two-week training program at a hospice as part of the PEPA initiative.</p> <p>The project also facilitated education opportunities for health professionals working in the community, which was provided by a visiting palliative care specialist.</p> <p>A number of resources were produced as part of the project. Information Packages were developed and provided to each of the 71 patients and their carers, consisting of:</p> <ul style="list-style-type: none"> <li>• Home notes</li> <li>• Carer respite and support resources, including CareLink</li> <li>• Centrelink payments</li> <li>• Supported travel information (Isolated Patient Travel Assistance Scheme - IPTAS)</li> <li>• Palliative Care brochure “What to do, What to ask”</li> <li>• Information on the dying process</li> <li>• Bereavement information</li> </ul> <p>In addition, 2500 Advance Care Directive proformas were developed, printed and distributed broadly across the region, including to twenty one residential aged care facilities.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>Consideration of the sustainability of the palliative care packages model was factored into the project planning and steering committee deliberations from the outset. The final report notes that this has been successful, and is evident by the receipt of additional funding from the Australian General Practice Network to continue the delivery of Rural Community Palliative Care Packages project for another two years.</p> <p>The partnership with the CCRC was a critical element in facilitating sustainability. The project was able to provide support to twice the expected number of clients and carers due to the ability of the CCRC and Intereach to absorb some brokerage through their existing programs. Involvement in the project has also led to the employment within the CCRC of a dedicated palliative care case worker. This was particularly important for those clients and carers who required ongoing support beyond the life of the project, where they meet CCRC eligibility criteria.</p> <p>The final report notes that palliative care champions were identified during the project, predominantly primary health care nurses associated with the Division across 13 small rural communities. It goes on to say that these health professionals would continue to facilitate client access to general practitioners, undertake assessments and clinical care, participate in MDT meetings, remain as a link for families to primary health care and be involved in coordinating community education.</p> <p>Despite the difficulties faced by the project regarding engagement with the GSAHS, the report notes there are a number of aspects which have now been incorporated into its service provision which appears to be an indirect outcome of the project. These include the adoption of the concept and use of the GSAHS home notes record as a standard policy and practice, and the creation of an after hours palliative care protocol.</p> <p>The resources developed as part of the project, such as the palliative care brochure, the “Caring at Home” booklet and the ACD proformas, will also continue beyond the life of the project. The Division is also investigating becoming a registered training organisation or working in collaboration with other organisations to offer Certificates III and IV in the palliative approach throughout the region.</p>
<p><b>Recommendations</b></p>	<p>The recommendations provided by the project regarding the project processes are listed as follows:</p> <ol style="list-style-type: none"> <li>1. Palliative care packages cannot be sustained without ongoing funding.</li> <li>2. Elements such as carer respite, carer support, some equipment hire and access to a 24-hour telephone number can continue where there are CCRC services available.</li> <li>3. The package model, with its focus on psychosocial aspects of care, seamless transition between settings and a holistic approach to the end stage of life cannot be implemented without additional resources.</li> <li>4. Where palliative care packages are implemented into regional settings, additional case management resources are essential.</li> </ol>

<b>Project title</b>	<b>NSW-10 - Decision making frameworks in advanced dementia: links to improved care</b>
<b>Keywords</b>	Local, major city, RACF, community care, specialist palliative care, dementia
<b>Host organisation</b>	University of Western Sydney
<b>Partner organisations</b>	Sydney West Area Health Service Primary Care and Community Health Network (SWAHS PC&CHN); Sydney West Area Health Cancer Services Network; Blue Mountains Division of General Practice (BMDGP)
<b>Project funding</b>	\$272,223.60 incl. GST
<b>Project timeframe</b>	01 June 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To implement and evaluate decision-making frameworks for people with advanced dementia living in residential aged care facilities (RACFs), targeting four main symptoms: pain; constipation, weight loss and agitation / confusion.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To develop decision-making frameworks for service providers caring for people with advanced dementia who experience either pain; constipation; weight loss; or agitation.</li> <li>▪ To pilot the decision-making frameworks, resources and education programs into RACFs.</li> <li>▪ To provide decision-making frameworks and education to other RACFs.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project has designed frameworks that will enhance care planning and collaboration between services by providing a logical sequence to follow to manage the symptom of concern, and by assisting nurses and care staff identify the goals of care in consultation with the general practitioner and family members. The project also developed tools that promote strategies to included carers and families in palliative care.</p>
<b>Project planning and development</b>	<p>A project officer was recruited and employed for the duration of the project. A project plan was developed and used to inform all stages of the project. Memoranda of Understanding formalised the terms of engagement between University of Western Sydney (UWS) and SWAHS; and UWS and Blue Mountains Division of General Practice (BMDGP).</p> <p>A steering committee was formed to oversee the project and provide advice to the project officer. Membership included representatives from the three partner organisations plus three Directors of Nursing from RACFs, Dementia Advisory Service manager and a consumer representative. The committee met ten times and functioned effectively throughout the project.</p> <p>A Working Party was also formed which met monthly (20 times) to provide clinical advice to the project officer, including reviewing relevant literature and providing advice on the content of each framework. The working party consisted of nine Clinical Nurse Consultants (CNC) from community and acute services, with expertise in palliative care, aged care, or dementia care. There were some membership changes in the first year; fortunately they were able to be replaced by other clinicians.</p> <p>Ethics approval was granted by both the SWAHS and UWS Human Research Ethics Committee in November 2006.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project developed four 'decision-making frameworks' to be used by nurses and care staff that care for people with advanced dementia in RACFs. The frameworks focused on symptoms known to cause distress to the person with advanced dementia, and/or the carers and family members: pain, constipation, weight loss and agitation. The project was divided into three stages.</p> <p>Stage 1: Framework development for pain, constipation, weight loss and agitation. A comprehensive literature review was undertaken for each symptom of interest. These reviews informed the development of each framework. The 'Supporting Resources' for each symptom contain a summary of the literature.</p> <p>Framework development was undertaken by a project officer in consultation with the working party. The draft documents were circulated to other medical and nursing staff, allied health professionals, and residential aged care managers for comment prior to</p>



<b>Project title</b>	<b>NSW-10 - Decision making frameworks in advanced dementia: links to improved care</b>
	<p>piloting and edited if necessary before stage 2 commenced.</p> <p>The four completed frameworks include: guidelines for nurses and care staff; flowchart(s); forms and assessment tools; supporting information; and a 'train the trainer' education package. The weight loss framework also includes a pamphlet to give to family members.</p> <p>Stage 2: Piloting the frameworks. The frameworks were then piloted in three RACFs using a 'Train the Trainer' model. Four CNCs volunteered to participate and act as 'Trainers' for the pilots, one CNC for each framework, resulting in 9-20 nurses and care staff trained in the use of each framework. A senior person (usually the nurse educator or quality improvement nurse) was identified in each facility to oversee the pilot phase and communicate with the project team. Mentoring was available during the pilot period of all four frameworks, but very little was required.</p> <p>The project recruited between four and eight residents to pilot the materials in each framework. The frameworks were evaluated using a range of data collection methods including pre and post resident file audits; pre and post training surveys; field notes; and a post intervention focus group.</p> <p>All four frameworks were edited based on the data gathered during the pilots.</p> <p>Stage 3: Dissemination of the completed frameworks and mentoring. All high-care facilities (60) within the SWAHS geographic area were invited to send participants to two full days of free training. Fourteen RACFs (23%) sent between one and three participants from each facility, resulting in 29 senior staff trained in the use of the four frameworks. Data collection included a knowledge quiz for each symptom; pre and post survey regarding frameworks; a training evaluation quiz; and a telephone survey.</p> <p>Each facility was offered mentoring from the project officer or CNC throughout to assist with incorporating the frameworks into practice.</p> <p>Participants were enthusiastic about using the frameworks with all participating facilities agreeing to implement one framework (pain = 4; constipation/bowel management = 2; agitation = 4; weight loss = 4), and to plan to introduce a second framework in the future. Participants thought it may take up to 12 months to fully integrate the use of a framework into their facility and undertake the cultural change required to sustain the use of the framework.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>A detailed evaluation plan developed at the start of the project outlined the evaluation methods for the key project activities. The project officer collected the data and they, with a senior research associate of the School of Nursing and Midwifery UWS, undertook data analysis.</p> <p>Stage 2: Piloting the four frameworks was evaluated using pre and post resident file audits to assess patient outcomes with the symptoms targeted by the framework (Level 1). Pre and post intervention surveys of nurses and care staff relating to their knowledge of symptoms and current use of frameworks and focus groups were also conducted at participating facilities to discuss framework use and impact (Level 2).</p> <p>Stage 3: Dissemination of the four completed frameworks was evaluated by a number of surveys: pre and post survey of attitudes towards frameworks, and confidence in symptom management of each of the four symptoms; a knowledge quiz relating to each symptom; and a training evaluation survey. These data were collected to evaluate the frameworks education, and the intention to implement the frameworks in the participating aged care facilities (Level 2). A telephone survey was undertaken to understand the implementation strategies being employed by facilities, and the sustainability of the frameworks (Level 3).</p> <p>The project final report explains that other data collection methods included accessing the community-health database to review the number of referrals to palliative care of residents from facilities participating in the project. This data will be collected over three months, while clinical mentoring is being offered, and the results reported to the Network Director, Primary Care and Community Health Network, SWAHS. This information will be used to determine the impact on community health services of providing intensive high-quality education and mentoring to residential aged care facilities, and whether this intervention can be sustained. The data was not available at the time of this summary.</p>



<b>Project title</b>	<b>NSW-10 - Decision making frameworks in advanced dementia: links to improved care</b>
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	<p>Stage 1: The four frameworks were developed during 2006-2008. Frameworks took on average eight months each to develop (range two months to 13 months), which was longer than anticipated.</p> <p>Stage 2: Each of the four frameworks were piloted from between two to four weeks, with an additional two weeks of training time each. Support was offered from the project officer and CNC. All frameworks required some editing, with the 'pain' framework requiring the greatest amount. Nurses and care staff (n = 9-20) who used the frameworks reported increased confidence in their ability to manage the symptom of concern; improved morale; improved team work in the intervention area; and increased confidence discussing the symptom and its management with family members and general practitioners. Difficulties encountered during this stage were usually related to lack of available staff, due to resignations and planned and unplanned leave from both the project team and RACF staff.</p> <p>Stage 3: Training was provided to 29 experienced participants (seven Directors of Nursing (DON) or Deputy DON; three nurse educators; and 19 registered nurses) in February to early March 2009 from 14 RACFs (Level 2). There was a statistically significant improvement in knowledge relating to constipation / bowel management and weight loss; and an improvement in pain and agitation knowledge at the conclusion of the training. The training was considered effective by 95% of participants in preparing them to use the frameworks to train their own staff.</p> <p>Participants agreed to implement one framework of their choosing into their own facility, with support available from the CNC if required (Level 3). The telephone survey undertaken three to six weeks after the training revealed that all of the 14 facilities were considering implementation, with some already underway. The most common barrier to implementation cited was impending auditing and accreditation of the facility. No facility was willing to implement a framework if accreditation was due within the next months.</p>
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>Four resources have been developed by this projects:</p> <ol style="list-style-type: none"> <li>1. Pain Management Decision-Making Framework for nurses and care staff caring for people with advanced dementia;</li> <li>2. Weight Loss Decision-Making Framework for nurses and care staff caring for people with advanced dementia;</li> <li>3. Constipation / Bowel Management Decision-Making Framework for nurses and care staff caring for people with advanced dementia;</li> <li>4. Agitation Decision-Making Framework for nurses and care staff caring for people with advanced dementia.</li> </ol> <p>Documents associated with each framework include guidelines for nurses and care staff; supporting information; and a train the trainer package. These four frameworks will be available on the UWS School of Nursing and Midwifery website (<a href="http://www.uws.edu.au/dementia">http://www.uws.edu.au/dementia</a>) in the future for free downloading and use by RACFs.</p> <p>UWS plan to use the lessons from this project work to springboard onto future funding opportunities. All 14 RACFs trained in the four frameworks are considering implementation.</p> <p>The project suggests that to sustain the achievements of their projects, further piloting of the frameworks would improve their reliability and acceptability, especially for less skilled care staff. Plus clarification for Area Health Services of the roles and expectations of NSW Health regarding service provision to RACFs is required, as well as the consideration of service agreements being developed between Area Health Services and RACFs.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. That the frameworks be implemented over a longer period to increase their reliability and generalisability.</li> <li>2. That NSW Health clarifies the responsibilities of Area Health Services in relation to providing clinical support and governance to RACFs.</li> <li>3. That NSW Health commences consultation with RACF providers to develop service agreements between the facilities and Area Health Services.</li> <li>4. That funding is enhanced to enable the nurse to resident ratio within RACFs to be improved, especially in relation to skilled staff.</li> </ol>

## NT Project Summaries June 2009

Project title	NT-1 – Top End Palliative Care Planning Project
Keywords	Local, regional, RACF, community care, primary care, specialist palliative care, ATSI
Host organisation	Top End Division of General Practice Inc. (TEDGP)
Partner organisations	Territory Palliative Care (TPC) Top End Service; Carers NT Inc
Project funding	\$273,322.50 incl. GST
Project timeframe	4 May 2006 to 31 August 2008 was varied to 15 July 2006 to 31 August 2008.
<p><b>Project aims</b></p> <p><i>What did the project set out to do?</i></p>	<p><i>Purpose:</i> To develop and trial a model to implement and improve case conferencing and care planning services for palliative care patients and their carers with GPs, Territory Palliative Care Top End service, community care centres and allied health professionals for the Top End region of the Northern Territory</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Increase the capacity of palliative care patients and their carers to have access to well co-ordinated routine care within the Top End by the Primary Health Care General Practice team utilising appropriate Medicare Chronic Disease Management (CDM) items.</li> <li>▪ Improve continuity of care by improving the availability and quality of communication between Territory Palliative Care Top End Service, community health centres, GPs, aged care facilities and palliative care patients and their carers.</li> <li>▪ Strengthen the capacity of carers of palliative care patients to provide advocacy for palliative care patients and be included in care planning decision making.</li> <li>▪ Facilitate the recognition by the primary health medical team of individual health needs and capacity of carers of palliative care patients as part of the care planning process.</li> <li>▪ Improve management of the dying patient.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> As the project developed, its scope was expanded in response to a growing recognition of the needs of palliative care carers. In addition, the boundaries of the project were redefined in a pragmatic way, as the issues regarding rural and remote palliative care in the Top End are quite different from the needs of the urban areas.</p> <p>This then called for a different aim for the project, addressing the variety of indicators outlined in the Deed of Variation. So, the broader aims became:</p> <ul style="list-style-type: none"> <li>▪ To explore the issues involved with urban GP participation with Territory Palliative Care Top End Service and how to increase that involvement; and</li> <li>▪ To explore ways that palliative care carers can be supported in the urban Top End.</li> </ul> <p>A goal was that the project would eventually result in more coordinated care for palliative care patients and their carer/s, and quality of life and quality of death improved for palliative patients. As such, this project is all about a cultural change in health care delivery: change in the specialist service to be more inclusive of GPs, and change for GPs to be more involved with palliative care.</p>
<p><b>Project planning and development</b></p>	<p>A project officer was appointed September 2006 until the project's completion. While the Director of Territory Palliative Care gave guidance and support to the project officer, the project officer was employed by TEDGP.</p> <p>A project steering committee was formed (December 2007) with representatives from Territory Palliative Care (TPC) Top End Service, Carers NT, Menzies School of Health Research, University of Queensland, plus a consumer representative, a GP champion, the project manager, and the project officer (community centre representative joined later). This process helped establish robust relationships and strong communication pathways between partners and stakeholders in the project, which were later formalised into policy and procedure.</p> <p>The initial project plan was very comprehensive, with many activities listed to be undertaken in two years and three months. It was revised into a more realistic plan. The "Palliative Care Work Plan 2007-2008" become the final project plan and expanded to include an evaluation plan and activities. A communication strategy was developed using a</p>

Project title	NT-1 – Top End Palliative Care Planning Project
	<p>community capacity building framework and documented as the Community Capacity Building Plan.</p> <p>A Memorandum of Understanding (MOU) between Carers NT and the specialist palliative care service (TPC) was established. The MOU clearly set out roles and responsibilities which state the parameters of relationships of the project's partners, and confirms a commitment to the development of the project.</p> <p>The Human Research Ethics Committee of the Northern Territory Department of Health and Families and the Menzies School of Health Research and Aboriginal Ethics Sub-Committee Meeting granted the project ethics approval in July 2007.</p>
<p><b>Delivery</b></p> <p><i>What did the project do, create, change?</i></p>	<p>This project was designed to encourage and support general practitioners (GPs) to take over the day-to-day care of palliative patients from the specialist palliative care service in the region, the Territory Palliative Care Top End Service (TPC). In addition, the project explored ways to provide support to palliative care carers in the urban Top End of the Northern Territory.</p> <p>The target group for the project was urban Top End GPs who had current TPC patients and carers and were willing and able to take part in care planning and case conferencing with TPC.</p> <p>Interviews with stakeholders at the commencement of the project showed that the community was happy with the palliative care services provided by TPC, although some were dissatisfied with the system of coordinated care between services. TPC staff perceived GPs' lack of involvement in palliative care as a lack of commitment to their palliative patients. There was little collaboration with GPs, and a 'them and us' mentality prevailed. GPs were generally seen as difficult to engage and to deal with.</p> <p>A literature review was conducted at the beginning of the project. This focused on the issues that affect GP engagement with palliative care services. The findings of the review were used in identifying key project activities and developing a variety of strategies to build relationships between the primary and tertiary sectors in palliative care in the Top End.</p> <p>Strategies were devised within the realm of the TPC structure to create sustainable systems. These included:</p> <ul style="list-style-type: none"> <li>▪ Education and training for GPs via workshops. Nine palliative care workshops were held, with expert speakers from TPC and from interstate.</li> <li>▪ One-to-one practice visits. In an effort to validate and promote the role of GPs in palliative care, one-to-one visits were conducted to all consenting GP practices in the Top End. Three-quarters of practices agreed to be involved in the care of their palliative patients and carers. The evaluation of the education and training showed that GPs were very keen to develop their skills in palliative care. Feedback from the practice visits showed that GPs were enthusiastic about improving their proficiencies in end of life symptom and medication management. A number of training opportunities were made available to GPs as a result. In addition, the feedback on the resources provided to GPs demonstrated that they were of great use and assisted them in the day-to-day care of their palliative patients.</li> <li>▪ Resource kits were given to GPs to support their involvement in palliative care plus there were online resources developed for GPs. They included a model of the project explaining how it will help them, a MBS flow chart for palliative patients and carers, a DVD on cultural safety, Carers NT referral kits, advanced care planning information, palliative care therapeutic guidelines, resources from Palliative Care Australia, care planning and case conferencing templates, and "Diamond Register / Palliative Care Partnership" brochures.</li> <li>▪ Case conference coordination. A major goal of the project was to facilitate the creation of care plans for palliative patients, along with case conferences among health professionals to reach a consensus on end-of-life decision making. The Diamond Register was an initiative of the project designed to promote the use of care plans and case conferences. The project also developed universal templates for care planning and case conferencing for all service providers in palliative care.</li> <li>▪ Use of secure clinical information systems. The use of the Secure Electronic Messaging System (SEMS) communication methods was promoted between stakeholders.</li> <li>▪ Role delineation and support for health professionals regarding prescribing end-of-life medications. This was achieved through standardising palliative shared care protocols which facilitated clear role delineation regarding prescribing medication during specific</li> </ul>

Project title	NT-1 – Top End Palliative Care Planning Project
	<p>end of life phases, encouraging GPs to prescribe palliative medications.</p> <ul style="list-style-type: none"> <li>▪ Promotion of case conferencing and care planning in residential aged care facilities (RACFs). The project officer also worked closely with TEDGP aged care project officer, aged care panel, and TPC aged care coordinator to foster communication between stakeholders and promote care planning and case conferencing initiatives in RACFs.</li> </ul> <p>Other strategies included the development and promotion of the “Diamond Register” and “Palliative Care Partnership” initiatives. The Diamond Register flags palliative patients and their carers in GP practices, so that meeting their needs is seen as a priority for the practice. Holding a Diamond Register means the GP flags palliative patients and carers as ‘Diamond Patients’ and is aware of and takes an interest in their care, by</p> <ul style="list-style-type: none"> <li>▪ Allocating priority and timely appointments</li> <li>▪ Instigating care plans and case conferences</li> <li>▪ Where possible, bulk billing during times when these patients and carers are seeking frequent appointments</li> <li>▪ Maintaining contact with the specialist service (TPC) and other organisations such as Carers NT.</li> </ul> <p>While the Diamond Register promotes the GPs’ relationship with the patient and carer, the Palliative Care Partnership initiative fosters the GPs’ relationship with TPC and other organisations such as Carers NT. Its goal is to build a bridge between the primary and tertiary health care sectors in serving palliative patients and their carers. Being a Palliative Care Partner means the GP and specialist service have jointly committed to:</p> <ul style="list-style-type: none"> <li>▪ A philosophy of holistic end-of-life care</li> <li>▪ Promoting carer support, including referral to Carers NT</li> <li>▪ Building primary care capacity within the community</li> <li>▪ Encouraging and supporting education in palliative care for practice staff and the wider primary health care sector</li> <li>▪ Nurturing and developing network partnerships to serve complex needs of palliative patients and their carers.</li> </ul> <p>Initial efforts to engage carers in education were unsuccessful. Instead, carers’ needs were addressed by providing systematic assessment and immediate referral to Carers NT, the non-governmental carer advocacy organisation of the Northern Territory, when the palliative patient was referred to TPC. Resource kits and practical help (e.g. respite, home cleaning) were provided. Resource kits were given to carers via the TPC case managers and included information on community support services, relaxation DVD, information from pharmacists regarding medications advise, a booklet for carer support including psychosocial support, plus access to palliative care-giving books on practical aspects of caring, for example manual handling.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Evaluation methods were formative and mainly qualitative.</p> <p>The impact on the health providers (Level 2) was obtained by using:</p> <ul style="list-style-type: none"> <li>▪ Questionnaires and feedback from education and training events for GPs.</li> <li>▪ Interviews conducted during GP practice visits.</li> <li>▪ A case study of the experiences of GPs at one practice, their working relationship with TPC and how they implemented the Diamond Register.</li> <li>▪ Informal interviews with TPC staff regarding care planning and case conferencing, their expectations of coordinated care, relationships with GPs and issues with GPs (focus groups were logistically impractical with TPC staff busy workload).</li> </ul> <p>The impact of the project on the Territory Palliative Care system (Level 3) was obtained using the following tools:</p> <ul style="list-style-type: none"> <li>▪ An evaluation of carer referrals to Carers NT and the circumstances of the referral.</li> <li>▪ The use of palliative care toolkit tools to take a ‘snap shot’ of the status of service provision approximately half way through the project (this was undertaken in collaboration with the NT Government Department of Health and Community Services).</li> <li>▪ Feedback from TPC staff on the changes in TPC policies and procedures.</li> </ul>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The GPs who were interviewed for the practice case study had become more involved with the palliative care of their dying patients. Their relationship with TPC has developed into a working partnership in the coordinated care of the palliative patient. The Diamond Register is proving to be a useful tool in flagging palliative care patients for prioritised care, as well as being bulk-billed and supported by the practice. The practice focused on in the case study did not, however, include palliative care carers in the Diamond Register as they felt</p>

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	<p>there was not the opportunity to focus on the carer during consults with the palliative patient. The GPs, however, were aware of the services that Carers NT offered and were quick to refer them.</p> <p>There were significant changes in palliative care referrals to Carers NT over the life of the project. At the beginning of the project there were no referrals from TPC for palliative care carers. By the end of the project, palliative care referrals made up 17% of all referrals to Carers NT and TPC had become the largest independent source of referrals to Carers NT. At the beginning of the project the hospital was the only health care provider referring to Carers NT. Over the life of the project, other health care referrals, importantly including primary health care providers, made up 13.15% of all referrals to Carers NT. After the April 2008 Carers Seminar, referrals to Carers NT increased by 50%. The improved, more practical model of service delivery for palliative care carers has also shown great results, with 99% of palliative care carers utilising respite options. This was an unexpected outcome.</p> <p>The project also resulted in the development of policy formally to include GPs, community nurses and Carers NT in TPC policies and procedures.</p> <p>The project was guided by the implementation of project key indicators using the quality improvement tools of Plan Do Study Act (PDSA) cycles where the implementation of the project was planned and actioned into small parts. The success of each planned activity was then studied and improvements for further implementation were devised. For instance, the lack of palliative care carers attending Carers NT workshops was reviewed and studied, and further implementation was changed to accommodate more practical assistance for these carers. The PDSA cycles were implemented continuously during the life of the project, requiring examination and changes in implementation.</p> <p>In summary, the major achievements of the project were reported as:</p> <ul style="list-style-type: none"> <li>▪ An increased GP engagement with Territory Palliative Care Top End Service (TPC) from 13.8% in 2006 to 75% in 2007.</li> <li>▪ An increase in GP preparedness to bulk bill, to attend to case conferencing, home visits and after hours care, as well as carer bereavement needs.</li> <li>▪ Development and implementation of the “Diamond Register” and “Palliative Care Partnership” initiatives that advocate and support the care of the palliative client and their carer/s.</li> <li>▪ More appropriate practical support developed for carers, with an exponential increase in the amount of palliative care carers referred to Carers NT.</li> <li>▪ Robust relationships nurtured between stake holders, enhancing capacity with numerous education and training opportunities provided and multi dimensional resources disseminated.</li> <li>▪ Development of policy formally to include GPs, community nurses and Carers NT in TPC policies and procedures.</li> </ul> <p>The project addressed community needs by improving the capacity of the primary health providers to support palliative care clients and their carers through skill development, clinical support and improved communications between stakeholders. Developing infrastructure at TPC encouraged involvement with the primary health care sector and Carers NT. The unique needs of palliative care clients and their carers were met through advocacy, service support and promotion to GPs.</p> <p>The project has succeeded in building sustainable relationships between stakeholders and systems for care coordination and carer support which are enshrined in policy. The primary health care sector provides the day-to-day care of the client, and the tertiary health care provider has a consultative and supportive role. This was achieved partly because of developing a clear model and systems to support it; by investing in multi-levelled human capital to build capacity; and by developing strong problem solving mechanisms, such as PDSA quality cycles.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>This project was very focused on ensuring that aspects of the project would continue. They attempted to build in sustainability from the start so that activities would continue at the project’s completion.</p> <p>As the project was mainly systems based with no direct contact with clients or carers, the sustainability is attainable via policy and procedure change and support, which have been developed with TPC during the project. The policies and procedures mandate GP involvement with the palliative care process in the following policies and procedures:</p>



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	<p>admission to TPC; hospice admission; care coordination; care plans; case meetings; client office file.</p> <p>The project is also sustainable for GP involvement with the utilisation of the MBS. GP management plans and team care arrangement have been particularly encouraged.</p> <p>Another area that will be continued is end-of-life planning, namely Advance Care Directives. TPC has a 0.6 FTE clinical nurse consultant working with that initiative.</p> <p>General Practice Network Northern Territory (GPNNT), formally known as TEDGP, have been successful in obtaining funding from DoHA via the Rural Palliative Care Program for a new project across the Territory. In this new project, lessons learnt in the Top End Palliative Care Planning Project are generalisable and also more directly relevant as the Rural Palliative Care Project will also be systems based.</p> <p>The robust relationships developed in the current project have greatly benefited the potential of the Rural Palliative Care Project, and are directly developing community capacity and professional capacity for TPC staff and primary health care providers.</p> <p>The project was cost effective as it mainly utilised resources, opportunities and infrastructure already in existence, saving costs of establishing new resources.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. It is important for short-term projects to utilise available systems for sustainability, for example MBS and available TPC infrastructural development.</li> <li>2. The Diamond Register and Palliative Care Partner initiatives provide a mechanism for the specialist (TPC) service to work at supporting and mainstreaming palliative care in GP practices.</li> <li>3. Primary health care communication needs to be maintained with community centres, RACFs, carers' advocacy groups and with palliative care. Relationships need to be fostered. Formal communication pathways need to be developed.</li> <li>4. Palliative care should be represented in every GP division nationally. The palliative approach should be promoted to GPs as it has the potential to benefit many of their patients.</li> <li>5. Mentorship of GPs by specialist palliative care staff provides essential support for their day-to-day role in caring for palliative patients.</li> <li>6. Wider promotion and availability for GPs to utilise the Program of Experience in the Palliative Approach (PEPA) opportunities to support primary health care development with palliative care.</li> <li>7. Advance care planning should be mainstreamed in general practice.</li> <li>8. Clients without GPs can be served via a weekly half-day GP clinic within the specialist facility.</li> <li>9. RACFs have agreements / MOU with practices to provide weekly clinics in RACF and on-site emergency medication for palliative patients.</li> <li>10. Government should recognise the nature of the GP palliative care relationship and devise an appropriate palliative care MBS item.</li> </ol>



## QLD Project Summaries June 2009

<b>Project title</b>	<b>QLD-1 - Fraser Coast Palliative Care Project</b>
<b>Keywords</b>	Local, regional, RACF, community care, acute care, primary care, specialist palliative care
<b>Host organisation</b>	Blue Care, Hervey Bay
<b>Partner organisations</b>	University of Queensland / Blue Care Research and Practice Development Centre
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	01 May 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop, trial and implement models of service that will integrate services and encompass comprehensive care planning mechanisms, continuity of care and improve transition phases from hospital to home, hospice and aged care settings.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Review existing models of palliative care service provision and develop a consistent approach to care planning and service delivery for people choosing to stay in the community.</li> <li>▪ Develop formal linkages between palliative care service providers on the Fraser Coast.</li> <li>▪ Review existing discharge planning processes and develop an integrated and coordinated approach to transition between settings.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The model of service delivery was based on a literature review, liaison with health providers and community consultations (needs analysis). Collaboration between providers was promoted through multidisciplinary education and training. Transitions between settings of care were supported through enhancing community awareness and implementing sustainable care planning processes.</p>
<b>Project planning and development</b>	<p>The original project officer was employed (after a delay) in October 2006 and left at the end of December 2006. Project work ceased for six months until a replacement was recruited as part of a partnership between Blue Care and the University of Queensland. The new project officer had only two years remaining to complete the project. There was a need to tighten the scope of the project as the original plan was not achievable.</p> <p>The revised activities comprised: literature review; consultation with health care providers and palliative care consumers; identification of staff education needs and learning strategies; development of a formal palliative care network (PallNet); enhancing community awareness and improving care planning processes.</p> <p>A reference group was established and met bi-monthly and the project officer had meetings with new stakeholders, including the palliative care consultant and new palliative care CNC at Hervey Bay Hospital, PresCare and local funeral directors. The palliative care network, PallNet, was established with broad representation from local stakeholders and clear terms of reference, to build relationships among palliative care professionals and community services in the local area. The plan was to make this self-sustaining; to this end, the project manager began mentoring locals with a particular interest in palliative care, and a public launch was held at Maryborough City Hall.</p> <p>Ethics approval for formative data collection activities was granted by Blue Care HREC.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project developed a proposed model of palliative care service delivery for the Fraser Coast. Project activities were organised around the three aims listed above. The main outcome of these activities was a recommendation for the establishment of a palliative care service development officer for the Fraser Coast region.</p> <p>A literature review was conducted to identify effective models of care and expected outcomes for palliative care clients, carers and providers. This explored issues such as establishing interagency partnerships to improve transitions between settings of care, the importance of identifying consumers' actual needs for palliative care services, and the desirability of enhancing community awareness of palliative care, death and dying, and bereavement. Lessons from the review were incorporated into the service delivery model.</p>

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	<p>Local health care providers were surveyed using questionnaires (see below) to identify existing and optimal approaches to palliative care and end of life care provision. Local palliative care consumers were also surveyed using questionnaires to ascertain their knowledge of palliative care and their needs for service provision. Community need was assessed through public forums and reviewing existing data about community awareness. This information was also used in the development of the model.</p> <p>Formal links between service providers were facilitated via the establishment of PallNet, and the signing of Memoranda of Understanding by local healthcare providers to facilitate transitions and referrals between settings. PallNet was established to meet the project's second aim. It is a network made up of community members and health care professionals whose goal is to promote coordinated, accessible care and support at the end of life. Members have a common interest in improving communication between existing service providers and raising community awareness of the issues arising around death and dying. When a local private palliative care provider closed, PallNet was approached by Queensland Health for ideas on strategic directions for the use of the funds returned. The role of the palliative care service development officer was proposed by PallNet on behalf of the local stakeholders and is viewed as complementary to existing clinical services provided by Queensland Health and non-government organisations in the region.</p> <p>Local care providers were liaised with through PallNet and existing care planning mechanisms were reviewed. A gap analysis was undertaken and strategies developed to promote improvement in care planning processes. From the consumers' perspective their participation in the care planning process was facilitated through the development of 'My Health Record'. This resource for patients and their families and caregivers to promote participation in the care planning process was based on a similar document produced in South Australia in 2006.</p> <p>The service delivery model was ratified and adopted by PallNet for implementation, along with the proposal to employ a service delivery officer which was accepted by Queensland Health. At the end of the project, a plan was in place for the appointment of an external evaluator (see below) to look at the effectiveness of the model and the new position.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Data were collected from health professionals and consumers in order to identify issues that the proposed model would need to address and to inform the development of appropriate strategies. To gather this information, a survey of health care practitioners (Level 2) and palliative care consumers (Level 1) was undertaken. Four evaluation tools from The Caring Communities Evaluation Tool Kit were adapted for this project, specifically targeting:</p> <ul style="list-style-type: none"> <li>▪ Health care professionals (including nurses, allied health practitioners and others)</li> <li>▪ General medical practitioners</li> <li>▪ Palliative care patients</li> <li>▪ Family carers of palliative care patients.</li> </ul> <p>The Centre for Palliative Care Research and Education has been contracted to provide an independent evaluation of the regional model of palliative care provision, including the role of the palliative care service development officer role, no later than 18 months after the commencement of the service agreement. The evaluation will identify strengths and weaknesses of the model and will determine whether the model was successful based on key performance indicators, such as the amount and effectiveness of:</p> <ul style="list-style-type: none"> <li>▪ professional development with primary providers</li> <li>▪ consultation and advice for primary providers</li> <li>▪ shared care (including details of the providers with whom care was shared)</li> <li>▪ direct care provided to patients.</li> </ul> <p>The external evaluation will also document the demonstrated links/networks with local providers and the CAHS Palliative Care Network and measure outcomes against:</p> <ul style="list-style-type: none"> <li>▪ National Palliative Care Performance Indicators</li> <li>▪ Palliative Care Australia Standards for Palliative Care Service Delivery</li> <li>▪ Queensland Health Clinical Service Capability Framework.</li> </ul>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>Health professionals surveyed for the project included representatives from community health organisations (n=13), community nurses (n=7), and general medical practitioners (n=12). The demographics of this group reflected those of the wider professional community engaged in providing palliative care: predominantly female and middle-aged, with a sizeable older cohort. Respondents demonstrated understandings of palliative care that were mostly consistent with national and international definitions, including elements of holism, the control of symptoms and information provision. Almost all considered</p>

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	<p>themselves to possess a general level of knowledge of palliative care, rather than specialist. Most respondents had received either on-the-job training or had attended short courses to increase their knowledge and skills in palliative care. Confidence levels were high, and for the most part, respondents believe their levels of support were adequate. For many respondents, end-of-life care represented a significant proportion of their work.</p> <p>In identifying local need, respondents viewed the following issues (in rank order) as the most significant barriers to palliative care provision:</p> <ol style="list-style-type: none"> <li>1. Insufficient after-hours coverage (both groups) AND insufficient professional development opportunities for health care professionals (equal first)</li> <li>2. Limited knowledge of palliative care amongst health care professionals AND low levels of community awareness of palliative care (equal second)</li> <li>3. Lack of consultancy service at hospital</li> </ol> <p>Amongst GPs, low levels of community awareness of palliative care was also considered a significant barrier.</p> <p>Strategies suggested by health professionals to address these gaps included: establishment of a consultative palliative care service at the local hospital; a freestanding local hospice; more professional development and education; more dedicated palliative care beds in local hospitals; more home-based care; improved awareness of palliative care in hospital; improved awareness among GPs of palliative care; improved awareness among community services; provision of a 24-hour phone service; more palliative care volunteers.</p> <p>Notably, shortly after the data collection period was concluded, the Hervey Bay and Maryborough Hospitals established a consultative palliative care service.</p> <p>In terms of professional development and education, lectures by visiting experts and small group workshops were the preferred learning styles of the health care professional subgroup. Priorities for palliative care topics were: physical symptom management; psychosocial issues; grief; and assessment. Many respondents commented on the perceived local need for a freestanding "cottage" hospice.</p> <p>Four palliative care patients and five carers responded to the invitation to take part in the survey. Palliative care patients and their carers identified troublesome physical and psychological symptoms and the social impacts upon family members as major issues. Whilst they expressed confidence in local palliative care services with particular reference to adequate provision of information and equipment there were a number of areas requiring improvement including the provision of after-hours support and clearer instruction in practical matters.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>PallNet was designed to be self-sustaining and to continue beyond the life of the project. At the end of the project the most important factor promoting the chances of project sustainability relates to the fact that PallNet has appointed a palliative care service development officer responsible for building the capacity of primary care with regards to end of life care. This position is auspiced by GP Links Wide Bay (formerly Wide Bay Division of General Practice) and funded by Queensland Health using funds returned from the closure of a local private palliative care service. Concurrent with this initiative, Queensland Health has funded the establishment of a small palliative care consultative team at the local hospital.</p>
<p><b>Recommendations</b></p>	<p>The project final report included the following recommendation:</p> <ol style="list-style-type: none"> <li>1. Project plans need to be well scoped and include very clear project management components supported by a realistic evaluation plan.</li> </ol>

<b>Project title</b>	QLD-2 - End of Life Care Pathways Project
<b>Keywords</b>	Local, major city, RACF, specialist palliative care
<b>Host organisation</b>	QEI Hospital Health Service District
<b>Partner organisations</b>	Brisbane South Palliative Care Collaborative, Aged Care Queensland, South East Alliance of General Practice
<b>Project funding</b>	\$274,777 incl. GST
<b>Project timeframe</b>	30 April 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop, implement and evaluate an end-stage care pathway that improves equity of access to quality palliative care for dying residents of residential aged care facilities (RACFs). The pathway incorporates evidence- and consensus-based best clinical management and care coordination for dying residents, and was evaluated against the Palliative Care Australia (PCA) Standards.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Adapt best-practice end-of-life care pathways (EoLCP) for use within Australian RACFs</li> <li>▪ Provide appropriate support, including education and documentation, to RACF staff to enable them to give high-quality end-of-life care to all residents</li> <li>▪ Facilitate access to appropriate end-of-life medication through the establishment of a medication imprest system in participating RACFs</li> <li>▪ Evaluate and demonstrate the effectiveness of the EoLCP in the Australian residential aged care context</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project developed a patient-centred pathway of care and associated infrastructure, tailored to RACFs that links generalist and specialist palliative care providers and contributes to seamless palliative care. Education was provided to RACF staff and general practitioners (GPs) and collaboration with specialist providers was improved. Ultimately, the goal was to ensure that support and guidance was available to primary care providers to facilitate high-quality care and dying in place.</p>
<b>Project planning and development</b>	<p>Formal letters of agreement were signed with partner organisations and an expert advisory group (EAG) established with terms of reference. Project officer was recruited in July 2006. Literature on EoLCP was conducted. Criteria were developed for identifying and selecting pilot RACFs to take part in the project.</p> <p>To establish a baseline, the project officer analysed data from a pre-existing audit of the movements of palliative patients in Brisbane South area and distributed the results to inform stakeholders. Qualitatively, the data indicated that dying residents of RACFs were being transferred inappropriately to acute care facilities at end stages of life but this could not be accurately quantified and it was decided that a prospective audit would be needed.</p> <p>Communication strategies with other national and international research groups were put in place and networks established with experts in this field including Dr John Ellershaw who developed the Liverpool Care Pathway in the UK.</p> <p>The project was approved by Princess Alexandra Hospital (Queensland Health) and Royal Australian College of General Practitioners ethics committees in January 2007.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>Seven RACFs were recruited, all run by non-government organisations, with a total of 693 high-care beds. Meetings took place between facility managers, clinical staff and project team members. Each facility signed a written agreement to participate and nominated a link nurse.</p> <p>The project team conducted an educational needs analysis and developed a curriculum for educating RACF staff and GPs prior to implementation of the RAC EoLCP. Two interventions were developed for RACF staff. The first was a one-hour workshop which introduced staff to the palliative approach and explained how to use the care pathway. A total of 157 staff attended the 17 workshops, which were held during day, evening and night shifts to maximise accessibility. One site was unable to arrange for any staff to attend scheduled workshops due to staff shortages and general lack of interest by staff and management. This site later withdrew from the project. The second intervention was a full-day workshop on managing change in the workplace, attended by 20 selected clinical and management staff.</p>

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	<p>A database of all GPs (more than 140) providing care to residents in the participating RACFs was established to facilitate consultation and engagement. Introductory letters were sent to all GPs requesting practice meetings; however, GPs' time pressure and lack of support from practice managers led the project team to revise its strategy. Instead, meetings were scheduled only with GPs who had large numbers of residents in their care. Following the educational needs analysis, two interventions were developed for GPs, both accredited for quality assurance/continuous professional development points. The introductory workshop on incorporating a palliative approach in RACFs and using the care pathway was attended by 43 GPs. The second, 'breaking bad news in the palliative care setting', attracted a capacity crowd of 40 GPs.</p> <p>A residential aged care end-of-life care pathway (RAC EoLCP) was drafted, based on components of existing pathways including the Liverpool Care Pathway (UK) and the NSW Central Coast Collaborative Pathway. Draft versions were reviewed by the EAG, Peter Cleasby (who implemented the NSW pathway), Dr Jo Hockley (who implemented the Liverpool pathway in nursing homes in the UK), a representative from the Liverpool Care Pathway group and the Health Insurance Commission. The final draft was reviewed by the link nurse group, refined further and implemented in the six remaining RACFs for an 18-month trial period, starting on 1 July 2007 and ending 31 December 2008.</p> <p>The project team researched jurisdictional requirements for medication prescribing and management and held meetings with the Queensland Health Environmental Health Unit to establish that it was possible to implement a medication imprest system in participating RACFs. This ensured residents on RAC EoLCP had timely access to appropriate medications. Guidelines were developed and training provided on management of the imprest system and familiarity with the medications. An imprest system was in place within all six RACFs from the start of the implementation phase.</p> <p>Before and throughout implementation, link nurses were supported via bi-monthly meetings, site visits at least weekly by the project officer (enabling opportunistic training and monitoring of evaluation activities), telephone support and the full-day workshop described above. The program of education for RACF staff continued over a 14-month period during implementation, with a calendar of session times and topics in each facility. Training was facilitated by specialist palliative care clinicians.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Evaluation was a major goal of the project and was integrated into project tasks. End-of-life care pathways have not been well evaluated previously except in terms of compliance and quality improvement – no patient outcomes had been reported.</p> <p>At Level 1, data were collected from carers as a proxy for patient outcomes, to answer the question, "Does standard of care improve as a result of this tool?" A 22-item questionnaire based on the PCA Standards was given to bereaved relatives (or those indicated as contact person for the resident).</p> <p>At Level 2, a 16-item questionnaire was administered to RACF staff confidentially pre-implementation and at three, nine and 18 months during the implementation phase. Staff were asked to rank aspects of care and education provided by their organisation. Items were directly related to the PCA Standards. Medical officers were asked to complete a short questionnaire each time they used the RAC EoLCP.</p> <p>At Level 3, the outcome measures were the uptake of RAC EoLCP and the rate of transfers out of RACFs into the acute care system, to address the question, "Does the tool prevent hospital admissions?" This outcome measure was based on an acknowledgement by PCA that hospitalisation during end stages of life may be inappropriate and is a potential indicator of sub-optimal care.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>Questionnaires were returned by 87 bereaved relatives: 21 during the pre-implementation period and 66 during the implementation phase (only those whose relatives were commenced on the RAC EoLCP were asked to take part). Response rates were 53% and 59% respectively. Satisfaction with care was very high throughout the project and there were no significant changes from pre- to post-implementation. Means were lower for two items relating to communication and bereavement support. This was noted during the six-monthly data 'snapshots' and a booklet for carers was produced to help address this issue.</p> <p>A total of 525 staff questionnaires were returned. Reliability analysis showed high internal consistency (Cronbach's alpha of at least 0.95 at each time point, based on staff who completed all questions) and principal components analysis indicated that one factor,</p>



Project title	QLD-2 - End of Life Care Pathways Project
	<p>perceived quality of care delivered, captured the variability (percent accounted for 59% to 74% across time points); factor loadings were at least 0.6 for all items. On all items (except item 10) there was evidence of a significant increase in ratings across the time points, as indicated by statistical test of linear trend. This indicated that staff perceived an improvement in the quality of end-of-life care provided by their facility following the introduction of the RAC EoLCP. This perception increased over time as the project progressed, possibly as a result of increased capacity of staff due to the ongoing education provided by the project. Item 10 did not increase over time, probably due to a ceiling effect as the pre-implementation mean was high.</p> <p>Compliance with the medical officer questionnaire was poor and there were too few data to analyse, therefore impacts on participating GPs were not reported. Six-monthly 'snapshot' audits of the pathway documents showed poor medical compliance with the documentation of care provided.</p> <p>A total of 299 deaths were audited: 46 before implementation and 253 during the implementation phase. The project provided clear evidence that residents who were started on the RAC EoLCP were more likely to die in place. Before implementation, 21.7% of dying residents were transferred to hospital. After implementation, this fell to 1.7% of the residents who were started on the RAC EoLCP, while the transfer rate among those not placed on the pathway remained the same (21.5%). This difference in frequency was statistically significant (<math>\chi^2 = 22.9</math>, <math>df=1</math>, <math>p&lt;.001</math>).</p> <p>Overall, 47% of dying residents were commenced on the RAC EoLCP during the implementation phase, which was a lower proportion than expected, although this varied considerably between facilities, ranging from 27.6% to 69.3%. The two facilities with the highest percentages of dying residents commenced on the pathway were the only RACFs that retained the same link nurses throughout the project, and also had the highest number of staff attending education sessions, suggesting higher levels of management support. Uptake was not correlated with facility size.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>During the project, the implementation was supported by the link nurses, who met regularly and were provided with ongoing education and monitoring; the change management workshop for key clinical and management staff; education sessions for RACF staff; and the imprest system enabling timely access to medications. Similar strategies would be required to sustain the use of the pathways in the longer term. Brisbane South Collaborative has a nurse practitioner who will continue to support RACFs in using the pathways after the project ends. The project team has scheduled meetings with Queensland Health to explore implementation opportunities. Aged Care Queensland has expressed interest in providing resources to the project's host organisation to develop an implementation plan for using the pathways in RACFs across the State.</p> <p>The project has had a number of 'side benefits' which are likely to increase prospects for sustainability. The imprest system has benefits for all residents needing immediate symptom control, not just those on EoLCP. The reduction in transfers to acute care will reduce pressure on the hospital system.</p> <p>Most importantly, the RAC EoLCP meets all requirements to allow facilities to gain complex health care funding for their residents under the Aged Care Funding Instrument (ACFI), which was introduced nationally in March 2008. The documentation allows for easy validation that the requirements have been met, namely a directive issued by a medical officer, palliative care specialised nurse or senior registered nurse; pain assessment; a care plan; and evidence of ongoing care. The ACFI therefore provides a funding mechanism which will encourage uptake of the RAC EoLCP.</p> <p>The pathway also provides sufficient documentation to enable GPs to claim payment via an Extended Primary Care item. Due to lack of evaluation data from GPs, it is not possible to say whether this was well utilised during the project. Difficulty in engaging GPs remains a challenge for sustainability.</p> <p>The project consortium is currently using the RAC EoLCP tool, the link nurse model and education curriculum in a follow-on project funded by the Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program. This is expected to provide further evidence of the effectiveness of the tool in RACF settings across Australia.</p>



<b>Project title</b>	<b>QLD-2 - End of Life Care Pathways Project</b>
<b>Recommendations</b>	Those recommendations provided by the project are listed as follows. <ol style="list-style-type: none"><li data-bbox="448 297 1374 353">1. It is recommended that the RAC EoLCP be made available to as many RACFs as possible.</li><li data-bbox="448 383 1426 439">2. The pathway and associated infrastructure improves outcomes for dying residents of RACFs and increases the capacity of RACF staff to provide high quality palliative care.</li><li data-bbox="448 468 1426 524">3. The model requires support from facility management and the presence of a dedicated link nurse.</li><li data-bbox="448 553 1358 624">4. Management support may be enhanced by linking the RAC EoLCP and its documentation to the operational requirements for the ACFI and/or accreditation processes.</li></ol>

<b>Project title</b>	QLD-3 - Collaborative approach to the planning and delivery of palliative care services for end-of-life care at Canossa Services in Oxley and in the South West Brisbane Community.
<b>Keywords</b>	Local, major city, RACF, specialist palliative care
<b>Host organisation</b>	Canossa Services, Oxley, Brisbane
<b>Partner organisations</b>	None
<b>Project funding</b>	\$115,777 incl. GST.
<b>Project timeframe</b>	28 April 2006 – 31 October 2007
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop care pathways and protocols to provide a collaborative inclusive care model for use by primary and specialist palliative care providers to deliver quality care to residents of Canossa Services Oxley, and patients living in the South West Brisbane community in the end stages of their lives.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Develop and implement a flexible model of service that meets the needs of each palliative patient in their local community.</li> <li>▪ Support the smooth and appropriate transition between settings of care - residential aged care, the person's home and inpatient facilities.</li> <li>▪ Reduce the need for aged care residents to be admitted to acute care facilities.</li> <li>▪ Measure, evaluate and benchmark outcomes.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project aimed to build links between the different parts of the Canossa facility (aged care and palliative care ward) through education and support and by encouraging nurses in aged care to contact and consult the palliative care specialists when necessary. The project supported smooth transitions by educating nurses to recognise signs of terminal events and move patients smoothly from one pathway to another. End-of-life care pathways (EoLCP) were explained to the general practitioners (GPs) whose patients were using the public beds; the project officer had individual meetings with each of the doctors to introduce the pathway and show where they could get information relevant to their patients.</p>
<b>Project planning and development</b>	<p>Initial recruitment of a project officer was unsuccessful so the position was re-advertised. A project officer was appointed full-time from 31 July 2006 until the end of the project.</p> <p>An advisory panel was established consisting of health professionals with a special interest in palliative and end-of-life care. They included a GP, a palliative specialist doctor, a pharmacist, an occupational therapist, a speech therapist, a physiotherapist, a volunteer, pastoral care worker, and two nurses from the palliative care unit. Terms of reference were developed and an establishment meeting held. A laptop and printer were purchased.</p> <p>Ethics approval was not sought for this project as it was seen as a quality improvement activity.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project began with a retrospective audit of existing care plans and review of pathway documents already used in the facility. End-of-life care (defined as care in the last three days of life) was not documented in standard ways so it was not possible to measure whether the care was effective. A literature review was conducted to identify evidence for best practice in end-of-life care planning and a pathway was developed modelled on the Liverpool Care Pathways and incorporating data collected by the Palliative Care Outcomes Collaboration (PCOC). Aged care nurses were asked to complete a survey assessing their knowledge and skills in end-of-life care (17/50 responded) and results were used to identify training needs.</p> <p>The new care pathways were trialled for one month in the facility's palliative care unit. Nurses in the unit were given training and a resource folder, and asked to complete a questionnaire (6/18 did so). Feedback from this trial was used in reviewing the pathways, resource folder and supporting documents.</p> <p>The final package for the RACF part of the Canossa facility included: an end-of-life care pathway, a symptom management tool (which included the Abbey Pain Scale for patients who cannot respond verbally) and a syringe driver checklist, supported by a resource folder.</p>

<b>Project title</b>	<b>QLD-3 - Collaborative approach to the planning and delivery of palliative care services for end-of-life care at Canossa Services in Oxley and in the South West Brisbane Community.</b>
	<p>It was agreed that end-of-life care could be initiated only after the treating GP reassessed the resident, ceased inappropriate medications and ordered medications suitable for anticipated symptoms. The GP was asked to document and sign that he/she agreed the resident was in a terminal phase.</p> <p>Resource nurses or 'nurse champions' were selected from each floor of the aged care facility and given three days' training in palliative care at a metropolitan specialist palliative care service in order that they could provide effective support for colleagues. Following their training, the nurse champions met regularly for ongoing encouragement and education and to build relationships with nurses from the palliative care unit, who were encouraged to attend these groups.</p> <p>Education was provided to the staff in RACF in two 20-minute sessions during work time (30% attended both sessions, 70% attended one session). Session one discussed palliative and end-of-life care and what constitutes a 'good death' as well as the management of the most common symptoms such as pain, nausea and vomiting, restlessness and dyspnoea (breathlessness). The second session discussed care pathways and introduced the end-of-life care pathway and the supporting documents.</p> <p>As GP involvement was crucial to the success of the project, two free workshops were planned which included food, drinks and an educational component. Speakers included specialist palliative care doctors and grief and bereavement consultants. Topics included symptom management in palliative and end-of-life care, ethical dilemmas and presentation of case studies as well as an open panel discussion. The first seminar attracted no registrants and the second (a day workshop offering credit points for attendance) was attended by seven GPs.</p>
<b>Evaluation methods</b>  <i>How was the project evaluated?</i>	<p>Level 1: People identified as next-of-kin were sent questionnaires six weeks after the death of their loved ones. These included 11 questions such as, "My relative/friend was free of pain and other discomfort" and "The nurses were kind and respectful of my needs", rated on a three-point scale (agree, disagree, unsure). Of the 85 sent out, 45 were returned. Families were generally happy with the care, but the data identified gaps in the provision of bereavement care and follow up.</p> <p>Level 2: Nurses who had used the end-of-life care pathway were asked to complete a questionnaire. Despite regular reminders, only nine nurses did so. There were 12 questions, rated on a three-point scale (yes, no, unsure), including "Was the end-of-life pathway easy to use?" and "Did it help determine any needs of your patient?" Feedback was positive, most people agreed that the documents were easy to use and were helpful in determining needs of the patient and family/carer.</p> <p>Level 3: Four audits of patient charts after death were conducted: at baseline (pre-implementation; 20 files) and at 4 (22), 10 (40) and 12 months (26) following implementation of the end-of-life care pathways. The audit tool listed 22 criteria for care that would help ensure a person could die with peace; these were based on an article, <i>A good death</i>, in the BMJ (Smith, 2000). Improvements were noted on almost all the criteria immediately following implementation and were maintained or continued to improve up to the final measurement at 12 months after implementation. For example, only 10% of patients at baseline were offered a family conference if appropriate; this rose to 77% by 12 months.</p>
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	<p>End-of-life care pathways have been designed to provide best-practice care, and nurses have been educated to use this tool to support decision making. This model of care has been implemented in all areas of the facility: the palliative and rehabilitation units as well as the RACF. As patients move between areas, their care plan follows them, ensuring a smooth transition. The pathways provide nurses with assessment criteria to identify when a terminal phase has been reached, and symptom management protocols to assist them in negotiating with GPs for appropriate interventions. It is likely that this will result in fewer transfers to acute care facilities at end of life, although this cannot be demonstrated with the available data. Use of the audit tool demonstrates positive outcomes for patients, families and nurses from the project. This tool has been implemented in routine practice, providing a means to continue monitoring outcomes for quality management purposes.</p> <p>A side benefit of the project has been the development of a closer working relationship between the hospital nurses and those in aged care. In addition, the project officer</p>

<b>Project title</b>	QLD-3 - Collaborative approach to the planning and delivery of palliative care services for end-of-life care at Canossa Services in Oxley and in the South West Brisbane Community.
	identified a need to provide bereavement care for families, resulting in the employment of a counsellor.
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>Use of the pathways in the palliative care ward and aged care will continue, and one nurse from each facility has been appointed to conduct chart audits as a quality management activity. The Quality Assurance manager at Canossa is involved in this process and results will be reported to her each month. Results will also be reported to managers and resource nurses who will use the information to plan appropriate ongoing education for staff. There has been an application for funds under Round 4 of the LPCGP to create a more formal education package.</p> <p>Education of nurses in the RACF will now be provided by the palliative care ward staff rather than the project officer. The resource nurses in aged care have received extra training to prepare them for their role in supporting colleagues, and it is planned for them to continue regular meetings (4-6 weeks) supported by the palliative care nurses. Despite the planning for sustainability, it was difficult for the project officer to maintain the enthusiasm of the resource nurses and their willingness to take on the extra responsibility of the role and this remains a challenge to the sustainability of the project.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. This project could be replicated at other RACFs using the same process as a way of improving knowledge and skills regarding end-of-life. Initial education and ongoing support for aged care nurses is imperative. The inclusion of a resource folder which explains the use of the care pathways and supporting documents has reinforced their use. Identification of nurse champions from each aged care area with the support of the expertise of the palliative care nurses has strengthened this initiative.</li> <li>2. In order for the best end-of-life care to be given to our aging population it would be beneficial for aged care nurses to be given regular and ongoing education about best practice in end-of-life care. This could be incorporated as part of the annual training which is given to every nurse and an expectation of their professional development.</li> <li>3. End-of-life care pathways provide a tool which gives nurses direction for this care and facilitates decision making about symptom management, thus providing evidence-based best practice in end-of-life care and improved outcomes for patients and residents.</li> <li>4. GPs have been hesitant to be involved in the introduction and use of the care pathways. This has resulted in poor support for the nurses in aged care as GPs are relied on for appropriate medical orders in end-of-life care. Further encouragement of local GPs is needed to attend education which informs best practice in management of end-of-life care.</li> </ol>

<b>Project title</b>	QLD-4 - Bayside Palliative Care Carers Support Group and Bayside Care4U
<b>Keywords</b>	Local, major city, community care
<b>Host organisation</b>	Spiritus Care Services
<b>Partner organisations</b>	None
<b>Project funding</b>	\$225,619 incl. GST.
<b>Project timeframe</b>	1 May 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop and implement a carer support model to support primary carers in their role, respond to their changing needs and assist them to participate in planning care for their care recipient. Throughout the model the emphasis is on empowering carers to access services and to be actively involved in planning care for their care recipient. The funding agreement was varied in June 2007 to include facilitation of networking between the Queensland Care Planning projects. A second contract variation was approved in late 2007 to provide a bereavement model as an adjunct to the carer support model. The purpose of the sub-project "Bayside Care 4 U" was to develop and implement a primary care model for bereavement support.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Enable carers to participate in care planning and enhance the care provided to their loved ones</li> <li>▪ Provide a forum outside the caring environment for carers to discuss and plan care and access services for the care recipient</li> <li>▪ Make carers aware of the services available to them</li> <li>▪ Enable carers to learn coping strategies and to focus on their own care needs</li> <li>▪ Provide care before and after death of the care recipient</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project aimed to introduce carers to a broad range of community services and give them support to maintain and enhance their own health as well as help them plan care for loved ones and be better prepared for end of life stages. It was hoped that enhancing carer well-being and confidence would reduce the likelihood of unnecessary admissions and increase chances of care recipients dying in place of choice (e.g. at home). The bereavement model was designed to assist in promoting community awareness of the normalcy of death, dying and bereavement.</p>
<b>Project planning and development</b>	<p>A project officer was recruited in July 2006 and employed one day per week. A literature review was conducted to look at approaches to working with family carers of people with a life-limiting illness. Key stakeholders were identified and invited to establish a steering committee.</p> <p>A Memorandum of Understanding was signed with the Commonwealth Carelink and Respite Centre (CCRC) Brisbane South (Spiritus agreed to provide support and education to palliative care carers; CCRC agreed to provide information to carers about the project and to participate in the steering committee and present regularly on the support group program).</p> <p>The project officer developed a project plan and assessed potential venues for the courses; discussed marketing options with the marketing manager for Spiritus; and drafted an outline for the course content and presented to the steering committee for feedback.</p> <p>While developing the bereavement model, the project manager and two facilitators attended a three-day workshop (Bereavement Summer School, run by Mal McKissock) to build knowledge and confidence in adult bereavement models and counselling. An assessment tool was adapted from existing tools to detect at-risk bereavement among those referred (or self-referred) to the group, and a bereavement model and course program was developed.</p> <p>Ethics approval for the carer support program evaluation was received from Spiritus Ethics Committee in March 2007. A second submission was made following a contract variation to develop the bereavement model, and this was approved in June 2008.</p>
<b>Delivery</b>	Each course involved six sessions run at weekly intervals, with a mix of presentations and opportunities for group discussion. Carers' groups ran for 90 minutes, bereavement groups

<b>Project title</b>	<b>QLD-4 - Bayside Palliative Care Carers Support Group and Bayside Care4U</b>
<p><i>What did the project do, create, change?</i></p>	<p>for two hours. Topics covered by the six carer support sessions were: group introduction and caring for you, the carer; symptom management; legal, financial and welfare issues; keeping yourself healthy; grief and loss; and complimentary therapies and stress management. Topics covered by the bereavement program were: understanding grief (different types of grief and risk factors); why do I feel this way (normalising grief); coping strategies – practical steps (turning grief into creative energies, e.g. journaling); care of self; gifts of grief (learning, strengths, focusing on the journey and the future); and remembrance (celebrating and releasing). Participants in the bereavement program were assessed before being invited to join, and had access to telephone support, visits and/or referrals to other services, and an annual memorial service. Written materials were provided to participants at each session.</p> <p>Group meetings alternated between two venues in the Bayside area to maximise accessibility, and a welcoming environment was created with the use of quiet music and aromatherapy oil burners. The programs were advertised in local newspapers, on community radio and via brochures, posters and email distribution lists. Other community domiciliary agencies were encouraged to refer carers.</p> <p>Respite care was available to carers to enable them to attend the groups. Those who missed sessions were mailed the written materials and offered make-up sessions in subsequent courses.</p> <p>Presenters and contributors to the groups included grief and loss educators, alternative therapies practitioners, a solicitor, a funeral director, a social worker, a palliative care clinical nurse consultant; the palliative care coordinator at the Bayside Health Services; and a Centrelink financial consultant. All provided their services free of charge. The carers groups were facilitated by the project manager or project officer, and the bereavement groups by a qualified bereavement counsellor.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The internal evaluation was mainly formative and focused at Level 1 (consumers and carers). An evaluation tool was designed to measure participant satisfaction with the courses. This was completed during the last session. Respondents were asked to rate their overall satisfaction with the course, the information provided and each of the six sessions, on an 11-point scale from '0 = very dissatisfied' to '10 = very satisfied'. Space was provided for comments. Two standardised assessment tools – the Carer Strain Index and the World Health Organisation Quality of Life survey - were also used with carers at the first and last sessions of the course. These were intended to provide data on changes in carer stress and health-related quality of life during the course of the programs.</p> <p>In addition to the internal evaluation, an external evaluator was appointed to conduct face-to-face interviews with five (former) participants in the carer support program and four from the bereavement program. Flexible schedules of open-ended questions were written by the evaluator, and participants also completed a satisfaction survey in which they rated aspects of the courses on 10-point scales from 1 = 'not at all satisfied' to 10 = 'very satisfied'. Interviews took approximately one hour each and were audio taped. Thematic analysis was performed to identify common experiences and opinions among the participants and behaviour and attitude changes associated with the programs. Any deviations from these common patterns were also noted.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>Twelve carer support groups and four bereavement support groups were run during the course of the project, involving a total of 96 carers. A minimum of six registrations were required in order to run a course. Due to ongoing difficulties in gaining enough referrals (despite paid advertising, use of free publicity in community newspapers and radio, and liaison with other community care providers in the area) several carer support courses had to be cancelled due to lack of numbers.</p> <p>Data from the internal evaluation indicated that participants were highly satisfied with the courses overall (70/92 respondents gave it the highest rating of 10, with no ratings below 6) and with the information provided (72/92 respondents gave it a rating of 10, with no ratings below 6). Sessions 3 and 4 were most popular in both courses. Qualitative data from the open questions showed that participants found the presenters informative, kind, gentle and caring and the groups were seen as safe places to talk about feelings, share thoughts and memories, without being judged. Three main themes emerged: participants now understood that grief was a process; no longer had thought they were 'going mad'; and wished they had access to the information earlier. Feedback from the satisfaction surveys was used to adjust and improve subsequent courses.</p>



<b>Project title</b>	<b>QLD-4 - Bayside Palliative Care Carers Support Group and Bayside Care4U</b>
	<p>Results were not reported for changes in carer stress and health-related quality of life following the carer support programs, except for the statement that there were 'little significant outcomes'. It was noted that the unstable nature of the palliation trajectory meant that many carers missed some sessions and it was therefore difficult to collect complete data. It appears that due to the low response rate for these questionnaires, the data were not analysed.</p> <p>The external evaluation provided rich qualitative and quantitative data on the impacts of the courses on participants and the aspects of the courses associated with these impacts. The evaluator concluded that these two programs provided effective and valuable support to palliative carers and bereaved individuals. Results indicated a high level of satisfaction with all aspects of the courses including content, organisation, staff, environment, follow-up and level of support provided. Strong community need for such courses was identified. There was some dissatisfaction with the final session in the bereavement course as some participants felt it would be better to end on an uplifting note. After reviewing the evaluation findings, participants in the bereavement courses were invited to an additional session to address these issues. The program was changed for future courses.</p> <p>Implementation of the bereavement model resulted in an additional, unexpected and beneficial outcome for the project by making community health staff more aware of their own needs for bereavement knowledge when visiting clients daily. As a result, optional grief and loss training was offered to all Bayside Spiritus staff during the project, and a total of four sessions were run, involving 58 staff members. The training was evaluated and feedback from surveys indicated that participants' confidence and competence in the language and issues surrounding grief and loss had increased.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>Costs of the courses were kept to a minimum through the use of free or low-cost venues and publicity. The presenters provided their services for free and have made a commitment to continue to do so.</p> <p>Skilled facilitators are required to sustain the courses. This role will be absorbed into the job description for the organisation's current Clinical Nurse. State funding under the Home and Community Care (HACC) program may also be used to provide education, counselling and information to carers of clients with a life-limiting illness. HACC funding is currently used by Spiritus and other agencies to provide support groups for chronic conditions.</p> <p>Grief and loss training will continue to be offered to staff at Spiritus Bayside. There is strong encouragement from the central office for this to be adopted at all branches within Queensland.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. The project has demonstrated positive outcomes for participants in the carer support and bereavement groups and these should continue to be offered by Spiritus Bayside.</li> <li>2. The course content should be continuously reviewed to ensure it remains current and relevant.</li> <li>3. Connections established by the project, with local hospitals and other key stakeholders, should be maintained. Relationships with key staff, guest speakers and volunteers need to be fostered to ensure sustainability of the program.</li> <li>4. Additional staff within Spiritus should be trained to facilitate the programs.</li> <li>5. Optional grief and loss training should continue to be offered to Spiritus staff at Bayside and extended to all branches.</li> <li>6. Research is required into the efficacy of the program in terms of reducing carer stress and improving quality of life.</li> </ol>

<b>Project title</b>	<b>QLD-5 – Hospital to Home: Palliation for Sick Hearts</b>
<b>Keywords</b>	Local, state-wide, major city, RACF, community care, acute care, primary care, specialist palliative care, non-malignant
<b>Host organisation</b>	The Prince Charles Hospital
<b>Partner organisations</b>	Royal Brisbane and Women's Hospital
<b>Project funding</b>	\$274,439 incl. GST
<b>Project timeframe</b>	9 May 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To improve the quality of life for patients over 18 and their carers living with advanced heart failure.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Assist health care providers in identifying when a patient is entering the palliative (end-stage) phase of heart failure.</li> <li>▪ Enhance patient comfort through the development and implementation of clinical protocols to manage end-stage heart failure symptoms.</li> <li>▪ Coordinate care planning for patients with end-stage heart failure.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> People with end-stage heart failure may have limited access to palliative care due to poor clinical identification and resource issues. An increasing number of patients are relying on hospitals for end-of-life care due to lack of support in the community for their complex needs. This project developed a protocol for end-stage heart failure incorporating information for specialist and primary health care providers regarding symptom management, communication and psychosocial support for patients and their carers in community settings. The goal was to identify end-stage heart failure as early as possible, provide guidelines on clinical care, and facilitate care planning related to activities of daily living, financial and psychosocial needs, and introduce advance care planning concepts.</p>
<b>Project planning and development</b>	<p>A project officer was appointed in October 2006. A steering committee was established, consisting of cardiology, general medical and palliative care medical specialists; nursing specialists in palliative care and heart failure; a pharmacist; nursing leaders from a community care provider and a hospice; and the Director of Teaching and Learning from the Centre for Palliative Care Research and Education.</p> <p>Originally the project plan included a heart failure nurse coordinator position and a training strategy for nurses in the use of home infusion pumps. After consultation with discharge coordinators, palliative care providers and the heart failure team leaders, it was decided that an additional coordinator position was not needed and would make communication and planning more complicated. Instead, the project would try to facilitate linkages between providers. Improvements in oral medications during the course of the project meant that intravenous Lasix infusions were no longer as widely used, so the focus of the project shifted from managing this specific practice to providing a broader management protocol.</p> <p>Ethics applications were made to the Royal Brisbane and Women's Hospital and The Prince Charles Hospital ethics committees in January 2007 and approved in June 2007.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>One of the key tasks for the project was to identify and gain clinical agreement on a set of indicators for end-stage heart failure. A draft document, <i>Heart Failure Palliative Phase Identifiers for Doctors</i>, was approved by the steering committee and feedback was sought from representatives of general practice and the Heart Foundation. A specialist group, the Southside Heart Failure Palliation Collaborative, also reviewed the document and provided feedback. The clinical indicators were accepted by the Southside Collaborative and also had wider support within Queensland after being presented at a state-level heart failure meeting. They were incorporated into the integrated protocol, discussed below.</p> <p>A home intravenous frusemide pathway was developed, along with a training program and consent forms. The goal was to support the use of this technology in patients' homes, enabling them to live in the community and have their symptoms adequately managed. The training strategy for community nurses involved a train-the-trainer approach. Blue Care agreed to be the main agency to provide this type of care, and a clinical nurse consultant was trained as a 'super user' to train and support other nurses using the pumps. Pumps were purchased and held at the Royal Brisbane and Women's Hospital so that infusion</p>

Project title	QLD-5 – Hospital to Home: Palliation for Sick Hearts
	<p>could begin there, and the supplier provided training to nurses in the acute wards. Links were made with another Care Planning project in Queensland (Qld-6) which was developing case conferencing protocols. It was planned to trial these with heart failure patients who were using the home-based infusions.</p> <p>The project officer developed written nursing action plans for use in community care, palliative care and nursing homes. These were pilot tested and feedback suggested that they were too generic, addressed core nursing care, and did not provide enough specific information on medical management and care planning. The project officer also drafted other documents, including medical protocols for dealing with symptoms such as refractory dyspnoea, nausea, volume overload, cachexia, insomnia, and depression. These detailed practice guidelines were thought by the steering committee to be replicating current guidelines. In addition, there was concern that lengthy action plans and guidelines would be difficult to use, to audit and to review regularly.</p> <p>As a result, the project was refocused in February 2008 and the steering committee took on the task of integrating the assembled information into one document: the <i>End-Stage Heart Failure Management Protocol</i>. This document included pathways, care plans and guidelines, with succinct information directing clinicians to the Therapeutic Goods Administration guidelines which are readily available in electronic and hard formats. The tool is designed to be used in various settings including inpatient, outpatient clinics, general practice, residential aged care facilities and community care. It contains specific information on medical leadership and decision making, with prompts for communication with patients and carers, and details on considerations around Implantable Cardiac Defibrillators with a deactivation checklist. In response to feedback from cardiology doctors and nurses, the word 'palliative' has been replaced by 'end-stage'.</p> <p>To support the introduction of the protocol, three seminars were presented to raise awareness among doctors of the non-medical needs of patients in the end stages of heart failure, and to provide training in breaking bad news. The focus was on the positive aspects of early identification of end-stage heart failure to enable patients and carers to plan for their physical and psychosocial needs. In addition, training on management of end-stage heart failure was incorporated into an annual two-day specialist heart failure course for nurses and allied health practitioners, and the project manager supports pilot sites by providing course content and arranging guest speakers for training in palliation.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Development of the protocol was informed by data collected from patients and carers. The project officer reviewed ten hospital charts (five from each site) of patients who had died in the previous 12 months. Data collected from the charts included: circumstances surrounding admission, number of admissions, expressions of distress or end of life issues, cultural issues, time line summary of contacts with acute setting, whether advance care directives discussed, anything that could be identifiers of palliative phase.</p> <p>Formative evaluation data were also collected via the following methods: a focus group was conducted with five bereaved carers; 21 heart failure nurses were sent a survey asking their opinions of what issues should be covered in patient and carer information; patient information literature currently provided by Palliative Care Queensland was analysed, looking specifically at its suitability and applicability for heart failure; 17 heart failure patients and their families completed a survey about their experiences of living with end-stage heart failure, using the Symptom Assessment Scale (SAS), the Nottingham Health Profile and the Carers' Experience with Palliative Care questionnaire.</p> <p>It was originally planned to conduct a before-after evaluation of the impact of the home intravenous frusemide pumps on patients' and carers' experiences and well-being. During the course of the project, improvements in oral medications meant that home pumps were rarely used and consequently very few patients were able to be recruited into this trial and also into the case conferencing trial.</p> <p>A process evaluation of the protocol is planned to take place in the second half of 2009. Implementation will be evaluated through an audit of the first 20 patients identified as in the end stages of heart disease by heart failure services at the two participating hospitals. The use of the protocol in a range of settings will be monitored to determine its usefulness and acceptance into clinical practice.</p>
<p><b>Impact &amp; outcomes</b></p>	<p>The deceased chart review showed that documentation was poor, with no evidence of adequate advance care planning. Only half the patients were referred to palliative care services and six out of ten patients died in hospital. Discussions about resuscitation took</p>

<b>Project title</b>	<b>QLD-5 – Hospital to Home: Palliation for Sick Hearts</b>
<i>What results were achieved?</i>	<p>place in the final days or hours of life when the family was likely to be under great stress. This information pointed to the need for support in acute care settings for the palliative approach.</p> <p>The carer focus group highlighted their need for more information about the end stage of the illness and found that breathlessness, fluid overload and medication withdrawal effects were the most difficult and distressing aspects of care during that time. Eighteen nurses replied to the survey of patient and carer needs (86% response rate). Topics identified as important were: managing symptoms such as anxiety; nausea; loss of appetite and depression; the importance of advance care planning; and explanations of how the progressing disease could affect loved ones' physical abilities and behaviours. There was also a need to explain the role of palliative care, and provide clear information about how to access equipment, nursing care and other support. The review of patient information literature in palliative care found that most of these documents were not useful for those living or caring for someone with advanced heart failure. These data informed the development of the protocol. They were also used to write a needs analysis for patient and family information which was submitted to the Heart Foundation with a request to consider producing materials specifically for the end stages of the illness. This request was declined, but led to the Heart Foundation's mentioning the trajectory of the illness more directly in its revised booklet, 'Living well with heart failure'.</p> <p>Findings from the patient and carer survey suggested that the most distressing symptoms were fatigue, pain and breathing problems (scores of 5/10 or higher on the SAS reported by 60-75% of patients). On the Nottingham Health Profile, patients reported that their greatest problems were sleep disturbance, poor energy levels and physical abilities, while carers reported difficulties with low energy levels and social isolation.</p> <p>The protocol was completed in March 2009 and was tested on 'a couple of patients' (according to the project's final report) during the process of tool refinement. Evaluation is planned for later in 2009. At the stage of writing this summary the protocol had yet to be formally accepted or trialled.</p>
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>The electronic information system developed for the heart failure services in Queensland has been modified to include information that identifies patients in end-stage heart failure, allowing better estimates of the number of patients requiring symptom palliation and care planning. At this stage, it is estimated that around 65 patients at any given time would be in need of heart failure palliation.</p> <p>Queensland Health and the Statewide Heart Failure Steering Committee are working together on a heart failure pathway for acute and post-acute settings. It is planned that the work of this project will be incorporated into the wider pathway which will ultimately direct care from referral to the end stages of the disease.</p> <p>If the trial is successful and the protocol is found to be acceptable and useful, an education and dissemination strategy is in place to promote it to clinicians. The protocol will be presented at hospital 'grand rounds' (weekly lectures) using a case study to illustrate its use. A 'road show' is also planned.</p> <p>The evaluation and dissemination of the protocol will be carried out as part of the role of the Statewide Heart Failure Coordinator (who was the project manager) in liaison with local hospital heart failure teams. This arrangement has the support of two senior clinicians, one in heart failure and the other in palliative care, who plan to continue developing the document and incorporating its use into the care their units provide.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. Once the protocol has been accepted and evaluated, it should be integrated into the pathway for heart failure management being developed by Queensland Health.</li> <li>2. Uptake should be monitored both through specialist heart failure services, via existing networks, and in primary care, which will require commitment and resources from the divisions of general practice and the management of non-government organisations.</li> <li>3. The project has resulted in improved understanding of what is required to achieve an integrated approach to palliation in heart failure. Initially a separate coordinator role was envisaged; however, it was realised that patients would best be managed under the care of cardiology teams with the input of palliative expertise. The protocol supports this integrated approach.</li> </ol>

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	<ol style="list-style-type: none"><li data-bbox="448 271 1433 383">4. More flexible funding and service provision is required for patients with advanced heart failure. Current arrangements do not serve them well, due to the unpredictable nature of their disease progression. Advance care planning should become a standard part of care, without destroying hope.</li><li data-bbox="448 405 1342 436">5. Patients and carers need more information about the end stage of heart failure.</li></ol>

<b>Project title</b>	<b>QLD-6 – Palliative Care Discharge Planning Project</b>
<b>Keywords</b>	Local, major city, RACF, community care, acute care, primary care, specialist palliative care
<b>Host organisation</b>	University of Queensland
<b>Partner organisations</b>	Palliative Care Service, Royal Brisbane and Women's Hospital
<b>Project funding</b>	\$268,411 incl. GST
<b>Project timeframe</b>	May 2006 to 31 October 2008, extended to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop and evaluate a discharge planning process for patients with palliative care needs treated at the Royal Brisbane and Women's Hospital (RBWH). The discharge planning process will include a patient-held record and case conference involving the patient's general practitioner (GP), the hospital team and relevant community-based services.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Assess the existing discharge planning processes from RBWH to home.</li> <li>▪ Develop and pilot test an improved discharge planning process including purpose-designed documentation.</li> <li>▪ Implement and evaluate the new process.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> There is anecdotal evidence of poor communication between the hospital and primary health care providers when patients are discharged from acute care. A complication at RBWH is that the palliative care service is consultative only and its advice may not be included in discharge information provided to community care. Discharge information can take several weeks to reach the GPs and may contain no mention of the referral to palliative care. Structural communication mechanisms are needed to save time, give patients more control, help them remember information given by many different clinicians and prevent inappropriate readmissions. This project trialled two mechanisms: patient-held records and case conferences for complex patients. These will take place by telephone, and involve the patient's GP plus multidisciplinary team (palliative care nurses, chaplain, social worker, physiotherapist, occupational therapist, etc).</p>
<b>Project planning and development</b>	<p>A steering committee was established, a project officer employed and a project plan developed, along with data collection protocols and instruments. Memorandums of Understanding were written and signed by project partners.</p> <p>Existing discharge procedures were reviewed. Chart audits were carried out, along with in-depth interviews with patients and carers, a survey of GPs, and six focus groups involving 21 hospital staff and five community health staff. The findings from these consultations were used in developing and refining the intervention documents including a process for patient discharge.</p> <p>To inform the design of the intervention, a systematic literature review was carried out focusing on discharge procedures for palliative patients and the information needs of patients, carers and community-based health care providers. (It was found that a comprehensive review had recently been published, which also provided an evidence base for the project.)</p> <p>Ethics approval was granted by University of Queensland 13 October 2006 and RBWH 1 December 2006.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>A patient-held record (PHR) folder was developed, endorsed by the steering committee, approved by RBWH and published. This consists of a green vinyl folder containing an information sheet, communication log, palliative care plan (PCP) form and envelope for summaries and medication lists, with key information on the front regarding the patient's preferred location for end-of-life care, and whether advanced health directives and enduring power of attorney are in place. An information sheet describing changes to discharge planning strategies was also developed, to explain concisely how the patient-held record folder is used.</p> <p>Summaries and consent forms for the case conferences were finalised. Implementation of the PHR and case conferences began in 2008. The project officer provided administrative support for the case conferences. Training and information sheets on the use of the PHR</p>



Project title	QLD-6 – Palliative Care Discharge Planning Project
	<p>were provided to hospital staff.</p> <p>A total of 31 patients received the intervention (the case conference, the PHR, or both; the report does not specify numbers in each group). The target group was discharged patients with complex medical and psychosocial issues. Originally only those with a prognosis of one month were recruited, but this was broadened to all patients with an Australian Modified Karnofsky Performance Score (AKPS) of 20. Due to the high attrition rate for patients, referral criteria were also expanded to include patients from general wards (not just oncology) and those living in regional areas.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The new discharge processes were evaluated with a pre-post cohort design. The evaluation plan included assessment of outcomes at three levels:</p> <p>Level 1 – “Do the interventions improve self-efficacy, symptom management, maintenance of function, quality of life and satisfaction with care for patients and carers?” (Patient and carer questionnaires on satisfaction with care (pre- and post-intervention); AQEL (quality of life scale) for carer and patient; AKPS for patient; demographics survey; patient enablement instrument (modified); palliative performance scale (PPSv2); interviews)</p> <p>Level 2 – “Do the interventions improve perceptions of professional support, clarity of roles and responsibilities, and communication between hospitals and primary care?” (GP surveys pre- and post-intervention; focus groups with health professionals)</p> <p>Level 3 – “Do the interventions reduce the rate of rehospitalisation and inappropriate admissions, increase the use of EPC items and change prescription patterns?” (hospital and Medicare data)</p> <p>Findings from Cohort 1 were compared with Cohort 2 (post-intervention). It was intended to split Cohort 2 into two sub-groups (PHR only; PHR plus case conference). It was expected that one in ten participants would receive a case conference; these would have the most complex needs and would therefore not be followed up regarding the PHR.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>Before implementation, ten interviews with patients and carers were conducted. They were asked about their preferences for content in the PHR. Surveys were sent to 410 GPs at 163 practices in the northern area of Brisbane, and 82 were returned (20% response rate). More experienced GPs (those with 21 or more years of experience) were more likely to be confident in their ability to provide palliative care; to know of a person, group or organisation they could call on for advice; and to feel satisfied that their after-hours arrangements met the needs of palliative care patients. They were also most likely to know which Medicare items supported GPs in providing palliative care in the community. Most GPs preferred telephone contact and written information (if timely) as methods of communication between themselves and the hospital, while teleconferences were seen as potentially too time consuming. About half the GPs who responded were in favour of patient-held records.</p> <p>Data collected from the first cohort, and from health professionals before implementation, contributed to the development of the intervention and documentation as described above. Due to difficulties in recruitment and patient attrition, both cohorts were considerably smaller than anticipated. Cohort 1 (usual practice) consisted of 33 patients recruited and followed up in the six months prior to implementation of the PHR. Cohort 2 (intervention) was a total of 31 patients. The report does not state how many case conferences were conducted.</p> <p>Qualitative feedback on the PHR indicated that it was useful to patients and carers as a source of information (e.g. contact details, medications list), for storage of relevant documents, as a mechanism for communicating between health professionals, for facilitating patient independence and providing support to carers. Benefits for health professionals were access to the contact details of hospital staff, a mechanism for communicating between health professionals, access to discharge documents and the palliative care plan which documents the patient’s end-of-life wishes at the point of discharge. There were some challenges associated with the PHR, including the fact that some patients and carers did not use it, either because they didn’t understand its purpose or were overwhelmed with other matters, and some health professionals were not sure how to use it. Documents were sometimes missing or not updated, and the PHR increased the workload for palliative care service staff.</p> <p>Qualitative data from health professionals regarding the case conferences indicated that this process helped them provide continuity of care and holistic care to patients and carers. Case conferences were seen as a time-efficient and effective way for the hospital and</p>

Project title	QLD-6 – Palliative Care Discharge Planning Project
	<p>community-based providers to communicate and solve problems, and also as a means for educating non-specialist health care providers in palliative care and building relationships between specialists and primary care. Aspects of care addressed by the conferences included: pain management, other symptom management, end-of-life wishes, access to palliative medicines, accommodation issues, psychosocial issues, managing patients' plans for travel and other activities away from home (e.g. a fishing trip), and procedures for readmission to hospital for terminal care. Challenges included: deciding when to hold it (pre- or post-discharge) and who needs one; the cost of the call; and increased workload for palliative care service staff organising the conference.</p> <p>Comparison of the two patient/carer cohorts indicated that there were significant pre-existing differences between the groups which may have limited the ability to detect an effect of the intervention. There were no differences between the patient groups in terms of function (AKPS), status (PPS) or quality of life (AQEL), but the post-intervention cohort scored significantly higher on the patient enablement index, with a greater understanding of their illness, better coping and a trend towards better self-management of their illness. Carers in Cohort 1 had higher quality of life (AQEL) than those in the intervention group, possibly due to pre-existing differences between the groups. Patients in the post-intervention cohort reported slightly higher use of GP home visits and fewer telephone contacts with the palliative care services at RBWH following discharge than patients in the first cohort. Medicare data on service use were not available to the project due to problems with the patient consent documents.</p> <p>At discharge, hospital nurses rated intervention patients as less affected by symptoms (other than pain), better able to share with family and friends, more involved in treatment decisions and having wasted less time on hospital appointments than the comparison group. The hospital nurses' observations of the discharge process favoured the intervention group, with more overall satisfaction and less time required to liaise with community-based providers. Five days after discharge, community nurses' observations of patient condition did not differ between the intervention and comparison groups. The intervention patients were more likely to have sufficient information for the planning of care post-discharge, and there was a trend for greater involvement in treatment decisions.</p> <p>Twelve community nurses and 13 GPs provided data on satisfaction with the PHR. Feedback was mixed: approximately half thought the PHR had been useful in various ways, including improving communication, helping the patient and carer manage care, and saving the provider time in finding missing information. Twelve health professionals who took part in case conferences provided feedback on the process. Almost all agreed that the information provided via the conference would assist in managing the patient concerned, and other palliative patients, after discharge from hospital; that the agenda was appropriate; and that they would use this strategy in future. All disagreed with the statement that the case conference was not a good use of time for organising post-discharge care.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The case conferences will continue, with administrative support now provided by the palliative care service (instead of the project officer). The PHR will probably not be sustained due to the work involved in managing the information and training people in its use. The palliative care service does not have the resources to carry this additional workload. However, there is a proposal for the community nurses to trial a modified version, giving it to patients earlier in the disease trajectory. There is also a possibility that electronic versions of some components of the PHR (the palliative care plan and case conference template) may be incorporated into the Enterprise Discharge Summary currently being rolled out in some parts of RBWH. This could enhance the PHR, but would not alleviate the significant problems of late completion of the Medical Discharge Summary and medications record, which need to be included in the PHR on discharge.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. The case conference model developed by the project promotes smoother transitions for patients from the hospital setting to the community and brings together hospital staff with primary care and community services.</li> <li>2. The PHR is difficult to implement in a setting that is not adequately resourced, but contains components that are not as resource-intensive and have been acknowledged as valuable.</li> <li>3. Both the case conferences and palliative care plan (part of the PHR) provide opportunities for informal training of non-specialist providers, particularly GPs and community nurses, in palliative care.</li> </ol>

## SA Project Summaries June 2009

<b>Project title</b>	<b>SA-1 – Case conferencing and care planning: an exploratory study</b>
<b>Keywords</b>	Local, major city, community care, primary care, specialist palliative care
<b>Host organisation</b>	Daw House Hospice Foundation Inc
<b>Partner organisations</b>	Southern Division of General Practice; Aged Care and Housing Group Inc.; University of Western Sydney; University of Sydney
<b>Project funding</b>	\$268,753.10 incl. GST
<b>Project timeframe</b>	24 April 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> Under a two-phased approach, to develop a care plan and case conferencing package, and undertake a study analysing case conferencing and care planning for people with a life-limiting illness.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Explore case conferences and General Practitioner Management Plans (GPMPs) / Team Care Arrangements (TCAs).</li> <li>▪ Develop an evidence-based case conference and GPMP/TCA information package tailored to the palliative care setting.</li> <li>▪ Develop a guide for palliative care services to maximise the effectiveness of care coordination.</li> <li>▪ Develop a PowerPoint presentation template for dissemination to other palliative care services.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The study developed and tested two strategies for coordinated care. Based on previous work, the study specified a trigger point for intervention when care coordination is likely to be most effective. This is based on the functional status of the patient. The study provided, compared and evaluated mechanisms for bringing together all services involved in the care of the patient, and involving the patient and carer in care planning. Case conferencing can be used for discharge planning, e.g. from home or inpatient facility to Residential Aged Care Facility (RACF), so it supports smooth transitions. The patient and family are central to the care coordination process and drive the agenda.</p>
<b>Project planning and development</b>	<p>A steering committee was established and the project officer set up systems to facilitate communication between the project, host organisation, steering committee and other stakeholders including the Southern Adelaide Division of General Practice.</p> <p>Protocols for the care planning processes to be trialled were drafted and quality checked by one of the project's principal investigators. Documents for care plans and case conferences were designed and submitted to project partners in Sydney for approval, to ensure they could be analysed. The project officer and manager role played and scripted the case conference process. Nine GPs took part in a focus group at which the goals of the study were explained and their input sought on practicalities such as roles, responsibilities and documentation. Their feedback informed the development of the patient questionnaires and the draft care coordination package.</p> <p>Ethics approval was granted by Repatriation General Hospital Ethics Committee on 19 January 2007. Changes to the study protocol required subsequent amendments to the approval.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>Adult patients referred to Southern Adelaide Palliative Services (SAPS) were eligible for the study if they lived within the geographic region visited by SAPS nurses, could speak English (or had an interpreter available), were willing to take part, had a GP willing to take part, and did not have impaired cognition. Functional status was assessed with the Australian Modified Karnofsky Performance Score (AKPS); a score of &gt;30 was required for entry into the study, and a score of ≤60 was the trigger for intervention (described below). Carers were eligible if they were willing and could speak English.</p> <p>The study was a cluster randomised trial: participants were randomised to intervention groups based on GP practice. Of the 162 patients referred to the project, 131 were assessed for eligibility and 52 ultimately took part in the study. These patients were</p>

Project title	SA-1 – Case conferencing and care planning: an exploratory study
	<p>randomised to the two intervention groups: case conferencing followed by a care plan (n=29) and care planning only (n=23).</p> <p>Documents used for case conferences were based on a kit used in the Palliative Care Trial conducted previously by the host organisation, and conformed to Medicare requirements for reimbursement. A conference was scheduled when the patient's functional status declined, indicated by an AKPS score of 60 (AKPS &lt;70 means the patient needs a carer to help with activities of daily living). This timing was based on previous work which found that patients at this point were most likely to benefit from case conferences. The project officer arranged each conference in consultation with the patient's palliative care nurse. Participants always included the patient and/or carer, the GP, the palliative care nurse and the palliative care consultant. Other current health providers known to the patient, such as the registered nurse from a residential aged care facility or a community-based allied health worker, may also be invited to take part. Case conferences were audio taped and transcribed for qualitative analysis. A total of 21 case conferences were held; eight did not eventuate because the patient died, his/her function declined to AKPS &lt;40, or the GP withdrew consent.</p> <p>After each conference, a care plan was written outlining the management goals and plans based around the patient's needs. The GP wrote the care plan, together with at least two other healthcare providers. The documentation conformed to Medicare requirements for reimbursement and involved a General Practitioner Management Plan (GPMP), a Team Care Arrangement (TCA) or both. A total of 15 patients who were not in the case conference intervention group also had care plans written for them by their GPs, working with at least a palliative care nurse and palliative care specialist. (The remaining eight patients in the 'care plan only' group did not have care plans written.)</p> <p>Based on the findings of the study, a care coordination package and template was developed, suitable for use by health care professionals in palliative settings. A PowerPoint presentation was written to provide training in the use of the package.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Level 1: Patient clinical outcomes were assessed using questionnaires. Measures included: AKPS, performance status, symptoms, quality of life, number of unplanned admissions, number of calls, number of services accessed, resource use. Satisfaction questionnaires for patients and carers were administered three weeks after the case conferences/care plan. These were designed for the study and piloted in a palliative care inpatient facility. Carers also completed the FAMCARE measure.</p> <p>Level 2: Naturally occurring variations in case conference processes were examined qualitatively, through grounded theory analysis of transcripts. Content analysis of care plans was conducted. Questionnaires were used to assess GPs' satisfaction with care planning processes.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>As indicated above, some of the patients randomised to groups did not receive case conferences or care plans. Their participation in the study was affected by their illness trajectory (including rapid changes in status) and varying ability to communicate due to illness. In cases where the patient was eligible and consented, a total of 22 GPs declined to take part. Some were too busy and felt burdened by extra paperwork; others worked part-time so were unable to fit a long consultation into their schedule; others could not do a home visit; or were away and their locum was unwilling to do a case conference. Some felt they knew palliative care staff well so there was no need. Some patients were unable to nominate a GP because they went to large clinics, where they saw a different doctor for each appointment.</p> <p>Sixteen patients and four carers completed satisfaction surveys. Both groups felt that the care coordination activities had given them an active voice in healthcare decisions; they felt listened to and involved in the decision making by the healthcare team. All patients felt their knowledge of their illness was viewed as useful and important, and all felt able to ask questions, and to talk about feelings.</p> <p>Sixteen GPs completed the satisfaction surveys. Only three of these respondents had been involved in a case conference. Average satisfaction with case conferencing and care plans were 5.7 and 5.0 respectively, out of a maximum score of 10. Nevertheless, GPs agreed that both care coordination methods allowed identification of patient symptoms and problems and they valued the interaction with the palliative care service. Interactive communication via case conferences was seen as more useful and effective than a written care plan. The quality of care plans was improved if a case conference was held first,</p>

Project title	SA-1 – Case conferencing and care planning: an exploratory study
	<p>according to two of the three respondents who had experience of this process. Paperwork and lack of time were the main barriers to participation in care coordination activities.</p> <p>Qualitative analysis of the case conferences identified a need to define the purpose, leadership, roles and responsibilities of participants more clearly and to check that patients and carers understand the information provided by the medical, nursing and other health professionals during the conference. The effectiveness of the case conferences could also be improved by providing a summary of the patient's recent medical history, including tests, medications, involvement of various healthcare services, and current or future needs, to each participant prior to the conference. This information should be tailored, with a 'different level of detail' for the patient and/or carer. More time could then be spent in planning and coordinating care, rather than on exchanging information. The thematic analysis found that care plans were not enhanced by a prior case conference.</p> <p>The evaluation concluded that care coordination should be part of the 'core business' of palliative care services rather than relying on GPs to drive this process. A dedicated person should be employed by the palliative care service to identify when case conferences are required and who should attend them, engage and reassure the GP, lead the case conference and formulate and implement outcomes.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The intention of the project was to make case conferencing part of routine clinical practice by demonstrating its effectiveness and providing guidance on how to achieve good results. The project examined the most effective aspects of case conferencing and produced a package and template for use by other services, with supporting training materials.</p> <p>To sustain care coordination there needs to be someone within the palliative care service who drives the process. The palliative care service is in the best position to identify the trigger for care coordination (i.e. reduction in patient's functional status), for example at weekly meetings, and should therefore initiate the process. Ideally there would also be someone (e.g. the practice manager) who ensures GPs attend case conferences and are remunerated. This should be formalised as part of their role (e.g. a dot point in their job description) and training provided.</p> <p>A follow-on NHMRC grant application is planned for the 2010 project grant round to continue this line of research and address questions raised by this study.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. Case conferencing is the preferred care coordination activity</li> <li>2. Case conferencing must be initiated by the palliative care service if it is to be successful</li> <li>3. Palliative care staff should receive training on how to conduct case conferences</li> <li>4. Before a conference, all relevant clinical information should be provided to participants, and the purpose of the conference made clear. The palliative care nurse should lead the conference, and each participant's role and responsibilities should be understood.</li> </ol>



<b>Project title</b>	<b>SA-2 – Mid North Palliative Care Referral and Care Planning Project</b>
<b>Keywords</b>	Local, regional, RACF, community care, acute care, primary care, specialist palliative care
<b>Host organisation</b>	Mid North Regional Health Service
<b>Partner organisations</b>	None
<b>Project funding</b>	\$134,101 incl. GST
<b>Project timeframe</b>	26 April 2006 to 30 June 2008
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop infrastructure and resources to enable a coordinated approach to care planning that will ensure that palliative care clients living in the Mid North region of South Australia will have access to the appropriate support and services they require.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Improve collaboration between services involved in providing palliative care services to people in the Mid North.</li> <li>▪ Establish a flexible regional referral and care planning process to meet the needs of palliative care clients in the Mid North area.</li> <li>▪ Increase the control and participation of palliative care clients in the development and review of their health care plans and access to services.</li> <li>▪ Support the smooth and appropriate transition between settings of care in the Mid North Health Area.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project was built around the three objectives of the program and involved setting up memorandums of understanding (service agreements) between the Port Pirie Hospital and area health service and the health units in outlying regions based on a gap analysis against the Palliative Care Australia (PCA) National Standards. The project established a flexible referral process to be used throughout the region, plus a patient diary and in-home care plans to facilitate smooth transitions and meet the needs of patients and carers.</p>
<b>Project planning and development</b>	<p>A project action plan was drawn up and a steering committee established. A project officer was appointed in October 2006. Twenty former carers were invited to form a focus group; 13 agreed, and a past carers' focus group was established to provide advice on the content and style of the patient diary. The project reimbursed carers' focus group members for expenses, including travel to meetings.</p> <p>The project began with a gap analysis for the region: a sheet was sent to regional areas outlining what should be delivered according to the PCA National Standards and identifying what was currently provided and where the gaps were. The regional services defined where they saw themselves in the levels. A workshop was held in Port Pirie, with a guest speaker to provide guidance. Following this workshop, individual service agreements with each regional health service were drawn up to address these gaps.</p> <p>Ethics approval was required for the evaluation of the patient diary. The application was drafted, approved by the regional health service management committee and submitted to the Department of Health HREC in Adelaide. Approval was granted in December 2007.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>A Memorandum of Understanding (MOU) was signed with the Royal Adelaide Hospital. The hospital formally agreed to provide after-hours support, education for specialist and primary care professionals on a routine scheduled basis, and participate in the care planning model. This helped define what services would be provided within the region, setting the scope for the regional model. Following consultation with senior health unit managers, MOU were developed between the specialist palliative care service and the primary care providers of the eight health units in the Mid North region. In addition, MOU were signed between the palliative care service and eight aged care providers.</p> <p>The project officer researched and reviewed other regional models of referral and care planning and developed a flow chart for referral to palliative care services in the Mid North region. A resource folder was assembled for each health service and residential aged care facility (RACF) in the region, containing flow charts/pathways developed by the project: in-home management plan; after-hours support for regional primary health care professionals; referral process for palliative care services; assessment and care planning for regional palliative care clients. All these resources were developed with reference to the PCA National Standards. The folder also contains the <i>Palliative Care Clinical Pathway and</i></p>



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	<p><i>Resources folder</i> developed by the Adelaide Hills Rural Palliative Care project, symptom control pathways and <i>Outline of Palliative Medicine</i> by Victor Chan. Education sessions for primary care providers on the use of the resource folders were carried out throughout the mid-North region.</p> <p>Over many years, the Port Pirie Palliative Care Team had noted the need for a systematic way for clients and carers to record and store information regarding their care, including doctors' names, appointments, treatments, travel dates and so on. Clients and carers often kept these records on loose sheets of paper or in notebooks. The information was not in any kind of order and there was a high risk of it being misplaced. To alleviate this problem, the project reviewed existing client-held records and selected the 'Patient Diary' developed by the Adelaide Hills Rural Palliative Care Project for trial in the Mid North region. The diary was included in the admission package for new clients of the palliative care service and staff of the service briefed clients on how to use the diaries. After it was identified that some clients had difficulty completing the diaries, palliative care volunteers and support workers were invited to attend a training session enabling them to assist clients (four attended). Diaries were also distributed through ten GP surgeries (with a total of 26 GPs). A wire binding machine was purchased for adding pages to the patient diary, and a procedure written for its use.</p> <p>Education sessions on the new referral and care planning processes were delivered to primary health professionals and nurses in hospitals, community health and RACF. The Mid-North Palliative Care Resource Guide was disseminated to primary health professionals. Diaries were distributed to patients via 26 GPs in the region and the distribution strategy was evaluated.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Level 1: Qualitative interviews were conducted with 17 patients or carers who had used or were using the diary. Interviews were conducted face-to-face with a schedule of ten questions. Past carers' group members also completed a survey about their experiences of the group.</p> <p>Level 2: Four individual surveys were distributed to 15 primary health professionals in the region who had palliative clients (this number was small because there were few palliative care clients in the region at the time of the project). These surveys focused on: the patient diary (seven responses); the Mid-North Palliative Care Resource Guide (ten responses), the after-hours support flow chart (seven responses) and the in-home management plan (two responses).</p> <p>Level 3: Feedback from GPs and practice nurses on the effectiveness of the distribution strategy for the patient diaries. A record was kept of the distribution, and surgeries were contacted by telephone six months later. Receptionists were asked whether they were familiar with the diary and how many they had left. A survey was sent to the 26 GPs at these ten clinics, with a 58% response rate.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>During the face-to-face interviews with three clients and 14 carers, saturation point was reached as later participants duplicated responses and information provided by previous participants. Ten of the 17 participants used the diary regularly. Of these, nine reported that health professionals had written in the diary and eight said health professionals had read the diary, reducing the need for the patient or carer to repeat information. Most took the diary to hospital with them, and all ten could recall comments from health professionals that the diary was useful. The key finding was that the diary improved client care and communication with service providers. In addition, seven people reported that the diary had improved communication between the patient and his or her family. Suggestions were made for adding pages to some sections of the diary, and these were acted on when it was reprinted.</p> <p>The patient diary was the subject of one of the surveys of primary care providers. Only three of the seven primary care providers who responded to the survey had palliative patients (all three were registered nurses). They had all used the patient diary, reporting that it had improved communication between service providers and was helpful to the service provider. Two had written in the diary.</p> <p>Only five of the primary care providers who responded to the survey had used the resource guide. The clinical pathways were seen as the most useful section of the resource guide. The low uptake was mainly because there were relatively few palliative clients in the region at the time. For the same reason, only two providers had used the after-hours support flow chart, but other respondents agreed that they felt supported in their role of caring for</p>

<b>Project title</b>	<b>SA-2 – Mid North Palliative Care Referral and Care Planning Project</b>
	<p>palliative clients by having access to the flow chart.</p> <p>The evaluation of the in-home management plan could not proceed as planned because no clients were currently using the plan. Two providers said it was inconvenient having to photocopy the form each time it was updated and they were not sure whether clients or carers referred to the form.</p> <p>Of the ten GP surgeries that received patient diaries, nine had given out at least one diary to a patient and six receptionists (who answered the phone on the day of the survey) were aware of the diaries. Fifteen GPs responded to the survey, indicating that they had been distributing diaries in their consulting rooms and would continue to do so. Their comments on the diary led to additions and modifications.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The project arose from an identified need and desire for change which predated the Care Planning Sub-Program. Key stakeholders were involved throughout the consultation and development period of the project and provided detailed input into the resources, including the flow charts and pathways. The project officer's position was within the regional palliative care team, so the project was regularly discussed at team meetings, helping to embed the new processes developed by the project into the team's routine practice.</p> <p>The Mid North Palliative Care Resource Guide will be updated, with dates set for an annual review. Palliative care volunteers have been trained to help carers to complete the patient diary, if needed and 1000 copies of the diary (with a new, local photo on the cover) have been purchased for distribution through GP surgeries. The Memoranda of Understanding between the palliative care service and the Royal Adelaide Hospital, primary care providers and residential aged care providers respectively have defined their roles and responsibilities in the new regional model. Each MOU has a review date.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. It is vital to gain the consumer's perspective in this kind of project and there is a need to establish a participation strategy (in this case, a past carers' group) to enable consumer involvement in planning and service development.</li> <li>2. At a national level it would be useful to consider producing a client-held resource or diary and making it available (free or at low cost) to all newly diagnosed cancer patients and others diagnosed with a terminal illness. The person should receive the diary as soon as possible after diagnosis.</li> </ol>

<b>Project title</b>	<b>SA-3 – Yorke Peninsula Palliative Care Planning Project</b>
<b>Keywords</b>	Local, regional, remote, RACF, community care, acute care, primary care, specialist palliative care
<b>Host organisation</b>	Northern Yorke Peninsula Health Service
<b>Partner organisations</b>	None
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	21 April 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a communication package that would improve transitions between settings of care and provide consistency of services for palliative care clients living on Yorke Peninsula.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Review and improve existing referral pathways and communication processes in line with community need, following consultation with stakeholders.</li> <li>▪ Centralise information with the client to promote optimal transfer of this information between providers and the client and carer.</li> <li>▪ Achieve greater continuity of care as a result of the client's enhanced ability to access and convey accurate information regarding their own care.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project was set in a rural area of South Australia, with up to four hours' travel time to metropolitan hospitals. When palliative clients moved between local primary care and specialist metropolitan services, poor communication often resulted in discharge planning issues, client confusion, delay in transmission of vital information, and potentially compromised client care. The diary was intended to improve referral processes and communication between clients, carers and service providers and promote autonomy and increased knowledge for the client regarding their own care.</p>
<b>Project planning and development</b>	<p>A project officer was appointed (full time) in January 2007. While the original project aimed only to create and implement a client-held record, the project was completely redesigned and a new funding application submitted to, and approved by, the Department of Health and Ageing in March/April 2007. The new project was broader in scope and aimed to adapt and trial a patient diary, based on the Adelaide Hills Rural Palliative Care Project's diary, as one component of a communication package. The other components were home-based record and a staff support folder.</p> <p>An advisory group was formed. Members included representatives from volunteer groups, allied health, Aboriginal health, staff of private and public hospitals and non-government service providers. In addition, a number of project 'champions' were identified, including several community health nurses, practice nurses and managers.</p> <p>Ethics approval was granted by the SA Department of Health HREC on 9 July 2007.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>Before developing the package, the project officer consulted community health staff through a series of workshops at all sites in the region. The purpose of these workshops was to identify needs and preferences around common documents and processes. This consultation was repeated to examine the draft resources. The project officer attended a Cancare retreat to talk to cancer patients and their carers about their communication needs and preferences, and also consulted with past carers via telephone and face-to-face interviews.</p> <p>The diary developed by the Adelaide Hills Division of General Practice during its rural palliative care project was judged to be a high-quality resource but too metropolitan in focus. Permission was given to adapt the diary and trial it in the Yorke Peninsula region. 'My health diary' was published as an A5 folder with a slip cover to enable patients to personalise it (this was later changed to a ring-bound A5 format to reduce costs). Much of the original content was retained but with simplified language and some new sections: patient goals; health service maps of the Yorke Peninsula and Mid-North; information on local services and contacts; accommodation in Adelaide; a transport plan and checklist; a section on 'Who has been to see me?'; a 'Jot that down' section for reminders to ask about medication, appointments etc; test results; glossary; family history of health problems relevant to the diagnosis. The need for signatures was removed from the medications</p>

Project title	SA-3 – Yorke Peninsula Palliative Care Planning Project
	<p>section. These changes were made following extensive consultations with the advisory group, past carers, current patients and health professionals.</p> <p>Following the amalgamation of the three health services on the Yorke Peninsula, there was a need to create and use a more consistent set of documents for community health workers with palliative clients. The project officer identified numerous examples of documents and staff were given the opportunity to examine these and give feedback on their preferences. The final Home-Based Record included an alert sheet; medication therapy sheet; information summary; health care plan; emergency care plan; client consent form; and progress notes.</p> <p>A support package was developed to help community nurses set patients up with the diaries. In addition, it was identified that some staff had little experience in providing palliative care, so there was a need for an induction process to promote effective use of the new resources developed by the project. This described the project's history, support networks and resources across the region, expectations, standards and processes and included several scenarios. Online training and mentoring by more senior staff was provided. The implementation of this induction package is ongoing.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Level 1: Questionnaires for patients/carers to identify outcomes and evaluate the diary. Level 2: Questionnaires for health professionals.</p> <p>The questionnaires were designed for the study, reviewed by the NET, Director of Community Health, Senior Community Health Nurse and the Advisory Group and granted ethics approval. Clients, carers and service providers were given a pre-implementation questionnaire and two implementation questionnaires, six weeks apart. The questionnaires included qualitative and quantitative responses.</p> <p>It was planned that clients would be referred through community health intake meetings. Suitable clients would be contacted by community health staff and introduced to the package, and the pre-implementation questionnaire would be administered. This did not work well, so it was agreed that community health staff would invite clients to take part and those who agreed would receive a home visit from the project officer. There were still very few referrals, however, and once clients were considered 'palliative' they were often far advanced in their disease trajectory and therefore less able to benefit from the project resources and to take part in evaluation. The referral criteria were then broadened to include clients with a variety of chronic and life-limiting illnesses.</p> <p>A total of 43 clients were invited to take part in the trial, and 39 accepted and completed pre-implementation data collection. The first and second implementation questionnaires were completed by 36 and 34 clients respectively. Twenty carers completed both the pre-implementation and initial implementation questionnaires and 16 completed the second implementation questionnaire.</p> <p>Pre-implementation questionnaires were sent to 110 and returned by 91 service providers, including volunteers, general practitioners, palliative care specialists, community, Aboriginal and allied health workers and hospital staff. Almost ¾ of participants were female, 14% identified as Aboriginal, and 42% were community health nurses. The two implementation questionnaires were completed by 62 and 63 service providers respectively. In order to increase the response rate from GPs, the project officer interviewed them face-to-face.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>No clients rated their communication with their service providers as 'unsatisfactory', and there was little change in their ratings of this communication over the course of the project. Before implementation of the package, the most common methods for clients to keep track of information relating to their care were lists, printed information, letters and diaries, while carers most often relied on lists and their memories. Only five of 39 clients strongly agreed that their existing methods improved communication between all those involved in their care, while 12 strongly disagreed. Following implementation, clients and carers were asked to rate the usefulness of elements of the communication package. The diary rated very highly with both groups (average of over 9 out of 10 on the final implementation questionnaire) and was seen as the most useful component.</p> <p>Service providers' ratings of their communication with each other improved over the course of the project, particularly relating to GPs, specialists and home visiting services. For these three groups, the proportion of respondents rating communication as 'good' rose from around a third to around half by the final questionnaire, although no inferential statistics were performed and around a third of service provider participants were lost to follow-up, so</p>

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	<p>these numbers are indicative only. Like clients and carers, service providers considered the diary the most useful component of the communication package, giving it an average rating of 7.73 out of ten on the final questionnaire (n=63).</p> <p>The home-based record was only used by three clients during the trial. Reasons for the low uptake included the fact that some clients were not referred through community health and so did not need this resource. Community health staff felt that completing the record took time away from addressing the client's needs. They were unwilling to duplicate information by writing in two separate documents, one in the client's home and one in the office. (The need for a review of documents has been acknowledged by others, however; Country Health SA is currently consulting with palliative and primary health providers on a proposal to standardise documentation for palliative care across the State.)</p> <p>Qualitative feedback from the evaluation showed that the patient diary had allowed clients to become more proactive in issues regarding their health care. It provided information they might otherwise have missed, for example on transport and accommodation, and encouraged discussions around topics that may not otherwise have been addressed, such as Advance Care Directives. It was acknowledged as a worthwhile record of a family's health history which can continue to assist carers and other relatives after the client is deceased. Positive feedback on the diary was also received from service providers.</p> <p>Those clients who used the diary did so very effectively, taking it with them to medical appointments. It was used successfully by a diverse group of clients, from age 12 to 80, with a variety of chronic or life-limiting diseases. Another group of clients did not use the diary at all, some due to poor literacy.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>There has been extensive consultation with stakeholders to ensure the diary is a relevant and useful resource, and preliminary evaluation results are encouraging. The diaries were reprinted in a cheaper, spiral-bound version with a local photo on the cover; a total of 500 copies are available for distribution.</p> <p>Although it was not needed during the project, as the project officer introduced the diaries to clients, the support package will be useful for sustaining the project. This document sets out in detail the process of referring patients who may benefit from the communication package and includes a script for the community nurse and copies of evaluation questionnaires for clients and carers.</p> <p>The Division of General Practice has been promoting the diaries and encouraging GPs to distribute them.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. The diary is an adaptable communication tool which is user-friendly. There is preliminary evidence that it empowers clients and gives service providers greater access to accurate information.</li> <li>2. In some cases, the diary's usefulness is limited by the client's or carer's low literacy levels. This problem could be addressed by training volunteers to assist with completing the diary.</li> <li>3. Further evaluation is required to establish the longer-term impacts on clients and carers.</li> <li>4. There is a need for increased awareness in the community of the services available to palliative patients and carers. This needs to be addressed at the initial consultation and plans need to be in place so that each client has a 'fallback strategy' to access services when the need arises.</li> <li>5. Having the word 'palliative' in the title of the project presented problems. Some clients and carers became distressed when confronted with this language as they had not thought of themselves or their loved ones in this way. For this reason, project officers conducting palliative care projects should receive bereavement training to deal with difficult conversations.</li> <li>6. The project could be sustained by distributing diaries through GPs, coordinated by Divisions of General Practice. Diaries should be given out at the time of diagnosis, possibly by practice nurses or by the community health team's palliative care coordinator or chronic disease nurse.</li> </ol>



<b>Project title</b>	<b>SA-4 – Metro Acute Palliative Care Resource (MAPCARE)</b>
<b>Keywords</b>	State-wide, major city, RACF, community care, acute care, primary care, specialist palliative care
<b>Host organisation</b>	Palliative Care Council of South Australia Inc
<b>Partner organisations</b>	Lyell McEwin Hospital; Royal Adelaide Hospital; Modbury Public Hospital; Queen Elizabeth Hospital; Repatriation General Hospital
<b>Project funding</b>	\$121,957.00 incl. GST
<b>Project timeframe</b>	1 May 2006 to 31 July 2007
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To create, distribute and introduce a user-friendly tool/resource in the acute care sector in Adelaide that would improve patient, carer and community outcomes by: streamlining palliative care referrals and care planning; directing primary health care providers to existing community resources and evidence-based information; supporting the implementation of best practice as defined by the <i>Standards for Providing Quality Palliative Care for all Australians</i>.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Build capacity of acute ward staff to provide quality end-of-life care.</li> <li>▪ Consolidate links between acute ward staff and specialist palliative care services.</li> <li>▪ Increase awareness of all aspects of palliative care.</li> <li>▪ Define roles and create networks between specialist and primary health care providers.</li> <li>▪ Reduce fears regarding referral to palliative care services by non-cancer specialist units.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The resource was designed to provide accessible, current information for acute health care providers to support their work and practice. For example, to help them in understanding criteria for referral, provide checklists of actions to consider when making decisions, and give grounded, practical assistance in planning care and discharge. The project involved use of multidisciplinary teams (MDTs) in focus groups to establish language and content and to review the resource to reflect their current standards of practice and expectations. The resource acts as a prompt for involving other disciplines, including allied health, in palliative care planning.</p>
<b>Project planning and development</b>	<p>The project officer was appointed on 10 July 2006 for the duration of the project. A steering committee was established and terms of reference developed. A Memorandum of Understanding (MOU) was signed between the host organisation and working partners. Project plan and timelines were developed. The project officer reviewed resources available locally and nationally and found that there was nothing similar to what was proposed for this project.</p> <p>Ethics approval was not required.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>A web architect was engaged to construct the website and design the navigation, and a domain name was registered. Webmasters from public hospitals in the Adelaide area were contacted to facilitate inclusion of the resource in their intranet sites. A graphic designer was engaged to create the format and logo for the resource.</p> <p>Focus groups were conducted at 11 sites, including staff from public and private hospitals, transition and residential aged care facilities (RACFs), with a total of 152 participants, and their feedback was integrated into resource. Detailed content of the resource was drafted and edited by the steering committee. In addition to the project tasks, the shared referral form used in Adelaide was revised and a map showing the locations of specialist palliative care services and community based supports throughout SA was created (a joint initiative with PCCSA). A communication plan was developed.</p> <p>The first draft of MAPCARE was reviewed by steering committee and other stakeholders and feedback incorporated into the resource, which was then piloted at 30 sites (wards/areas) in metropolitan Adelaide. Questionnaires were distributed with the pilot copies. The final version was prepared and distributed and senior managers and hospital staff who could potentially influence adoption of the resource were invited to attend the launch.</p>



Project title	SA-4 – Metro Acute Palliative Care Resource (MAPCARE)
	The final hard copy and online version of MAPCARE were made available on 5 July 2007 and 200 copies of the folder were distributed. This was rolled out with an introductory CD with PowerPoint presentation and a poster. The website is live: <a href="http://www.mapcare.org.au">www.mapcare.org.au</a> .
<b>Evaluation methods</b>  <i>How was the project evaluated?</i>	<p>This was the shortest Care Planning project, and its timeframe (15 months) allowed only for the development of the resource, with no time or budget set aside for evaluation of impacts. Therefore the evaluation activities were mainly formative, and focused at Levels 2 (providers) and 3 (health care system). However, the project steering committee has remained active and further evaluation has been proposed.</p> <p>Level 2 evaluation activities included stakeholder focus groups and a resource user satisfaction questionnaire, developed by the project.</p> <p>The main Level 3 evaluation activity was the use of Tool 8 (System level impacts and outcomes) from the CHSD toolkit. In addition, a questionnaire was developed for Chief Executive Officers of hospitals, with four questions: did you know about it, have you used it, has it had any impact in your organisation, how will your organisation support the use of this resource? Future evaluation at this level could measure the use of the resource in various organisations; case studies of instances in which the resource has been helpful; feedback from staff of various organisations regarding the usefulness of the resource; and potential impacts on accreditation processes (evidence-based practice).</p>
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	Initial feedback has been positive. Comments included: “MAPCARE is an excellent resource and one that has been needed for some time”; “Allows me to view the whole scope of care for palliative patients”; “Will be very useful in providing knowledge to staff re services, what they provide, how to access”; “Greater understanding of palliative care clients’ needs, especially with regard to discharge planning. Also specific consideration of clients’ needs from different cultural backgrounds. Found the section on self care useful.”
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	The project steering committee will take responsibility for the rollout strategies and regular review and updating of the resource to ensure the information and web links remain current.
<b>Recommendations</b>	<p>The project report does not contain formal recommendations. The project officer and manager were asked to reflect on their project and experiences during the exit interview, and a number of themes emerged:</p> <ol style="list-style-type: none"> <li>1. The MAPCARE project met a real, identified need and was consistent with the goals of the host organisation. As a result, stakeholders were eager to contribute time and ideas, and the resource produced was of high-quality, practical and widely applicable.</li> <li>2. The website model could be used widely, as a template for similar information tailored to other areas. It contains a mix of generic information about palliative care and specific information about the model of care in the Adelaide region.</li> <li>3. It is important to engage stakeholders respectfully and value their input. Important relationships should be identified at the start of the project. If the project officer is new in the organisation, the support of the project manager is crucial in building relationships of trust and cooperation with stakeholders.</li> <li>4. For project officers in small organisations, there is a risk of isolation. The project manager or sponsor’s role includes linking the officer with the organisation and removing barriers to completion.</li> <li>5. A guide to project initiation would be useful for host organisations receiving funding through similar programs. It could standardise the project management tasks so that people could move on quickly to creative, localised, insightful project work.</li> </ol>

<b>Project title</b>	<b>SA-5 – Linking palliative care services and generalist providers in the South East of South Australia</b>
<b>Keywords</b>	Local, regional, remote, RACF, community care, acute care, primary care, specialist palliative care
<b>Host organisation</b>	South East Regional Health Service Inc
<b>Partner organisations</b>	South East Directors of Nursing
<b>Project funding</b>	\$272,415 incl. GST
<b>Project timeframe</b>	26 April 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a flexible, patient-centred model of care that will have the potential to be applied more widely in rural and remote areas. The model will broaden the pool of staff with skills in palliation across a wide geographic area and increase the provision of palliation services outside the hospital environment.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Improve communication between primary and specialist care providers.</li> <li>▪ Identify avenues of referrals and access to the service based on assessment of needs.</li> <li>▪ Encourage primary and specialist providers to see themselves as part of a continuum/system delivering palliative care to the community.</li> <li>▪ Ensure the delivery of care accords with evidence-based protocols.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project developed practical strategies to improve collaboration mainly through multidisciplinary and multi-agency team meetings. Referral systems were set up so that generalist care providers know how and when to access specialist services. Education was provided to primary care providers (e.g. in RACFs) so that all people have access to palliative approach. Strategies to enhance transitions, such as protocols and end of life care pathways, were developed or adapted for use by the project, along with tools on how to manage palliative patients.</p>
<b>Project planning and development</b>	<p>The project was designed to address the recommendations of a review of palliative care services in the South East region of South Australia which took place in 2005. The project officer was appointed in October 2006. Partnerships were developed with stakeholders including acute health services, palliative care service, general practitioners, community care, and residential aged care.</p> <p>A project steering committee and a working party were established (first meetings were February 2007) with terms of reference for both. Membership was drawn from stakeholders including directors of nursing, SA Ambulance Service, general practitioners and Limestone Coast Division of General Practice (DGP), residential aged care facilities (RACFs), carers, community nursing and a Level 3 palliative care service based in Adelaide.</p> <p>The project did not require ethics approval.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>One of the first tasks of the project was to establish links with stakeholders who could contribute to developing the model. Referral procedures and documents were drafted, including a form used to notify patients' GPs of their referral to the palliative care service, and these were reviewed by the steering committee. Partnerships were formalised via a Memorandum of Understanding (MOU) between the specialist palliative care service and primary care providers of the region. This set out the model of care and framework (described below), services provided, referral procedures and expectations of the education and support to be provided by the specialist service to primary care providers as needed.</p> <p>The regional model of care and service framework was based on three Palliative Care Australia documents: the national standards; the planning guide; and <i>A Guide to Palliative Care Service Development: A Population-Based Approach</i>. In addition, it drew on a framework describing relationships between specialist services at Levels 1 and 3 and primary care providers. The model directs the provision of health care resources according to patient needs, by primary care providers, the specialist service, or a combination of both. It recognises three sub-groups of patients and promotes continuity of care by primary care providers while defining the role of the specialist service in delivering education and support. The service framework sets out procedures for referral and communication, describes resources available and how to access them, and includes liaison with a Level 3</p>

<b>Project title</b>	<b>SA-5 – Linking palliative care services and generalist providers in the South East of South Australia</b>
	<p>service (Southern Adelaide Palliative Services).</p> <p>Under the regional model, patients referred to the palliative care service are assessed using standard tools. This comprehensive assessment is included in the patient's case notes, with a package of documents which provide a format for communication between providers, recording the patient's needs and future care plans. For example, one of the forms in the package is the Palliative Care Clinical Assessment Form, which is used when providers believe the patient may present to the hospital accident and emergency department due to an unstable, deteriorating or terminal phase of illness. This form assists clinicians in the A&amp;E department by providing information on current symptom management, goals of care (including advance care plans) and contact details for care providers.</p> <p>To support the adoption and use of the model, a range of education activities were carried out. These were based on the 2005 regional review of palliative care, which identified a need for education on symptom management, the role of the palliative care team, and procedures for referral (these goals were endorsed by the project steering committee). The project officer reviewed existing education resources and developed a CD resource which directs generalist providers to evidence-based materials that support best practice in palliative care. A palliative care information package was prepared for use in the regional general hospital medical ward. Principles of symptom management, referrals to palliative care, and the needs-based model of palliative care were topics covered in a study day for clinicians from RACFs and acute wards. In addition, they were presented with information about the Program of Experience in the Palliative Approach (PEPA), took part in a case study discussion, and completed computer exercises utilising the CareSearch and MAPCARE resources. Education for GPs focused on referrals to the specialist palliative care teams based on need, symptom assessment and management, and available evidence-based information resources. Graduate nurses received training on similar topics. In addition, 15 registered nurses working in the acute and community sectors in the South East region took part in a ten-week distance education course in palliative care.</p> <p>Education also took place informally via the weekly interdisciplinary meetings instigated by the project. Topics included: introduction to interdisciplinary meetings; fatigue in advanced cancer; the Palliative Care Outcomes Collaboration; medications; delirium; the CD resource; anorexia and cachexia planning; infection control. The interdisciplinary team meetings began following the project officer's review of existing protocols and practices in the region, and a review of multidisciplinary approaches to care. New protocols were developed and incorporated into the CD resource, information package and MOU. To encourage closer communication between providers, interdisciplinary meetings were initiated in April 2008. Participants included the palliative care team, allied health providers, GPs and external stakeholders. The costs of teleconferencing were borne by the project.</p> <p>An additional project activity, not originally planned, was the establishment of weekly meetings at a large GP clinic in Mount Gambier, attended by palliative care staff and focusing on care planning and symptom management for palliative care patients using that clinic.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The main focus of the project was at Level 2 (providers). Evaluation considered the processes of interdisciplinary team meetings, provider understanding of referral processes and impact on their practice and confidence, and effectiveness of education strategies. Three aspects of the project were evaluated: the interdisciplinary meetings and the education (Level 2); and the referral procedures (Level 3).</p> <p>Information was collected from health care providers who took part in the education sessions, via interviews and questionnaires. Questions were asked about their understanding of course content, including referral processes, identifying complex situations for patients and carers, and the palliative care team. Feedback sheets were included in self-education packages.</p> <p>Records were kept of attendance at the interdisciplinary meetings, the number of clients discussed and education provided. Each completed care plan was recorded and included in the patient's notes, with a copy forwarded to the patient's GP.</p> <p>Data on referral practices were obtained via an audit of case notes before and after the project. Indicators of the appropriateness of referrals were recorded, including whether referral was based on assessment of patient/carer needs or on diagnosis alone.</p>

<b>Project title</b>	<b>SA-5 – Linking palliative care services and generalist providers in the South East of South Australia</b>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>This project did not provide a comprehensive evaluation report, so detailed information on project outcomes is not available. Therefore this section is based on some general comments included in the report to the Department of Health and Ageing.</p> <p>The inclusion of the palliative care tools and protocols in the patients' case notes has resulted in GPs feeling more included in the wider team of care for the patient, and has encouraged some home visits by GPs and the palliative care team jointly for assessment and care planning.</p> <p>Feedback from surveys indicates that the knowledge base of health care providers who took part in palliative care education via the project has improved.</p> <p>A total of 20 interdisciplinary meetings took place during the life of the project, and 82 patients were discussed. Half of the participants returned evaluation questionnaires (the report does not specify how many participants or responses there were). There was a general consensus that the focus of the interdisciplinary meetings was appropriate, the tools and common language used with palliative patients were easy to understand and adopt, and they could see the relevance within the broader picture. Participants did not feel hindered in contributing to the clinical discussion. One participant confirmed that this approach helped target their assessment and care planning for palliative patients. Most participants were satisfied with the location, time and duration of the meetings. The education component was seen as beneficial, contributing to improved clinical practice.</p> <p>Providers report that they are confident in their practice when referring to the palliative care service. The new referral documents and procedures are used for 60% of new referrals to the service, and there appears to have been a change in attitude, with generalist providers now recognising their ongoing role with these patients, rather than feeling that they are 'handing over' to the specialists. Referrals are more appropriate than previously and contain more information about phases, diagnosis, problem severity (observed by the primary care provider, or self-assessed by the patient or carer using the Symptom Assessment Score). Referral practices follow the guidelines outlined by the project.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The palliative care service will continue to hold interdisciplinary team meetings, with the support of management. The meetings provide a forum for client discussion, education and care planning. The costs associated with the meetings are a matter for negotiation. In addition, the weekly meetings at one large GP clinic in Mount Gambier, between GPs and palliative care staff, are considered very valuable and will continue to be supported by the palliative care service.</p> <p>Standardised documents for referral to the palliative care service will continue to be used as these have been adopted into routine clinical practice for many providers. External stakeholders have access to the protocols and forms via the CD resource and information package.</p> <p>The MOU was released at a regional palliative care forum in May 2009 and there are plans to review it annually. Formal education workshops are planned for health providers throughout the region and will be provided on demand. The 15 registered nurses who completed distance education are seen as 'champions' of the new model who will engage in the interdisciplinary team meetings and support care planning processes.</p> <p>Further evaluation of the GP education will take place through the Rural Palliative Care project being run by the Limestone Coast DGP. This project grant from the Department of Health and Ageing (DoHA) began in July 2008 and will support GPs in their care of patients living with terminal illness through education and care planning. The successful grant application resulted from partnership development between the DGP and the South East Regional Palliative Care Service, which continues to be involved in supporting the project through its steering committee.</p> <p>A second 'spin-off' from the project, which is likely to enhance its sustainability, is the inclusion of an RACF at Mount Gambier in the project, 'Implementation of a comprehensive evidence-based palliative approach in Residential Aged Care', which is part of the national Encouraging Best Practice in Residential Aged Care (EBPRAC) program funded by DoHA. The RACF was approached to take part due to its engagement with the local palliative care service, which will continue to support the facility beyond the lifetime of the project.</p>

<b>Project title</b>	<b>SA-5 – Linking palliative care services and generalist providers in the South East of South Australia</b>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"><li>1. This project provided a sustainable model of service delivery for palliative care patients in the South East region of South Australia. The Level 1 palliative care service and generalist care providers now have access to standardised referral procedures, assessments and care planning tools to assist with collaboration between providers and ensure smooth transitions for patients. The new model is consistent with and based on national and state directions for palliative care service provision.</li><li>2. Further evaluation of the project – particularly the use of care plans, the A&amp;E Department pathway and related documents – could be considered.</li></ol>

## TAS Project Summaries June 2009

<b>Project title</b>	TAS-1 - Multidisciplinary palliative care plans for specialist and primary care providers of palliative care and consumers
<b>Keywords</b>	State-wide, community care, primary care, specialist palliative care
<b>Host organisation</b>	Tasmanian Department of Health and Human Services
<b>Partner organisations</b>	No formal partners
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	1 July 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To enhance the quality, knowledge, awareness, understanding and consistency of palliative care practice across the health sector in Tasmania through the development and implementation of multidisciplinary generic palliative management plans. In addition the State is also required to develop fact sheets for patients and their families and carers.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To organise the infrastructure to undertake this project.</li> <li>▪ To develop generic multidisciplinary palliative care plans.</li> <li>▪ To develop consumer fact sheets for patients, their families and carers.</li> <li>▪ To evaluate project outcomes.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project has developed web based multidisciplinary assessment tools and consumer fact sheets for use by Tasmania's palliative care services, associated health professionals and consumers, which will assist to improve collaboration between specialist and primary care services involved in providing palliative care.</p>
<b>Project planning and development</b>	<p>A project officer commenced full time employment in December 2006 until early 2009. A project team was established in February 2007, consisting of senior palliative care clinicians / managers and the project officer. The team reported to a steering committee throughout the life of the project.</p> <p>The project management documentation was based on the Tasmania Government Project Management guidelines and included a business plan, communication strategy and an evaluation plan. The business plan comprised the project plan and time line, including a risk analysis.</p> <p>Recruitment difficulties resulted in a five-month delay in commencing the two-year project. A Deed of Variation was submitted and approved to extend the timeline of the project for six months given the recruitment delays.</p> <p>Ethics approval was deemed not required by the project.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>This was a state-wide project that covered the three regions of the Tasmania - South, North, and North-West - including rural and metropolitan regions.</p> <p>The project has made available to primary care providers and consumers generic multidisciplinary care management guidelines, and accompanying fact sheets for consumers</p> <p>Care management guidelines: There are nine multidisciplinary care management guidelines which provide details on the initial assessment and management of a number of conditions that may present to clinicians who see and care for palliative patients. The care management guidelines are designed to:</p> <ul style="list-style-type: none"> <li>▪ acquaint the health professional with the clinical problem and provide practice advice regarding assessment and management of the problem</li> <li>▪ facilitate the multidisciplinary care planning process (specialist and primary care providers of palliative care working collaboratively) being promoted by the Tasmania Palliative Care Service through its service delivery model and integrated networks</li> <li>▪ provide an accessible reference, guiding possible course of action and as such assist primary care providers to develop individualised care plans for patients.</li> </ul>



<b>Project title</b>	<b>TAS-1 - Multidisciplinary palliative care plans for specialist and primary care providers of palliative care and consumers</b>
	<p>An expert panel of palliative care medical specialists convened to draft the initial management guidelines with all resources based on best practice. The drafts were circulated widely amongst the three regional palliative care teams for comment. A final review of all management guidelines was made by the palliative care medical director.</p> <p>The nine care management guidelines including the following:</p> <ul style="list-style-type: none"> <li>▪ Breathlessness</li> <li>▪ Clinical decision making at end of life</li> <li>▪ Emergencies in palliative care (including spinal cord compression, hypercalcaemia, superior vena cava obstruction, haemorrhage)</li> <li>▪ Constipation</li> <li>▪ Delirium</li> <li>▪ Fatigue, anorexia and cachexia</li> <li>▪ Nausea and vomiting</li> <li>▪ Pain management</li> <li>▪ Terminal care.</li> </ul> <p>The care management guidelines provide information on key principles, assessment, diagnosis, management, consultation and advice and definitions.</p> <p>For each generic multidisciplinary palliative care plan developed there are corresponding facts sheets for the patients, their families and carers. They serve as a reference for patients and carers and also to assist patients and carers in self management.</p> <p>Consumer fact sheets: Twenty two plain language consumer fact sheets were developed after consultation with local palliative care volunteer bodies. Consumer consultation highlighted the importance of presenting the information in a plain and concise style, and in hard copy A4 sheets, in addition to web based resources. The final drafts were reviewed by the multidisciplinary panel before publication.</p> <p>The facts sheets available are:</p> <ul style="list-style-type: none"> <li>▪ Advance care plan</li> <li>▪ Breathlessness</li> <li>▪ Caring for the dying</li> <li>▪ Considerations after death</li> <li>▪ Constipation</li> <li>▪ Delirium</li> <li>▪ Dying at home</li> <li>▪ Emergencies in palliative care</li> <li>▪ Fatigue</li> <li>▪ Haemorrhage and bleeding</li> <li>▪ Hypercalcaemia</li> <li>▪ Laxatives in palliative care</li> <li>▪ My pain chart</li> <li>▪ My diary of pain and pain medication</li> <li>▪ Nausea and vomiting</li> <li>▪ Medicines for nausea and vomiting</li> <li>▪ Pain and pain relief</li> <li>▪ Pain medication</li> <li>▪ Pain</li> <li>▪ Spinal Cord Compression</li> <li>▪ Superior Vena Cava Obstruction</li> <li>▪ Wills and wishes</li> </ul> <p>Another two tools, though not originally planned, were developed during the project to complement and support the symptom management guidelines.</p> <p>One was the development of an inpatient integrated end of life pathway.</p> <p>The second tool developed was a formulary for adult palliative care. It is an alphabetical quick reference medication guide developed to provide information for those healthcare professionals involved in prescribing and caring for adult patients receiving palliative care. The formulary was adapted from the New Zealand Nurse Maude palliative care formulary and developed by a palliative care medical specialist in conjunction with the University of Tasmania's School of Pharmacy.</p>

<b>Project title</b>	<b>TAS-1 - Multidisciplinary palliative care plans for specialist and primary care providers of palliative care and consumers</b>
	<p>The formulary, which is 220 pages long, is split into five main sections:</p> <ul style="list-style-type: none"> <li>▪ Matching symptoms to medication</li> <li>▪ Medication monographs</li> <li>▪ Use of syringe drivers</li> <li>▪ Prescribing outside of license</li> <li>▪ Drug interactions</li> </ul> <p>The formulary introduction states that 'it is planned to review this document at six-monthly intervals and for it to evolve to meet the needs of those who use it' (p 3).</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Though an evaluation was planned, it appears that none of the evaluation activities were undertaken. The delays in the project activities, such as organising access to the website, meant that the completed management guidelines and fact sheets were posted into the website at the project's completion. This meant there was no time left to conduct evaluation activities such as monitoring website usage in accessing management guidelines and fact sheets or surveys of primary care providers and clients.</p> <p>However, the content of all materials generated by this project were reviewed and edited by palliative care experts.</p> <p>DHHS reports that they will monitor website usage of the resources giving an indication of general interest in the resource for future evaluation.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The materials generated by the project (management plans, formulary and consumer fact sheets) were made available late in June 2009. As a result no formal evaluation of their impact has been undertaken by the project.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The project reports that the management guidelines, consumer fact sheets and formulary are all sustainable. The resources will be available on the DHHS website, where they can be used at a state-wide level.</p>
<p><b>Recommendations</b></p>	<p>The recommendation provided by the project is as follows.</p> <ol style="list-style-type: none"> <li>1. Clinical input takes time. This needs to be carefully factored into project management plans.</li> </ol>

## VIC Project Summaries June 2009

<b>Project title</b>	VIC-1 – Listen up! Hearing all the voices in caring for palliative patients in a regional / rural setting
<b>Keywords</b>	Local, regional, community care, primary care, specialist palliative care
<b>Host organisation</b>	Ballarat Health Services – Grampians Regional Palliative Care Team
<b>Partner organisations</b>	Ballarat and District Division of General Practice Inc
<b>Project funding</b>	\$206,317.10 incl. GST
<b>Project timeframe</b>	25 May 2006 to 31 October 2008
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a process to allow sharing of patient information and advanced directives for care between all carers working with palliative patients. This will provide flexible service delivery; improve collaboration between services supporting palliative care; and address care planning and crisis situations to assist in home care.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ For multidisciplinary team (MDT) members to agree on care planning.</li> <li>▪ To determine the current state of satisfaction with care planning in palliative care services.</li> <li>▪ To provide written guidance to nursing staff for use when facing difficult palliative care situations.</li> <li>▪ To develop a data base set for existing palliative care patients in the Grampians Health Region.</li> <li>▪ To skill staff in developing pathways and train palliative care staff in the use of palm pilots and personal computers for data management.</li> <li>▪ To develop appropriate care plans for palliative care patients and keep up-to-date.</li> <li>▪ To check patient, family and carer satisfaction with care planning in palliative care services.</li> <li>▪ To review staff satisfaction with content and process.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project facilitated the sharing of patient information and advanced directives for care in the Grampians Health Region by developing a Patient Information Form (PIF).</p>
<b>Project planning and development</b>	<p>A project officer was employed part-time to both manage and evaluate the project. The project team was established, with core membership of six, which increased with another two members later in the project.</p> <p>The project was based on an action research approach. A project plan was developed which included evaluation methods and tools.</p> <p>A Memorandum of Understanding was signed between the Grampians Regional Palliative Care Team and the Ballarat and District Division of General Practice.</p> <p>The project was granted ethics approval by the combined Ballarat Health Service Ethics Committee and St John of God Human Research Ethics Committee in June 2006.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>This project developed a Patient Information Form (PIF) as a way of sharing patient information and advanced directives for care between all carers working in the Grampians Health Region. This included engaging the patient and family in the care planning process.</p> <p>Focus groups with GPs and palliative care clinical nurse consultants (CNCs) were held to gain feedback about the process of care planning for palliative patients. From this feedback a draft PIF was developed.</p> <p>The draft version of the PIF was reviewed through an action research process. The PIF contains sections for recording patient demographic information, current clinical condition, current symptoms, (including the RUG, Karnofsky and phases), current medication, advanced planning, spiritual emotional assessment, volunteer involvement, social work, and nursing notes. Training in the use of the PIF was provided to nurses and GPs and a 'summary of procedures' sheet was developed to support the use of the PIF.</p>

<b>Project title</b>	VIC-1 – Listen up! Hearing all the voices in caring for palliative patients in a regional / rural setting
	<p>The PIF was entered onto personal and hand-held computers at Ballarat Hospice Care Inc. and trials started in January 2007. The project reported that the planned procedure was that following patient admission to the palliative care service, the PIF was completed and faxed to the appropriate GP with a covering letter containing a request to comment on the relevance and accuracy information contained in the PIF. The PIFs were centrally located on computers within palliative care services and updates were recorded each weekday and made available to service providers on major changes in the patient's condition.</p> <p>The project developed generic symptom problem sheets for six sets of cancer diagnosis loaded on the hand held computers. The project reported that though good in principle they proved cumbersome to use and were discarded. They also trialled using a secure e-mail system – ARGUS – to send the patient information forms. The results of the three-month trial showed that while GPs were happy to receive the information this way, they were unable to reply to the emails. Therefore, the project reverted to sending faxes.</p>
<b>Evaluation methods</b>  <i>How was the project evaluated?</i>	<p>The evaluation methodology used a mix of quantitative and qualitative methods. The purpose of the evaluation was to review the effectiveness of the means of communication about care planning for palliative care patients. To answer this the following tools were used:</p> <p>Level 1: Patient and carer satisfaction was measured using a 20-item, modified FAMCARE scale (from a 5 to 7 point likert) and an associated PATCARE scale at enrolment in a written form, at one month in a personal interview and at three months after enrolment by a phone interview.</p> <p>Level 2: Focus groups, discussions, emails and surveys with key health providers to ascertain how communication between health providers could be improved. For GPs and practice nurses methods included an evaluation survey sent in January and March 2008, phone survey asking five questions conducted within one week of GPs being sent a PIF. For PCNC and other palliative care staff feedback was obtained through informal communication such as the weekly meetings, and formally feedback from focus groups and a 7-question survey.</p> <p>Also, an action research process gained feedback from community based palliative care services, GPs and specialists to continually refine the development of the PIF.</p> <p>Evaluation resources available from the project include a 20-item PATCARE and a modified FAMCARE scales with 7-likert response to assess patients' and carers' satisfaction with palliative care services.</p>
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	<p>By using the action research approach, the PIF under-went six transformations throughout the project, with the final version currently being used at Ballarat Hospice Care Inc.</p> <p>Level 1: Comprehensive evaluation data was collected from 84 patients and 45 carers. The results from the modified PATCARE and FAMCARE scores revealed that patients and their carers were generally satisfied to very satisfied with their inclusion in the planning process and the level of service they received from the palliative care service.</p> <p>Level 2: Comprehensive evaluation data was collected from eight palliative care CNCs and 58 GPs. Evaluation results demonstrate that the project enhanced the confidence of palliative care CNCs and the GPs valued the communication.</p> <p>The project final report states that the Listen Up! Project has formalised the process of communication about palliative care patients between staff in community-based palliative care services and GPs and some specialists. It has also facilitated the transfer of information on admission to inpatient palliative care units. The PIF provides a concise and comprehensive framework for care planning, with flexibility to suit the needs of a diverse range of palliative care services ensuring that "all voices are heard".</p>
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>Sustainability was planned by ensuring that all existing staff were trained. This training would be supported by a training mechanism for the future. The project suggests that to sustain the achievements of the project, staff training needs to continue especially in IT skills, to assist in the transition from paper-based to computer-based patient records.</p> <p>At the end of the funding period it is important to note that Ballarat Hospice Care Inc. has fully integrated the Listen Up! Project into its policies and procedures. Also Bacchus March</p>

<b>Project title</b>	VIC-1 – Listen up! Hearing all the voices in caring for palliative patients in a regional / rural setting
	<p>Palliative Care Service is currently using the Listen Up! procedure to aid communication with GPs in 'after-hours' scenarios.</p> <p>The PIF is offered free of charge to anyone who wants to use it as a basis for gathering essential data for communication related to care planning for palliative care patients.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project regarding the project processes are listed as follows.</p> <ol style="list-style-type: none"> <li>1. All palliative care services should adapt the Listen Up! Project procedures to suit their local needs in providing holistic care.</li> <li>2. Ethics approval for multi-site studies should be facilitated by mandating a timeline for endorsement at subsequent sites following approval from a properly established NHMRC HREC at the first site.</li> <li>3. For future funding opportunities indicative funding should be advised to all participants considered worthy of support, so that opportunities for communication between applicants could minimise duplication of ideas and optimise the strengths of researchers through potential collaboration.</li> </ol>

<b>Project title</b>	VIC-2 – Being smarter – a partnership model of palliative care
<b>Keywords</b>	Local, major city, community care, specialist palliative care, non-malignant
<b>Host organisation</b>	Melbourne Citymission Inc
<b>Partner organisations</b>	Royal District Nursing Service
<b>Project funding</b>	\$254,656.60 incl. GST
<b>Project timeframe</b>	26 April 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> The aim of this project was to design, develop, trial and implement a service model that would enhance the delivery of palliative care services to better meet the needs of people with a terminal illness.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Identify and explore issues in developing a consultancy-based specialist palliative care service with primary care partners that conform to Palliative Care Australia (PCA) standards.</li> <li>▪ Develop an implementation plan for the consultancy-based model of palliative care service provision and the greater involvement of services providing primary care.</li> <li>▪ Identify, implement and evaluate components of the plan that can be implemented.</li> <li>▪ Identify barriers to full implementation and provide specific recommendations.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The aim of this project was to design, develop, trial and implement a service model. At this stage, they have designed and developed the model of care which aligns with all relevant policy directions from Department of Health and Ageing (DoHA), Victorian Department of Human Services (DHS) and PCA.</p>
<b>Project planning and development</b>	<p>The project was managed throughout by the manager of the Melbourne Citymission Palliative Care (MCMPC) Service. In the initial phase, a consultant was contracted to prepare the project plan, conduct the initial stakeholder interviews and complete a demographics assessment. A project officer (32-hours per week) was appointed in February 2007 to complete the project and remained in the role until the project's end.</p> <p>The project is overseen by the Project Management Group, comprising of senior staff of Melbourne Citymission Palliative Care and Royal District Nursing Service (RDNS). The group met on a monthly basis and were actively involved in all decision making processes throughout the project. The makeup of the project management group changed at times during the course of the project. A MOU between MCMPC and RDNS Melbourne was developed and signed.</p> <p>A detailed project plan was developed and documented in three phases: Phase 1 consultation and review of current model; Phase 2 design, development, trialling and evaluation of new model of care; and Phase 3 recommendation and implementation of new model of care. In addition, a communication strategy was developed to promote and encourage effective involvement of, participation by and consultation with partners and relevant stakeholders.</p> <p>The Project Management Group decided that ethics approval was not required for this project.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>This project designed and developed a service model for the delivery of community-based palliative care services for people living with a terminal illness, their carers/ families and those providing support to them in the Melbourne Local Government Areas (LGAs) of Darebin, Hume, Moreland and Yarra.</p> <p>From 1998, MCMPC had a shared care model with RDNS, and in 2003 moved to an Integrated Model of Care which had resulted in a very strong collaborative working relationship for clients residing in the LGAs.</p> <p>At all stages, this project has kept in mind the federal, state and professional body policy directions when developing the new model of care, such as <i>A Guide to Palliative Care Service Development: A population based approach</i> (PCA document) and <i>Strengthening Palliative Care: a policy for health and community care providers 2004-2009</i> (Victorian DHS policy document).</p>



Project title	VIC-2 – Being smarter – a partnership model of palliative care
	<p>The key project activities completed to inform the model were:</p> <ul style="list-style-type: none"> <li>▪ Literature review - undertaken to determine the patterns and models of community based palliative care, both in Australia and internationally</li> <li>▪ Catchment analysis – analysis of the demographic and socio-economic profiles of the catchment area</li> <li>▪ Current service delivery arrangements jointly provided by MCMPC and RDNS in the northern metropolitan region</li> <li>▪ Death statistics review</li> <li>▪ Workshops – one for senior staff and another for nursing and allied care staff</li> <li>▪ Examination of the service against the PCA Standards</li> </ul> <p>All these activities contributed to the design and development of the model - “A partnership model of palliative care”. This document outlines the rationale and changes between the current and new models of care, as well as giving a full description of the new model. There are five levels of care proposed:</p> <ol style="list-style-type: none"> <li>1. Primary palliative approach</li> <li>2. Interdisciplinary consultation / liaison approach</li> <li>3. Episodic care</li> <li>4. Direct ongoing / complex care</li> <li>5. Post death of a person with a terminal condition (bereavement care and support)</li> </ol> <p>Clients and carers may enter at any of the levels and move between levels depending on the phase of care when they are referred to MCMPC. Some clients may experience multiple levels of care, while others might remain in only one level depending on their care need. The level of care required will determine input from both the specialist palliative care service (SPCS) and the generalist service.</p> <p>Issues surrounding a final agreement on the new model of care meant that the piloting of the new model of care has not taken place. However, the structure of the new model was formally agreed upon in April 2009, with the decision taken to move directly to the new model without a formal pilot period. In preparation for this, an implementation plan is currently being developed to ensure the transition is as smooth as possible. Despite this, the project reports that elements of the new model are already in place and being well regarded by both staff and clients.</p> <p>New Resources Developed:</p> <ul style="list-style-type: none"> <li>▪ Document “A partnership model of palliative care”</li> <li>▪ Malignant and non-malignant disease trajectories and scenarios</li> <li>▪ Levels of care overview</li> <li>▪ Client types overview</li> <li>▪ Client Flowcharts e.g. Client is stable at referral</li> <li>▪ Referrals Policy and Procedure</li> <li>▪ Triage Policy and Procedure</li> <li>▪ Triage Tool</li> <li>▪ Ambulatory Clinic Policy and Procedure (draft)</li> </ul> <p>Dissemination of pertinent and relevant information to appropriate stakeholders has been ongoing throughout the life of this project. This has taken place through a variety of methods, including face-to-face meetings, newsletters, presentations, informal discussions with staff and workshops.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Due to the delay in the implementation of the new model of care, evaluation of the model is not possible during the life of this funded project. Evaluation, when it occurs, will be carried out by the project officer during and after the implementation period for the new model of care.</p> <p>Data that was collected during the course of the project was evaluated and incorporated into the design of the new model where appropriate. This occurred through the literature review, visits to other community-based palliative care services and workshops held with staff. A review of the current and projected populations in the four LGAs serviced by MCMPC underlined the need for a change in the way palliative care is provided in the community. In addition, the recognition of earlier referrals and an increase in the number of non-malignant referrals to palliative care services put further emphasis on the importance of the design of the new model of care.</p>

<b>Project title</b>	<b>VIC-2 – Being smarter – a partnership model of palliative care</b>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The project reports that the development of a community-based palliative care model that takes into account current and future trends in referrals and care has been a major achievement.</p> <p>This new model is more focused on the level and complexity of a client and their family's needs, including the capability of the care giver to manage and support the client, rather than focusing on numbers of palliative care clients per organisation for case management purposes. This approach ensures that the most appropriate service will attend to the client's needs at the right time. This model has care as a dynamic process, with client movement occurring from one level to another, and from one service to another as required.</p> <p>The project outlines two unexpected outcomes that occurred during the project. Firstly, access to timely client information. RDNS provides after-hours care to clients case managed by MCMPC. In the last 12 months, MCMPC and RDNS have worked together to improve access to up-to-date client information for the RDNS Customer Service Centre (CSC) who triage the after-hours calls. By giving staff at the CSC read-only access to MCMPC's PalCare system, information regarding any client can be accessed immediately, and used to assist with the issue at hand. This provision of real-time client information for the CSC staff has meant a more streamlined and client-focused approach to after-hours care provision for clients case managed by staff from MCMPC. In addition, read-only access to the PalCare system is available in the three RDNS Support Sites that work closely with MCMPC in the catchment areas – namely Heidelberg, Moreland and Yarra.</p> <p>Secondly, MCMPC established the role of an aged care nurse case manager position. Over the past 12 months, 140 referrals for clients residing in a residential aged care facility (RACF) have been received, with half of these referrals coming from the RACF itself. Only 31% of these clients had a known malignancy at referral. The nurse case manager has assessed 50% of these 140 referrals face to face, and provided telephone consult and support to a further 25%. The final 25% of clients had referrals that were found to be inappropriate, or died prior to assessment. A large part of this role has been the provision of education and support for RACF staff, to enable them to become more confident and comfortable when dealing with clients requiring palliative care or a palliative approach.</p> <p>Some other unexpected activities and outcomes achieved whilst undertaking the project included:</p> <ul style="list-style-type: none"> <li>▪ Referral coordinator - the importance of this role was recognised, and this role has been replicated in other community-based organisations in the region</li> <li>▪ Ambulatory clinic - will be established at MCMPC in the near future</li> <li>▪ Medication access - MCMPC signed a Memorandum of Understanding with the Peter MacCallum Cancer Centre Pharmacy in 2008 to enhance timely and cheaper access to medications for clients case managed by MCMPC</li> <li>▪ Mercy Palliative Care – working together as both organisations were undertaking reviews of their models of care and coming up with similar findings. This relationship is continuing with sharing of resources to develop implementation plans for their new models of care.</li> </ul>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The model has been endorsed by the Project Management Group and will be implemented without a pilot phase. This implementation phase of the model will be managed by an Implementation Working Party who will continue to meet on a monthly basis, but with revised terms of reference to reflect the new emphasis of this group. The project reports that they envisaged that the group membership will largely remain the same, leading to continuity of staff and level of knowledge and understanding of the model and its aims.</p> <p>The project reports that some changes in the new model can be, and indeed have been, implemented within existing resources. The ability to fully implement and sustain the proposed future model of care will require collaboration between MCMPC and DHS with regards to funding for the model. This will be taking place in the context of the current DHS Service Delivery Framework / Funding Model Review and the Palliative Care Policy Refresh currently taking place in Victoria.</p> <p>Two positions that will assist in the sustainability of the project are the aged care nurse case manager and the designated referrals coordinator position.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. There is a need for MCMPC to work closely with generalist community care services to increase their skills and knowledge in the provision of a palliative approach to care to clients, families and carers through education and specialist advice.</li> </ol>

Project title	VIC-2 – Being smarter – a partnership model of palliative care
	<ol style="list-style-type: none"> <li data-bbox="448 271 1433 465">2. The expected increase in the numbers of referrals to specialist palliative care services (in accordance with Victorian government policy), due in the main to the ageing population, an increase in referrals for paediatric clients and those with non-malignant disease, is an area that requires further exploration. In addition to these groups, access to culturally sensitive palliative care for clients from a culturally and linguistically diverse (CALD) or Aboriginal or Torres Strait Islander (ATSI) background should be specifically addressed.</li> <li data-bbox="448 495 1433 600">3. It is anticipated that the DHS will support a regional approach to the implementation of future models of care across the north and west region within the local Consortium. This can then lead to discussion and set a direction of change for a more consistent approach to the provision of palliative care in the metropolitan region of Victoria.</li> <li data-bbox="448 629 1433 734">4. It is envisaged that funding issues will continue to have an impact on the provision of palliative care services. This is especially evident with the Home and Community Care Program (HACC), the main source of funding for RDNS, and its' ambiguity regarding palliative care service provision.</li> <li data-bbox="448 763 1433 1122">5. The issues and challenges regarding the provision of specialist palliative care into the future are highlighted in Chapter 7 of the interim report from the National Health and Hospitals Reform Commission. Emphasis is placed on improving access to effective palliative care in the arenas of chronic diseases, such as Alzheimer's and degenerative and other non-malignant conditions, as well as to the CALD populations. This can only be achieved through appropriate funding of the generalist services which provide a palliative approach in the care of those who are dying. In addition, the recognition of the increase in people requiring palliative care means that the integration of their care between the specialist, generalist and primary care services will become more important. Any of these changes need to be sustainable, as the role of the specialist service shifts to include providing education and support, consultancy and research. To ensure this can occur, there may be an increase in the client numbers seen by the generalist services, and the funding received by them should reflect this.</li> </ol>

<b>Project title</b>	VIC-3 – What happens after dark? Improving ‘after hours’ palliative care planning in urban and rural Victoria, for patients, their carers and health professionals
<b>Keywords</b>	State-wide, community care, primary care, specialist palliative care
<b>Host organisation</b>	Monash University, School of Primary Care
<b>Partner organisations</b>	Royal District Nursing Service; Department of General Practice, School of Primary Health Care, Monash University
<b>Project funding</b>	\$263,972.50 incl. GST
<b>Project timeframe</b>	15 May 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To examine after hours palliative care services and develop care planning strategies that will better meet the needs of patients, families and health professionals.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Describe the types of “after hours” palliative care services in rural and urban Victoria and identify gaps in service.</li> <li>▪ Validate the issues identified in the interviews of patients, carers and health professionals, utilising a larger, random group of health professionals.</li> <li>▪ Develop educational strategies to enhance after hours palliative care service delivery.</li> <li>▪ Implement and evaluate the educational strategies developed, with a smaller number of general practitioners and nurses.</li> <li>▪ Develop a set of recommendations outlining how the results of the project could be implemented throughout Victoria.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The purpose of the project was to increase care planning and integration between services, and to improve communication through the development of strategies to enhance after hours palliative care planning and (for GPs) the use of the Enhanced Primary Care Medicare items. This work will support policy and practice development across the State through recommendations made to the Victorian Department of Human Services.</p>
<b>Project planning and development</b>	<p>The project was undertaken by the Palliative Care Research Team at Monash University (Peninsula Campus). During the life of the project there were three different project officers, one for each project phase, which did not seem to affect the project.</p> <p>The project was overseen by a project manager, co-investigators and a reference group. The project reported that the co-investigators and reference group members, including a consumer (carer) representative, were dedicated and remained committed to the project throughout the three years.</p> <p>Ethical clearance for this project was received from Monash Standing Committee on Ethical Research Involving Humans, Royal District Nursing Service Research Ethics Committee and Calvary Health Care Bethlehem Research and Ethics Committee.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project was conducted over three geographically diverse Divisions of General Practice: Moorabbin (Monash Division), Peninsula (Mornington Peninsula Division) and Gippsland (East Gippsland Division).</p> <p>The project aimed to investigate ways in which after hours palliative care services could be improved and was planned in three phases as follows.</p> <p>Phase one (needs assessment): A literature review was undertaken to investigate the different models of after hours services in rural and urban Victoria to identify gaps in service delivery. Semi-structured interviews (n=38) were conducted to investigate the challenges involved in the provision of after hours services to people receiving palliative care at home in the three Divisions of General Practice.</p> <p>Phase two: The outcomes of phase one were used in the design of questionnaires to facilitate further exploration of the challenges of providing after hours care for people receiving palliative care at home. These were distributed to palliative care nurses and GPs. Data analysis was assisted by SPSS data analysis software</p> <p>Phase three: Four key findings from phase two were identified for focus in the production of</p>

<b>Project title</b>	<b>VIC-3 – What happens after dark? Improving ‘after hours’ palliative care planning in urban and rural Victoria, for patients, their carers and health professionals</b>
	<p>educational materials in phase three of the study. These were:</p> <ul style="list-style-type: none"> <li>▪ Reluctance of patients and carers to utilise available after hours services.</li> <li>▪ Poor utilisation by GPs of Enhanced Primary Care (EPC) Medicare Items for palliative care planning and team communication.</li> <li>▪ Importance of advance care planning in relation to appropriate after hours care.</li> <li>▪ Communication within multidisciplinary teams (MDTs) which include the GP.</li> </ul> <p>Two educational tools were developed to address these issues. The first was a brochure directed to patients receiving palliative care and their carers. The other was a DVD and related web based program designed to be used in training sessions for health professionals from a variety of disciplines.</p> <p>Brochure: designed for people receiving palliative care and their carers was developed focusing on expectations of after hours care emphasising the importance of using these services when needed. The brochure was produced using the Palliative Care Victoria brochure template and copies have been distributed to about 300 palliative patients by Royal District Nursing Service (RDNS) nurses in the urban and urban/rural participating divisions.</p> <p>DVD: was developed directed towards health professionals focusing on utilisation of EPC items, advance care plans and MDT communication. It was produced with the advice of experts in multimedia educational tools and the DVD was distributed to two palliative care consortia managers (both rural) for a trial. A small pilot evaluation was undertaken which informed the production of a web site version.</p>
<b>Evaluation methods</b>  <i>How was the project evaluated?</i>	<p>Phase one: The project conducted semi-structured interviews with people receiving palliative care and their carers (Level 1) and semi-structured interviews with service providers (GPs, nurses, managers) (Level 2). The language texts were entered into the Qualitative Solutions Research (QSR) NVivo (7.0) computer program and thematically analysed. All participants’ comments were coded into nodes (a collection of references about a specific theme) and the emergent themes identified. These interviews explored the experiences of the after hours service from the perspectives of both the recipients of care and the providers.</p> <p>Phase two: Additional questionnaires were designed for GPs and nurses to further explore the challenges of providing after hours care for palliative care patients in their own homes (Level 2). Quantitative data were analysed with the assistance of SPSS software and qualitative data were thematically analysed.</p> <p>Phase three: The project evaluated the two educational tools developed in phase one and two. For the brochure, patients and carers completed a questionnaire to provide feedback on the usefulness of the brochure plus the number of people accessing the after hours service was also determined (Level 1). Nurses were also interviewed to provide further feedback on the brochures. The DVD was reviewed by health professionals in a pilot (Level 2).</p>
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	<p>The findings reported by the project across the three phases are as follows.</p> <p>Phase one: Semi-structured interviews were conducted by two experienced qualitative researchers with nurses (n=12), managers (n=5), GPs (n=12), and also with people receiving palliative care and their carers (n=9). Main themes included: communication issues between professionals in MDTs, use of locum services, GP availability, access to medication, equipment and interpreters after hours, staff safety, availability of palliative care beds and utilisation of after hours services by people receiving palliative care and their carers.</p> <p>Phase two: Of the 524 questionnaires posted to GPs within the three participating divisions, 114 (22%) were returned by GPs. A further 122 questionnaires were distributed to nurses in Victoria through the special interest palliative care group. Fifty-two nurses (43%) returned their completed questionnaires. The project felt that the poor return rate and incomplete forms may have been due to the questionnaires being too long and timely to complete. Due to the low percentage return rate for GPs and some ambiguity in a few of the questions descriptive statistics only were utilised.</p> <p>The majority of GPs were associated with a practice which provided some after hours</p>

<b>Project title</b>	<b>VIC-3 – What happens after dark? Improving ‘after hours’ palliative care planning in urban and rural Victoria, for patients, their carers and health professionals</b>
	<p>services but palliative care was not a strong focus for most. More than half of both nurses and GPs, however, were aware of palliative care resources to which they could access.</p> <p>Factors such as poor communication and limited availability of after hours services were identified as most likely to impact negatively on service provision. Strategies considered most likely to improve after hours services were individual patient protocols, palliative care trained respite carers and regular MDT meetings that included the GP.</p> <p>Phase three:  Brochure: Of the 320 questionnaires distributed, only 15 were returned which was too low for statistical significance although all indicated a very positive view of the brochure. There was no significant change in after hours call numbers compared to the period immediately before distribution. In addition nine palliative care nurses working from the participating RDNS sites took part in a short semi-structured interview. The majority of respondents considered the brochure to be easy to read and understand. Lack of applicability of content to all areas and print size were considered problems by some respondents.</p> <p>DVD: A small pilot study in which the DVD was reviewed by a total of six health professionals, including those specialising in multi-media education, was undertaken. A short questionnaire was utilised and in addition participants were invited to make unstructured comments. This was considered to be a potentially useful educational tool. Some technical improvements were recommended for the web based version.</p> <p>Web based version: This is now publicly accessible at: <a href="http://www.med.monash.edu.au/ahpc">www.med.monash.edu.au/ahpc</a>.</p>
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>At the beginning of the project it was hoped that issues relating to the sustainability of project outcomes would be assured by changing the way in which health providers provide care and services. It was hoped that this would be facilitated by influencing local area health policies with regards to the delivery of palliative care services locally.</p> <p>The extent to which local palliative care service provision has been influenced by this project is unclear. However, complimentary copies of the brochure and the DVD (200) have been widely distributed to key stakeholders within Victoria. The material on the DVD is also freely available on the web at: <a href="http://www.med.monash.edu.au/ahpc/">http://www.med.monash.edu.au/ahpc/</a>.</p> <p>Importantly, 2000 brochures were donated to Palliative Care Victoria (PCV) and the brochure is also available on the PCV website <a href="http://www.pallcarevic.asn.au/">http://www.pallcarevic.asn.au/</a>.</p> <p>Sustainability of the brochure has been assured through transfer of copyright to PCV and the full report of the project findings and recommendations are to be published by Monash Press with a registered ISBN.</p>
<b>Recommendations</b>	<p>The project developed a set of recommendations outlining how the results of the project could be implemented throughout Victoria as follows:</p> <ol style="list-style-type: none"> <li>1. The Royal Australian College of General Practitioners (Victorian Faculty), General Practice Divisions Victoria (GPV) and the Nurses Board of Victoria continue to make the utilisation of EPC Medicare items, the development of advance care plans and the enhancement of communication about after hours care in MDTs which include the GP a focus for educational programs for health care professionals.</li> <li>2. The “About After Hours Care” brochure continue to be promoted by PCV, (who now own the template), and be used as a guide to the development of after hours service information for patients and carers with space available for the addition of specific local details.</li> <li>3. The Department of Human Services policy that all community palliative care clients be able to access a palliative care trained nurse at some stage of the after hour call service process be further reviewed.</li> <li>4. The impact of the use of locum services in the provision of after hours services for people receiving palliative care be further investigated by relevant medical authorities.</li> </ol>



<b>Project title</b>	VIC-4 - I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)
<b>Keywords</b>	Local, major city, RACF, community care, primary care, specialist palliative care
<b>Host organisation</b>	Mornington Peninsula Division of GP Inc renamed to Peninsula General Practice Network (PGPN)
<b>Partner organisations</b>	Peninsula Hospice Service; Peninsula Health
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	24 April 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a system based program of palliative care support to the clinical staff of the residential aged care facilities (RACFs) in the Peninsula General Practice Network catchment area and the general practitioners who provide care to the residents of these facilities.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Establishment of specialist palliative care nurse co-ordinator role to work in close liaison with Peninsula Hospice staff to achieve improved outcomes for residents, general practitioners (GPs) and RACFs.</li> <li>▪ Care planning for residents of aged care facilities who require palliative care.</li> <li>▪ Joint educational programs with local palliative care providers for RACF staff.</li> <li>▪ Raising awareness and understanding for palliative care in RACFs – introducing and implementing system.</li> <li>▪ Development of partnerships in care.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project appointed a specialist palliative care nurse consultant (SPCNC) to support GPs, staff of RACFs, and the providers of specialist palliative care services to improve collaboration; and support the smooth and appropriate transition between settings of care (i.e. RACFs, the person's home and the hospital). Though not initially planned, the project developed and implemented a model of service delivery, which was adopted at the project's completion.</p>
<b>Project planning and development</b>	<p>A specialist palliative care nurse consultant (SPCNC) was appointed part-time for the duration of the project. A project work plan with time lines was developed from the project's funding application.</p> <p>The project management was undertaken by the PGPN Executive Manager who was supported by the PGPN Executive Team and assisted by the IMPACT Advisory group. The IMPACT Advisory group consisted of members from the previous Caring Communities Program project committee plus other stakeholders.</p> <p>Memorandums of Understanding were established with the Peninsula Hospice Service, Peninsula Health, Lorikeet Lodge RACF, Baptist Village Baxter RACF and PGPN.</p> <p>Prior to this project, the PGPN reported that there were well established communication mechanisms in place. The specialist palliative care nurse consultant (SPCNC) built on these and developed additional communication strategies.</p> <p>The project approached the Peninsula Health Human Research and Ethics Committee who deemed that no ethics approval was necessary if a project based, rather than a research framework, was applied and on the condition that clients and families were not surveyed.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>A specialist palliative care nurse consultant (SPCNC) was employed to build the capacity of RACF staff to provide a palliative approach to care. This specialist nurse acted as a liaison, support and educational provider to palliative care patients, their families, RACF staff, current palliative care services and GPs within the Peninsula GP Network.</p> <p>The Mornington Peninsula has 45 RACFs with over 3,000 residents, and the PGPN has approximately 270 GP members. Project activities were developed based on the assumption that a skilled and educated aged care workforce would lead to better</p>

Project title	VIC-4 - I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)
	<p>experiences for residents and their families. Therefore, consultation and education was aimed at up skilling care staff and GPs so current and future residents and their families would benefit.</p> <p>A pathway for resident referrals was successfully implemented. Of the 370 residents referred to the SPCNC, 169 had their GP recorded by the SPCNC and 50% of these residents were cared for by 12 GPs. Over 60 GPs were contacted by the SPCNC during the project to discuss clinical issues related to individual residents. The project reported an increased use of advanced care planning, with only a small number of case conferences.</p> <p>There were a range of education programs conducted by the project, with the content consistent with the APRAC 'Guidelines for a Palliative Approach to Residential Aged Care'. Programs consisted of:</p> <ul style="list-style-type: none"> <li>▪ Education provided at the bedside based on needs of individual staff members identified during resident consultation.</li> <li>▪ In-service education provided within aged care facilities to address needs of staff within the facility as identified during resident consultations.</li> <li>▪ Regional education forums conducted for all RACF staff on the Mornington Peninsula based on best practice.</li> <li>▪ Regional education forums conducted for GPs based on PGPN's continuing professional development survey of GP members.</li> </ul> <p>Overall the SPCNC provided 80 in-service education programs to 36 different RACFs; coordinated the provision of a further seven programs to GPs; and provided three presentations to practice nurses and acute care staff.</p> <p>The project raised awareness and understanding of palliative care in RACFs through strategies such as:</p> <ul style="list-style-type: none"> <li>▪ Regular meetings with key RACF staff which were used to review tools and templates used in palliative care, for example, pain management charts and advanced care plans.</li> <li>▪ Establishing the Palliative Care Special Interest Group for GPs.</li> <li>▪ Contributing to the redevelopment of the Palliative Care Special Interest Group for Aged Care staff.</li> <li>▪ Regular correspondence to Directors of Nursing regarding palliative care education and events.</li> <li>▪ Redevelopment of PGPN website with dedicated palliative care page <a href="http://www.pgpn.org.au/page.php?base=35">http://www.pgpn.org.au/page.php?base=35</a></li> <li>▪ Publishing articles in Peninsula Health's Residential Outreach Support Service newsletter and PGPN's newsletter.</li> </ul> <p>There was an increase in referrals from RACF staff and GPs. In the first six months of the project 27% of referrals came directly from RACF staff and none from GPs, and in the last six months 57.1% of all referrals came from directly from RACF staff and 6 (7%) from local GPs.</p> <p>A number of tools and templates have been developed or adapted from other organisations to assist in the provision of palliative care. These include:</p> <ul style="list-style-type: none"> <li>▪ '10 steps to residential care using MBS schedule' (by Knox Division of General Practice)</li> <li>▪ Pain and Symptom Management in Residential Aged Care – a protocol to guide aged care staff in the principles of symptom management</li> <li>▪ A suite of resources to support the use of syringe drivers in residential aged care</li> <li>▪ Advanced care planning templates (based on those created by Osborne Division of General Practice, WA).</li> </ul> <p>The project funded the development and printing of an information book for families and carers about the provision of palliative care. The booklet 'Palliative Care in Residential Aged Care: information for families and carers' was developed in conjunction with the Peninsula Hospice Service, Carrum Downs Private Nursing Home and with the permission of Silver Chain for use of the content.</p>
<b>Evaluation methods</b>	The evaluation plan focussed on three of the 14 project activities, with the evaluation tools listed as a draft evaluation tool – APRAC Guidelines; an evaluation tool based on MBS item numbers; an evidence file; a dissemination log; log of issues; and an education log

<b>Project title</b>	<b>VIC-4 - I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)</b>
<i>How was the project evaluated?</i>	
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	<p>Three hundred and seventy (370) residents were referred to the SPCNC during July 2006 and February 2009. While 370 residents and their families/carers benefited from the involvement of the Specialist Palliative Care Nurse Coordinator (SPCNC), residents have also benefited from a skilled and educated workforce providing a palliative approach to care and specialist palliative care consultancy.</p> <p>The outcomes for residents included:</p> <ul style="list-style-type: none"> <li>▪ Raised awareness of a palliative approach to residential aged care amongst staff and an understanding of how to refer for specialist support when needed. This was shown by the increase in referrals from RACF staff from 27% in the first six months to 57.1% in the last six months of the project.</li> <li>▪ An increased number of residents able to die in comfort and dignity in their place of choice. Individual cases have been identified where the resident would have been admitted to the acute sector for symptom management if the SPCNC had not been available to support staff to provide palliative care within the RACF. Similarly, RACF staff have reported that they are more confident in providing care knowing that the SPCNC is available for consultation;</li> <li>▪ Improved symptom management for a number of residents who received Specialist Palliative Care Consultancy, e.g. increased use of pain assessment tools and pain charts. The SPCNC facilitated the audit of pain assessment tools in at least two facilities;</li> <li>▪ Improved discharge planning leading to reduced length of stay in acute services, as described in the evidence file by the palliative care nurse consultant at the acute hospital.</li> <li>▪ Reduced incidence of readmission to the acute setting due to supported advanced care planning as can be seen in the increased number of referrals directly from RACFs, and decreased referrals from the acute hospital during the project.</li> <li>▪ Improved care for residents through the provision of multidisciplinary care, i.e. team based care including RACF staff, specialist palliative care providers and GPs. Individual cases have been identified where the SPCNC acted as a liaison between RACF staff and GPs to improve communication regarding the resident's care and increase the satisfaction of staff and families in their loved ones care; .</li> <li>▪ Improved care planning through the use of care planning tools. At least four RACFs amended care planning tools within their facility or adopted new resources provided by the SPCNC which are consistent with the principles outlined in the 'Guidelines for a Palliative Approach to Residential Aged Care' and are considered best practice. This is evidence that provision of care planning tools were adopted by the sector.</li> <li>▪ Improved resources for residents, their families and carers, such as the Information booklet for families and carers, advanced care planning tools, pain assessment tools, use of MBS items etc.</li> </ul> <p>The project reported that anecdotal evidence suggests decreased numbers of inappropriate patient admissions to the acute facility. The number of referrals from the acute hospital fluctuated over the three years of the project, but in the first six months they accounted for 24.3% of all referrals and 12.5% in the last six months.</p> <p>As a result of the project activities there are a number of implications for service providers. Again, the evidence for this is largely anecdotal:</p> <ul style="list-style-type: none"> <li>▪ An increased confidence of RACF staff in providing care to residents as can be seen by their engagement in the project and participation in the SPCNC services;.</li> <li>▪ An increased confidence of specialist palliative care staff in the acute sector that treatment plans would be continued following discharge. This was evident when residents were discharged from the acute sector earlier than the would otherwise have been.</li> <li>▪ Raised interest of the community palliative care service in residential aged care evidenced by the increasing number of referrals.</li> <li>▪ Raised awareness of palliative care services of the need for access to multidisciplinary care, not just nursing consultancy. This was identified when the SPCNC role moved to the community based specialist palliative care provider – Peninsula Hospice Service (PHS). The needs of residents and their families could not always be addressed by the SPCNC. It was a limitation of the SPCNC role developed by PGPN and has been addressed by the multidisciplinary role provided by PHS.</li> </ul>

<b>Project title</b>	<b>VIC-4 - I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)</b>
	<ul style="list-style-type: none"> <li>▪ Meaningful discussion about the palliative care needs of the community at the Executive and Board level which could be seen in the Advisory Group meeting minutes. The minutes reflect the broad discussions about palliative care extended beyond topic relating the project activities.</li> <li>▪ Evidence of the need for ongoing support for RACF staff in providing a palliative approach. As described below, the provision of education built on the capacity of RACF staff to provide palliative care but it was not in a sustainable way.</li> </ul> <p>They also reported that the project has led to an increase in the knowledge, skills and confidence of RACF staff in palliative care. The education programs were well attended by participants who rated their usefulness as high. The project raised awareness of the APRAC Guidelines amongst RACFs which previously were not aware of their existence; and increased use in those facilities that were aware of the guidelines but did not apply them to current practice.</p> <p>However, the project reported that there is no evidence that education led to sustainable change to the practice of the staff. The reason for referrals did not change significantly over the course of the project as might be expected if staff improved their clinical knowledge in a permanent way. For example, a shift from 'specific symptom management' to 'staff confidence'. The number of referrals did not decrease as might be expected if staff confidence grew or improved with care planning.</p> <p>The most significant and positive consequence of the project is that Peninsula Hospice Service (PHS) has extended its service model to include consultancy, by providing funding from the existing (PHS) budget to support the role. This decision was based on evidence, which supported the benefit of the SPCNC role and the lack of evidence that education lead to sustainable change.</p> <p>The final report notes that palliative care now has a higher profile in residential aged care as a result of project activities aimed at raising awareness of and increasing the skills and knowledge of GPs and RACF staff. The PGNP has an increased awareness of the needs of stakeholders through the coordination of the special interest groups.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The project has established the need of an ongoing role of specialist palliative care nurse consultant. At the project's completion, the Peninsula Hospice Service will undertake this role as part of their ongoing business. Therefore, the work of the project will be sustained.</p> <p>Though not originally planned, the specialist palliative care nurse consultant took leave during the project. This gave an unexpected opportunity for the Peninsula Hospice Service to take over the consultancy and education components of the project. It was felt this assisted in the understanding and development of an ongoing role provided by PHS.</p> <p>Mature and stable relationships between different stakeholders were noted as crucial for the sustainability of the project.</p> <p>Of the two special interest groups, the group for GPs is to continue with financial support from PGNP. However, the group for RACF staff is under review as this group attracted participants from facilities who already had relationships with specialist palliative care providers and accessed support regularly. The group was not attracting participants who would benefit the most from support.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. It appears that working more intensely with three or four RACFs works better than trying to provide support across many (45) facilities.</li> <li>2. There is a need for ongoing education programs and ongoing training as RACF staff left and new staff are recruited.</li> <li>3. RACFs need ongoing support from the palliative care sector. Making sustainable change and building capacity requires time and should be viewed as an ongoing role that is coordinated.</li> <li>4. The success of the project was largely due to the collaborative relationships which had been developed between specialist palliative care providers, acute inpatient services and the Peninsula GP Network. These partnerships enabled a shared vision and a</li> </ol>

Project title	VIC-4 - I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)
	<p>generosity of spirit in undertaking and successfully implementing the project activities.</p> <ol style="list-style-type: none"> <li>5. Formal advance care planning initiatives for residents needs to be undertaken at a regional level.</li> <li>6. Using or modifying existing resources rather than creating new resources. For example, rather than developing a palliative care patient RACF record, the 'Yellow Envelope' was adopted by the acute hospital and RACFs as a means of transferring patient information with the potential for the Comprehensive Medical Assessment completed by the resident's GP to be included.</li> <li>7. Joint education sessions contributed to increased communication between multidisciplinary team members and use of a common language.</li> <li>8. Further activities which facilitate the engagement of GPs in facilities need to be explored.</li> </ol>

<b>Project title</b>	VIC-5 - Way to Go project – creating partnerships to enhance access to palliative care
<b>Keywords</b>	State-wide, local, major city, regional, primary care, specialist palliative care
<b>Host organisation</b>	Palliative Care Victoria Inc
<b>Partner organisations</b>	No formal partners
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	24 April 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a decision making resource for use by general practitioners to assist in the referral of terminal patients and enhance the relationship between general practice and palliative care sectors.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Development of the care plan with decision making tool.</li> <li>▪ Utilising findings from the early implementation phases within the Way to Go Project undertake action research within the rural township of Castlemaine to develop a decision making resource that will enhance the relationship between general practice and palliative care sectors and assist in the referral of terminally ill patients.</li> <li>▪ Utilising a problem solving methodology, develop strategies for the development of a decision making resource within the town of Castlemaine.</li> <li>▪ Pilot the model to those general practitioners working within Castlemaine.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project developed a number of recommendations to improve collaboration between services involved in providing care, specifically GPs and palliative care providers.</p>
<b>Project planning and development</b>	<p>A project officer was employed from June 2006 until the project's completion (May 2009).</p> <p>A Project Advisory Group was formed (June 2006) with representation from the eight Regional Palliative Care Consortium groups, Carers Victoria, Victorian Division of General Practice, Department of Human Services, a GP and chaired by the CEO Palliative Care Victoria. The Advisory Group met for the first 12 months of the project and then reformed into an Implementation Group. The Implementation Group comprised the Chief Executive Officer of both General Practice Victoria, Palliative Care Victoria and senior management from both the Department of Human Services and Carers Victoria. The aim of this group was to monitor and guide the implementation phase of the project.</p> <p>A Working Group was formed, with representation from both GPs and palliative care sectors, to be involved in the development and implementation of a decision making resource for GPs and provide advice in the final project phases.</p> <p>A project plan was developed and modified when the project changed its scope, objectives and strategies. These changes required an amended deed of variation which documented the modified project purpose, aim and activities.</p> <p>A Castlemaine Reference Group was established with representation from stakeholder groups across the sub-region of Castlemaine, Bendigo and Gisbourne. There were three meetings held, with the final meeting taking the form of a strategy meeting.</p> <p>Initially, ethics approval has been deemed as not required by the project. With the project re-scoping, ethics approval was obtained from the University of Queensland.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>Originally the project was to be conducted over three phases. Developmental phase: involving consultation to develop the care plan and decision making tool, an education strategy and carers resource. Trial phase: to trial the three components within one metropolitan and two rural regions in Victoria. Implementation phase: to roll out state-wide of the decision making tool, education strategy and carer resource.</p> <p>The project conducted activities in the development phase, including a literature review, care planning and decision support tools audit, referral audit, and consultations with key stakeholders.</p> <p>A literature review was outsourced by the project to the Palliative Care Unit La Trobe</p>



<b>Project title</b>	<b>VIC-5 - Way to Go project – creating partnerships to enhance access to palliative care</b>
	<p>University (and completed May 2007). The review included sections on: decision-making tool for GPs; education strategy to assist GPs; and carer resource.</p> <p>An audit of existing care planning and decision support tools used across Victorian palliative care consortia was not undertaken due to re-scoping of the project with emphasis being placed upon work within general practice. However, the final report notes that preliminary findings identified a range of care planning and support tools were used within palliative care consortia across Victoria.</p> <p>The project reported that a referral audit was undertaken within general practice and palliative care to identify the number of decision-making resources currently being used within referral processes by the respective sectors. The outcome of the referral audit was that there was a range of documentation and computer software programs in existence creating little uniformity, leading to a lack of consistent practice within the referral of terminal patients to palliative care services across the State. However, the final report notes that processes have been developed within Government, in consultation with key stakeholders, to address this issue, and programs are currently in the process of being implemented across the State to build common referral practice.</p> <p>‘In recognition of the work currently within both general practice and palliative care sectors in regards to referral documentation and resources, the project identified that rather than developing another referral tool, that there would be real value to take a step back and consider, and explore the decision making processes that influence or ‘trigger’ a referral to palliative care’ (Way to Go Project, Final Report, May 2009, p26). At the September meeting of the Advisory Group in 2006 it was agreed that this would be the future direction of the Way To Go Project.</p> <p>The project conducted primary and secondary consultation processes with GPs across Victoria.</p> <p>In May 2008 there was a re-scoping of the project. This meant that the education strategy and carers resources (Developmental Phase 1) was not undertaken, nor were Trial or Implementation Phases.</p> <p>Instead the project undertook a project in the township of Castlemaine aiming to examine the relationship that existed between general practice and palliative care. In particular, to explore the issue of communication regarding the accessing of palliative care medicines after hours and to build a shared understanding of service provision issues within the local community. The project reports that this was addressed by the development of a service mapping document outlining current service provision and identifying any service gaps; and the development of strategies for issues to be addressed. University of Queensland were contracted to undertake an independent evaluation of this work.</p> <p>It was planned to undertake a ‘pilot’ of the preferred strategy with those GPs working within Castlemaine, however the project reported that this was not undertaken due to timing limitations.</p> <p>There was an official launch of the Way to Go project in May 2009.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>Part of the Developmental Phase was to consultant GPs across Victoria, involving two separate processes (Level 2).</p> <ul style="list-style-type: none"> <li>▪ Primary consultation: A GP decision-making resource survey was developed and disseminated to a sample of eight GP Networks involving four rural and four metropolitan regions. Of the 815 surveys distributed to GPs, 91 (11%) were returned.</li> <li>▪ Secondary consultation: Three GP focus groups, plus eight phone and two face-to-face interviews were conducted within both rural and metropolitan networks. In total, 25 GPs participated in these consultations.</li> </ul> <p>The project reports that in total, 145 GPs participated in either surveys, focus groups, face-to-face or phone interviews.</p> <p>With the re-scoping, a consultation was conducted for the Castlemaine project. The project reported that 73 face-to-face interviews, conducted by the project officer, were held with GPs, inpatient and allied health professionals including community palliative care and district nursing staff and community agency workers. The issues discussed in the</p>

<b>Project title</b>	<b>VIC-5 - Way to Go project – creating partnerships to enhance access to palliative care</b>
	interviews included the interface between general practice and palliative care, and an exploration of experiences and perceptions in relation to palliative care provision within Castlemaine. The University of Queensland were contracted to undertake an independent evaluation of Castlemaine part of the project.
<b>Impact &amp; outcomes</b>  <i>What results were achieved?</i>	<p>The following results were reported by the project.</p> <p>Primary consultation key findings (level 2) identified a variation between GPs in terms of age, how many palliative care patients seen by GPs each year and their ethnic identity. Of those GPs surveyed, approximately 50% identified they saw either more than five and between ten to fifteen or more palliative patients per year. The final report notes that this shows that a higher number of palliative patients are managed by GPs than is the current understanding within the palliative care sector (that is, GPs seeing less than five palliative patients per year). This highlights that greater numbers of palliative patients are being managed by GPs within local communities.</p> <p>The most significant finding from the secondary consultations was that GPs want a relationship with palliative care providers. The final report further identified this as having information about the local palliative care service, how it operates and when is it appropriate to refer patients.</p> <p>For the Castlemaine project, it was reported that the service mapping processes found that current service provision worked well between key stakeholder groups, which were based on long standing relationships between key stakeholders. A lack of information concerning the local community based palliative care service and referral processes was reported as evident from the stakeholder consultations. The current service provision levels were identified and the service gaps were identified within communication and referral processes within the key stakeholder groups. The strategies recommended to address these service gaps include:</p> <ul style="list-style-type: none"> <li>▪ Development of service brochure.</li> <li>▪ Increase in liaison with relevant stakeholder groups.</li> <li>▪ Practice visits to build relationships.</li> <li>▪ Provide education and information resources within the community regarding the community based palliative care program.</li> </ul> <p>The project's final report summarises the key findings as follows:</p> <ul style="list-style-type: none"> <li>▪ 'A range of referral processes exist that are involved in the referral of patients from general practice to palliative care leading to a lack of common practice.</li> <li>▪ The relationship between a GP and palliative care provider determines the likelihood of a referral being made.</li> <li>▪ Referral is a highly individual process with patient need and choice being critical to the process occurring.</li> <li>▪ Communication within the relationship between general practice and palliative care is critical. In particular, communication processes in relation to accessing palliative medicines after hours' (Way to Go Project, Final Report, May 2009).</li> </ul>
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>The project reported that the methods used were underpinned by community development principles, to ensure that project outcomes were responsive to the needs of respective stakeholder groups and activities would be sustainable into the future.</p> <p>The project will disseminate their key findings across Victoria and especially to the GP Networks in the Castlemaine area.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. That general practice and palliative care providers work to develop and enhance those elements of the referral process that impact upon effective working relationships between the two sectors.</li> <li>2. That consultation occurs with GPs to ensure their continued and increasing involvement within care planning activities for palliative patients and their carers.</li> <li>3. That pivotal to referral is the relationship between general practice and palliative care and that this is understood as critical to referral processes.</li> <li>4. Relationship building strategies, particularly those where personal contact can be made, are undertaken.</li> </ol>

<b>Project title</b>	<b>VIC-5 - Way to Go project – creating partnerships to enhance access to palliative care</b>
	<ol style="list-style-type: none"> <li>5. That it is accepted by all providers that ultimately it is the patient's choice to accept a referral to palliative care.</li> <li>6. That it is accepted by all providers that referral to palliative care at the point of diagnosis is not always possible, and that referral needs to occur at a time that is born out of patient need and their choosing.</li> <li>7. That the relationship formed with patients and carers is one hallmarked by an earned trust and that health professionals work to earn and guard patient and carer trust.</li> <li>8. Strategies to increase GPs involvement should aim at increasing their knowledge and interest in palliative care.</li> <li>9. Innovations in service provider models are required to overcome the barriers to provision of after hours care.</li> <li>10. Support for developmental work being carried out to enhance and build consistent practice within referral processes across the State continues.</li> <li>11. That palliative care services foster and enhance relationships with local GP Networks to gain access to local doctors and to provide content for continuing professional development modules.</li> <li>12. Work be undertaken to address GPs' information, education and training needs of palliative care issues, especially in terms of pain management and symptom control.</li> <li>13. Palliative Care Victoria addresses mixed perceptions within individuals, families, health professionals and general community through promotion and education of palliative care issues.</li> <li>14. The palliative care sector continue to develop and implement strategies to promote a positive image within local communities regarding what palliative care is, its services and the types of support it provides.</li> </ol>

<b>Project title</b>	VIC-6 – Improving palliative care services for adolescents and young adults with cancer
<b>Keywords</b>	State-wide, community care, primary care, specialist palliative care, adolescents and young adults
<b>Host organisation</b>	Peter MacCallum Cancer Centre (PMCC)
<b>Partner organisations</b>	Project was conducted collaboratively between the PMCC Department of Pain and Palliative Care (DPPC) and the onTrac@petermac Victorian Adolescent and Young Adult Cancer Service (onTrac@petermac)
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	27 April 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a model of palliative care service delivery for adolescents and young adults with cancer, within a comprehensive cancer centre, in which specialist palliative care is intimately integrated with primary health care provision.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Develop understanding of barriers to referral to specialist palliative care within a comprehensive cancer centre.</li> <li>▪ Develop integrated model of specialist palliative care service delivery for adolescents and young adults (AYA) with cancer.</li> <li>▪ Establish integrated model of specialist palliative care service delivery within onTrac@petermac.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project developed a model of integrated palliative care for AYA cancer patients that supported smooth transitions between settings of care, was flexible to accommodate the individual needs of patients in their local communities, and promoted strong collaborations between services involved in providing their care. This was achieved through the use of care planning, and communication of these plans to all services involved.</p>
<b>Project planning and development</b>	<p>A project officer was recruited as 0.5 EFT (June 2006) and incrementally increased to full-time (October 2008 until project completion). This position involved a dual role of project officer and clinical nurse consultant. Specialist palliative care physician and registrar were not appointed out of project funding but allocated from existing palliative care team. Data managers were involved at setup and evaluation activities. A part-time project advisor was appointed in December 2006, who assisted in the project management and evaluation activities.</p> <p>A Project Management Team was formed (June 2006) to oversee the day to day management of the project including advising and supporting the project officer. In addition, a steering committee was convened (August 2006) to support the project management team, monitor project tasks / timelines and ensure maintenance of best scientific and ethical practice. The committee also assisted in the service delivery model development of the model of service delivery and facilitating awareness of the project among primary care providers.</p> <p>A project plan with projected timelines was developed (May 2007), followed by an evaluation plan (August 2007).</p> <p>Ethics approval was granted by Peter MacCallum Cancer Centre Ethics Committee.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project was conducted in four phases: developmental, implementation, evaluation and final reporting. Developing and testing the model of service delivery were the major activities of the project.</p> <p>The project conducted three preliminary activities aimed to develop an understanding of barriers to referral to specialist palliative care within a comprehensive cancer centre. These activities included undertaking a retrospective audit to examine barriers and establish baseline items for later comparison, conducting focus groups with key stakeholders, and carrying out a pilot of the model.</p> <p>Whilst providing information about referral patterns and end of life care, the retrospective audit failed to provide adequate insight into barriers to referral to palliative care. However, it gave direction for focus group questions. Barriers to referral to palliative care from the</p>

<b>Project title</b>	<b>VIC-6 – Improving palliative care services for adolescents and young adults with cancer</b>
	<p>focus groups included: treating teams reluctance to “abandon” patients to palliative care; difficult transition from cure to palliation for patients/families; and societal norm that young people should not die. From these focus group results, three major areas were identified for the project to address:</p> <ul style="list-style-type: none"> <li>▪ increasing timely access to palliative care</li> <li>▪ improving communication between service providers</li> <li>▪ improving discharge planning and continuity of care across settings</li> </ul> <p>An eight-month pilot of the model was conducted (from August 2006 to March 2007) which removed the barrier of referral to palliative care by integrating palliative care into the onTrac@petermac team. The project officer assessed all onTrac@petermac patients, initiating involvement of other members of DPPC team as required, dispensing with the former system requiring a formal medical referral prior to DPPC involvement. Palliative care was added to the onTrac@petermac referral form as a service provision for selection, becoming an integral part of the onTrac@petermac multidisciplinary team. During the pilot, the project officer was involved with 25 patients. Lessons from the pilot, such as the importance of care coordination, were incorporated into the refined model. The pilot also established relationships with stakeholders within and outside of PMCC and trialed care planning and case conferencing tools, developed by the project.</p> <p>From 1 August 2007, the project commenced a 12-month implementation of the model. Over this period specialist palliative care was routine care for all onTrac@petermac patients with a palliative goal of care. Key components of the model were:</p> <ul style="list-style-type: none"> <li>▪ early integration of palliative care into the multidisciplinary care of AYA achieved by inclusion of palliative care nurse position in onTrac@petermac and removing the need for referral;</li> <li>▪ development of care plans;</li> <li>▪ development of clinical partnerships with community care providers (GPs, community palliative care) through case conferences and frequent liaison;</li> <li>▪ extension of hospital-based specialist palliative care into the community to up skill and support community service providers;</li> <li>▪ a move from crisis-based management to proactive follow-up;</li> <li>▪ cross specialisation skill development within the multidisciplinary teams of onTrac@petermac and DPPC.</li> </ul> <p>Despite the pilot and preliminary work undertaken, the model was subject to ongoing revision and refinement throughout the 12-months.</p> <p>Resources produced by the project include a flow chart and accompanying guidelines for multidisciplinary palliative care telephone case conferences plus an age appropriate fact sheet on palliative care.</p> <p>The project documented the retrospective audit, the pilot project and the telephone case conferences as separate quality improvement activity reports.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The project conducted an evaluation of the 12-month implementation of the model. The project used data taken from patients involved with onTrac@petermac prior to the project, during the implementation and feedback post-implementation.</p> <p>The evaluation methods included the:</p> <ul style="list-style-type: none"> <li>▪ Comparison of key criteria for deceased patients involved in the project with patients in the retrospective audit to measure the impact of the intervention (application of the model) on key indicators of service provision, particularly timing of referrals to palliative care, transitions between settings of care, and issues surrounding end of life care</li> <li>▪ Use of various assessment tools to better describe and understand the patient population</li> <li>▪ Collection and reporting of Palliative Care Outcomes Collaboration (PCOC) data to allow comparison of the population with other palliative care populations</li> <li>▪ Use of care plans to further describe the population and the interventions required for collaborations with other services that support transitions between settings of care and meet the patient/family needs within their local communities</li> <li>▪ Feedback from participants (GPs) involved in case conferences to assess efficiency and effectiveness of this intervention</li> <li>▪ Focus groups, surveys and interviews with key stakeholders involved in the project to provide feedback on the impact of the project and suggestions for the future.</li> </ul>

<b>Project title</b>	<b>VIC-6 – Improving palliative care services for adolescents and young adults with cancer</b>
	<p>Assessment tools used included Edmonton Symptom Assessment System (ESAS), Palliative Prognostic Score (PaP), and Edmonton Classification System for Cancer Pain (ECS-CP).</p> <p>During the evaluation period a data manager was engaged and hours were increased for the project officer and the project advisor (which had been planned from the outset).</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The project report includes detailed information on the evaluation results for the population of 32 patients, the impact of the model, care coordination (including six case conferences), and end of life care planning. The overall evaluation results reported in the project's final report include the following findings.</p> <p>During the pilot and model implementation periods, 58 patients were included in the onTrac@petermac program who had a palliative goal of care, and they received palliative care involvement at earlier phases of care than prior to the project. There has been an increase in access to palliative care for AYA cancer patients (from one patient to almost three patients per month). The development of systems and processes for care planning enabled all but one patient involved in the 12 month implementation to have extensive documented care plans used to address their identified palliative care needs and appropriately coordinate care. Of the 29 patients who died during the project, 95% had access to community palliative care, with a change of focus for referral from end of life care to symptom management and psychosocial support.</p> <p>Changes in workplace practices as a result of the project included increased discussions around goals of care and palliative care issues generally, improved patient documentation in the form of care plans, increased coordination between services, which included the use of telephone case conferences. At PMCC, care for these patients shifted from a consultative model to one of shared care with treating teams.</p> <p>Data collection throughout the project enabled a better description and understanding of this AYA palliative care population, from the time of transition to a palliative goal of care through to end of life. The majority of patients were symptomatic, the predominant symptoms being fatigue, pain, anorexia and insomnia. Symptom clusters were a common feature as were complex pain syndromes. Most patients had identified psychosocial needs, and impact on their families was recognised as being significant.</p> <p>The project found that AYA tend to maintain their functional status longer when compared to other palliative care groups, and that once reaching the deteriorating phase tend to die quickly. Place of death appeared to be influenced by dyspnoea, seen as the dominant symptom in patients dying in an inpatient setting, and the major factor that appeared to influence death at home was the patient and family's desire and preparedness to do so. Achievement of a home death relied on collaboration between and commitment of services to support the AYA at home, and having access to specialist palliative care.</p> <p>A number of risk factors for complicated grief were identified, exacerbated by loss of a young person, and care plans around these issues ensured appropriate bereavement care was available.</p> <p>The feedback from stakeholders was very positive and they hoped that the integrated model of specialist palliative care for AYA would continue.</p> <p>The project concluded that AYA with cancer with a palliative goal of care are a complex patient population with significant, persistent and complex symptom burdens and unique psychological and social needs. An approach that recognised that the shift of focus from cure to palliation is not experienced as a single event but a slow process of increasing awareness, and this was fundamental to developing a model of early integration of palliative care that would underpin a smoother transition for this population. The importance of AYA's relationship with the primary treating team was acknowledged, and the model relied on an integrated relationship where the oncology team remained the primary treating team. Recognition that AYA easily disengage from services and will not always contact health care professionals when problems arise, dictated that a proactive, preventative model of service delivery was necessary to avoid the crisis interventions that were common prior to commencement of the project. This involved an ongoing relationship rather than the consultative model generally practiced by DPPC.</p>



<b>Project title</b>	VIC-6 – Improving palliative care services for adolescents and young adults with cancer
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>Since the conclusion of the implementation phase, the project reports that the level of service delivery has not been continued due to lack of staffing resources. The relationships between onTrac@petermac and DPPC continue, with DPPC representation at weekly onTrac@petermac multidisciplinary meetings continuing, and onTrac@petermac staff organising case conferences.</p> <p>The project reports that additional staff positions are required to sustain the improvement achieved by this project. Specifically, additional palliative care nursing staff would sustain care coordination, care plans, case conferences and community partnership and increased palliative care medical specialist staff would assist in the development of state-wide partnerships and support AYA dying in rural and regional areas.</p> <p>Policies and procedures are in development and include a statement of Best Practice for Improving Care of Adolescents and Young Adults which will be presented to the Clinical Governance committee at Peter MacCallum Cancer Centre.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project regarding the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. Features of a model of palliative care provision for AYA should include: <ul style="list-style-type: none"> <li>- Early and ongoing palliative care involvement</li> <li>- Care integrated with the primary treating team</li> <li>- Multidisciplinary care within an AYA cancer team</li> <li>- Proactive, preventative care</li> <li>- Continuity of care</li> <li>- Importance of supporting family throughout, including end of life</li> <li>- Bereavement follow-up</li> </ul> </li> <li>2. Coordination of services is paramount and requires: <ul style="list-style-type: none"> <li>- Role clarification</li> <li>- Collaborative care planning</li> <li>- Access to specialist palliative care</li> <li>- Access to primary treating teams</li> <li>- Use of case conferences – telephone case conferences should be considered for all AYA with complex palliative care needs</li> </ul> </li> <li>3. End of life care (EOL) planning: <ul style="list-style-type: none"> <li>- Recognition of the difficulty in engaging AYA in EOL care planning</li> <li>- Increased expertise in engaging AYA in EOL conversations</li> <li>- Adoption of common language in relation to goals of care</li> </ul> </li> <li>4. Professional support: <ul style="list-style-type: none"> <li>- Formal support for individuals and teams working with AYA is essential</li> <li>- Specialist AYA palliative nursing needs to be integrated within broader nursing roles, including the whole AYA population, for sustainability</li> <li>- The palliative care nurse needs to be supported within a specialist palliative care team to ensure professional support for the individual practitioner. This should include professional mentoring and supervision, and ongoing education.</li> </ul> </li> </ol> <p>Those recommendations provided by the project regarding the project processes are listed as follows.</p> <ol style="list-style-type: none"> <li>1. Up front development of the project plan with assistance from services such as National Evaluation Team in setting up evaluation plans as part of the overall strategy.</li> <li>2. Greater project management skills development for project officers.</li> </ol>

<b>Project title</b>	VIC-7 - A national approach to referral and care planning in paediatric palliative care
<b>Keywords</b>	National, community care, acute care, primary care, specialist palliative care, paediatrics
<b>Host organisation</b>	The Royal Children's Hospital Inc.
<b>Partner organisations</b>	The Children's Hospital at Westmead, Sydney; Sydney Children's Hospital; Child, Youth and Women's Health Service, Adelaide; Royal Children's Hospital, Brisbane
<b>Project funding</b>	\$267,100.90 incl. GST
<b>Project timeframe</b>	1 May 2006 to 31 December 2008 was varied to November 2006 to April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop a set of resources for health professionals including care planning guidelines and tools to assist with the planning process aimed at improving the experience of care of children (0-18 years) with life-limiting conditions and their families.</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ Recognise that, in many instances, some or all of the elements of paediatric palliative care are provided by health care professionals whose substantive work is not palliative care and seeks to build the capacity of the broader system to provide this care according to best practice.</li> <li>▪ Leverage the collective expertise of key centres of excellence in paediatric palliative care to create tools for use more broadly.</li> <li>▪ Ensure consistent standards of care across a wide range of diagnostic groups, health care settings, geographical locations, and cultural groups.</li> <li>▪ Utilise the existing evidence-base to inform care planning practice.</li> <li>▪ Generate tools to assist with the assessment of individual patient needs as well as enabling providers to anticipate and plan for changes in needs.</li> <li>▪ Encourage closer collaboration between providers in the paediatric and palliative care sectors as well as across acute health and community settings.</li> <li>▪ Generate tools to assist in planning for important transitions between care settings and optimise opportunities for families to receive care in the setting of their choice.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project has developed care planning tools and guidelines to assist health practitioners working with children and adolescents (0-18 years) living with life limiting conditions. The project anticipates these tools will help provide a consistent standard of care across a wide range of diagnostic groups, health care settings, geographical locations, and cultural groups. The care plans and tools will assist in the assessment of individual patient needs as well as enabling providers to anticipate and plan for changes in needs. They will assist in planning for important transitions between care settings and optimise opportunities for families to receive care in the setting of their choice. Finally, it is anticipated the PaedPalCarePlan will encourage closer collaboration between providers in the paediatric and palliative care sectors and assist in coordinated care for children.</p>
<b>Project planning and development</b>	<p>The project team consisted of the project officer, who was employed specifically to fulfil the tasks set out to achieve the deliverables; the project manager, manager of the Victorian Paediatric Palliative Care Program (VPPCP); and the consultant paediatrician with the VPPCP. During the course of the project, there were two different project managers and in the last eight months or so of the project, the project manager position was filled by the project officer.</p> <p>A Reference Group was established and comprised of representatives from Sydney Children's Hospital (New South Wales), The Children's Hospital at Westmead (New South Wales), the Royal Children's Hospital (Queensland), and the Child, Youth and Women's Health Service (South Australia). The Reference Group members were funded to provide input to the project by sharing expertise and practice experience; reviewing draft guidelines and tools; assisting the project worker to access key stakeholders within their organisations; supporting the pilot and the evaluation phase; plus assisting with implementation. They met face-to-face annually to discuss the project, in addition to email and telephone correspondence over the course of the project.</p> <p>A project plan was developed outlining the different phases and tasks required to fulfil the project, including objectives, key activities and performance indicators. Small changes were made to the project plan. Changes included the development of the prototype, which had not been included in the original project plan.</p>

<b>Project title</b>	<b>VIC-7 - A national approach to referral and care planning in paediatric palliative care</b>
	<p>A Memorandum of Understanding was developed between the RCH (host organisation) and the other four collaborating organisations. Only one organisation returned a signed copy of the Memorandum of Understanding.</p> <p>Ethics applications were approved by the Royal Children's Hospital, Melbourne Human Research Ethics Committee (September 2007; June 2008; February 2009).</p>
<p><b>Delivery</b></p> <p><i>What did the project do, create, change?</i></p>	<p>This project developed the PaedPallCarePlan, which is a unique suite of web-based tools to assist health professionals plan palliative care for children with life-limiting conditions and their families. The tools are located at <a href="http://www.paedpallcareplan.org.au">www.paedpallcareplan.org.au</a>.</p> <p>The contents of these resources have been developed after review of the available literature and consultation with experts in paediatric palliative care. Forty-four health practitioners were interviewed either by telephone or in person and in group settings or individually between September 2007 and March 2008 to determine the relevant items and issues that needed to be included in the care planning tools. Thematic analysis from the consultation process resulted in 13 themes being identified. Following health practitioner consultations it became clear the care planning tools and guidelines needed to be web-based and a user friendly prototype of the care planning tools and guidelines was created.</p> <p>A prototype was developed by 3rd Year University of Melbourne students from the Department of Information Systems and then completed (May 2008), after consultations with health professionals regarding the utility and useability of the prototype; and with experts in web-page design. It was planned to conduct prototype consultations with parents to check the suitability of questions and items included in the tool. However, time constraints prevented parent consultations taking place but feedback from one parent was received.</p> <p>The prototype PaedPallCarePlan consisted of care plans, tools, information and resources / contacts. The six care plans included: i) Diagnosis of a life limiting condition; ii) Stable Phase; iii) Deterioration or crisis; iv) Transition between care settings; v) End of life care; and vi) Bereavement care.</p> <p>Five tools were developed to be used either in conjunction with the care plans or to be used on their own. These were: Child and Family Information; Assessment Tool; Pain and Symptom Management Plan; Referral Template; and Documenting Goals of Care and Treatment Decisions.</p> <p>A second consultation phase was conducted by emailing the prototype web address to 53 health practitioners who had either participated in the initial consultation phase or expressed an interest in providing feedback. Those participating were asked to view the prototype and provide feedback anonymously via an e-survey.</p> <p>A pilot was conducted over five months, where key health practitioners were invited to trial the revised tools. Participants were asked to complete an e-survey every time they used the care planning tools and guidelines when working with a child with a life limiting condition. The tool was modified according to the evaluation feedback.</p> <p>The project reports that the care planning tools and guidelines (comprising the PaedPallCarePlan) will assist with:</p> <ul style="list-style-type: none"> <li>▪ Referral to specialist paediatric palliative care services.</li> <li>▪ Management of the child's physical, emotional, psychological and spiritual needs across a range of care settings.</li> <li>▪ Planning for transitions between health care settings (e.g. hospital to home, hospital to hospice, home to hospital) and ongoing care in those settings.</li> <li>▪ End-of-life decision-making and documentation.</li> <li>▪ Bereavement care of parents and siblings.</li> </ul> <p>A national program of awareness-raising and professional education about the PaedPallCarePlan was planned. This will be achieved through distributing brochures and postcards (which have been developed) and scheduled educational seminars. However, the project may be funded to conduct more extensive evaluation to determine the effectiveness of the care planning tools. Therefore plans to disseminate the new program have been put on hold to restrict exposure to the new resources. Once the evaluation phase is complete the PaedPallCarePlan will be launched.</p>

<b>Project title</b>	<b>VIC-7 - A national approach to referral and care planning in paediatric palliative care</b>
	<p>The project's final report includes:</p> <ul style="list-style-type: none"> <li>▪ Literature review summary document, detailing the relevant literature. A draft manuscript providing a more comprehensive review of the literature relating to care planning is being prepared for publication.</li> <li>▪ Health practitioner interviews summary document, which highlights the relevant themes identified.</li> <li>▪ Prototype consultation report, which contains a list of health practitioners / agencies involved in the prototype consultation process, along with feedback and comments on the tools and the results of prototype consultation.</li> <li>▪ Pilot study report, detailing the survey tool and findings.</li> </ul>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The final resource has not been evaluated, though the project is applying for additional funding to conduct an extensive evaluation to test the hypothesis that the resources contained within the PaedPallCarePlan will improve the quality of palliative care provided.</p> <p>However the project did conduct a series of evaluations to test the relevance, effectiveness and functionality of the care planning tools and guidelines with the consumers (i.e. health practitioners).</p> <p>In order to collect feedback, e-surveys were developed using SurveyMonkey (<a href="http://www.surveymonkey.com">www.surveymonkey.com</a>), which is an American-based website designed to assist with the development of professional online surveys as well as collecting responses and analysing the results. Three separate e-surveys were developed, one each for the prototype consultation, parent consultation and pilot study.</p> <p>Prototype consultation evaluation: The prototype web address was emailed to 53 health practitioners who had either participated in the initial consultation phase or expressed an interest in providing feedback. Those participating were asked to view the prototype and provide feedback via the e-survey on the layout of the prototype and the issues and items included. Feedback was anonymous, however, a database was collected of the individuals and agencies who initially agreed to participate. Of the 53 who agreed to provide feedback, 37 participated (response rate of 70%). Of the 37 who participated, 28 surveys were completed in their entirety (75.7%). During the prototype consultation phase, those contacted to provide feedback were invited to pass the web address and e-survey onto colleagues they thought may be interested in the care planning tools. The website had a total of 1560 hits, averaging 223 hits per month, between July 2008 and January 2009.</p> <p>Parent consultation evaluation: Unfortunately due to time constraints only two parents were able to view the PaedPallCarePlan prototype and only one parent completed the survey in full.</p> <p>Pilot evaluation: Participants were asked to complete an e-survey every time they used the care planning tools and guidelines when working with a child with a life limiting condition. Each agency/organisation was given a code to use when completing the survey, which tracked how many times agencies used the PaedPallCarePlan. E-survey responses were unable to be tracked, so responses were anonymous.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The findings from the prototype consultation evaluation revealed the majority of health practitioners providing feedback were female and from metropolitan areas. Nearly all participants liked the layout of the PaedPallCarePlan. The most popular care planning tools viewed were the Assessment Tool, Pain and Symptom Management Plan, Diagnosis of a Life-limiting Condition and the Child and Family Information. Nearly two-thirds of participants believed all the care planning tools would be helpful. Ninety-two percent of participants believed the care planning tools would help them plan care for children with life limiting conditions and 93% of participants reported they would recommend the care planning tools to colleagues to help plan care for children.</p> <p>A small pilot study was conducted between September 2008 and January 2009. A total of 14 agencies/departments agreed to participate across Victoria, New South Wales, South Australia, Queensland and Western Australia including a paediatric hospital in New Zealand. A total of 16 surveys were completed from five of the 14 agencies/departments who initially agreed to participate. All participants were female and from metropolitan areas. No standard tools were currently being used by paediatric hospitals or palliative care agencies, except tools that each organisation had created for their own use. The End of Life care plan and the Assessment Tool were the most used care plans and tools, followed</p>

<b>Project title</b>	<b>VIC-7 - A national approach to referral and care planning in paediatric palliative care</b>
	<p>by the Child and Family Information and the Pain and Symptom Management Plan. Nearly all participants indicated the PaedPallCarePlan was effective in helping plan care for children with life limiting conditions. The average time taken to complete the care plans and care planning tools was 9.4 minutes. The majority of participants reported they would recommend the PaedPallCarePlan to colleagues to help them plan care for children with life limiting conditions, however, four were unsure as to whether they would recommend the care planning tools. Feedback from the pilot suggested the PaedPallCarePlan could be used by the majority of health practitioners who work with children with life limiting conditions, including general practitioners, clinical nurse coordinators, nurses and nurse practitioners, palliative care workers, allied health workers and social workers.</p> <p>The final product, The PaedPallCarePlan, (care planning tools and guidelines) is anticipated by the project to assist with:</p> <ul style="list-style-type: none"> <li>▪ Referral to specialist paediatric palliative care services;</li> <li>▪ Management of the child's physical, emotional, psychological and spiritual needs across a range of care settings;</li> <li>▪ Planning for transitions between health care settings (e.g. hospital to home, hospital to hospice, home to hospital) and ongoing care in those settings;</li> <li>▪ End-of-life decision-making and documentation;</li> <li>▪ Bereavement care for parents and siblings.</li> </ul> <p>These resources will both support individual health practitioners and assist primary and specialist providers to work collaboratively.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>The PaedPallCarePlan will be hosted by the RCH website without ongoing costs. Monitoring and updating of the website will be supported by a team of web experts who have been involved in the design and creation of the site and are familiar with its purpose and content.</p> <p>The Victorian Paediatric Palliative Care Program will continue to support and monitor the use of the guidelines and tools through its work within the paediatric and palliative care sectors across acute and community contexts in Victoria. The Children's Hospital at Westmead, the Sydney Children's Hospital, the Royal Children's Hospital in Brisbane and the Child, Youth and Women's Health Service in Adelaide will adopt similar supportive and monitoring roles within their individual states. The collective input of these organisations will then be used by the Paediatric Palliative Care Reference Group in ongoing evaluation and revision. The project reference group also functions as the Australian and New Zealand Paediatric Palliative Care Reference Group, and so will continue after the project is completed.</p>
<p><b>Recommendations</b></p>	<p>Those recommendations provided by the project are listed as follows:</p> <ol style="list-style-type: none"> <li>1. Further evaluation is undertaken.</li> <li>2. The web-based tools are further developed so that data may be held, accessed and updated over time by the full range of health practitioners involved.</li> <li>3. The possibility of adapting these resources for use internationally and in other care settings be explored.</li> <li>4. The PaedPallCarePlan be linked to initiatives such as the National Standards Assessment Program to facilitate the provision of quality palliative care to children.</li> </ol> <p>Lessons learnt from the project include:</p> <ol style="list-style-type: none"> <li>5. Health practitioners are asking for consistent standards of care across care settings.</li> <li>6. Health practitioners believe care planning tools will help improve the quality of care received by children living with life limiting conditions.</li> <li>7. Care planning tools need to be short, easily accessible and easy to use.</li> <li>8. Care planning in paediatric palliative care requires continuity of care, coordinated care and a multidisciplinary approach.</li> </ol>



<b>Project title</b>	VIC-8 - A framework for supporting a patient / family centred palliative approach in a regional rural acute care setting
<b>Keywords</b>	Local, regional, community care, acute care, specialist palliative care
<b>Host organisation</b>	Wodonga Regional Health Service
<b>Partner organisations</b>	Northeast Health Wangaratta; Ovens and King Community Health Service; Goulburn Valley Hospice Care Service Inc; Goulburn Valley Health; Wodonga Regional Health Service; Benalla and District Memorial Hospital; Numurkah District Health Service; Seymour and District Memorial Hospital
<b>Project funding</b>	\$275,000 incl. GST
<b>Project timeframe</b>	1 May 2006 to 30 April 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To pilot a rural Integrated Inpatient/Community 'shared care' Palliative Care Model (ISC) that enhances palliative care planning for patients and their families through the home, hospital and residential aged care continuum.</p> <p><i>Aims:</i> The project aim and objectives were redefined after the commencement of the project and the project title changed from Regional, integrated inpatient/community 'shared care' palliative care model, (ISC) PC Model. The new aim was the development, establishment and trial of a framework which fosters and supports a palliative approach to care in a regional / rural acute care setting, which may be generalisable to other sites. With the new project objectives being to:</p> <ul style="list-style-type: none"> <li>▪ Embed palliative care in the structures and processes of the organisation.</li> <li>▪ Support the development of sustainable quality improvement activities.</li> <li>▪ Develop community partnerships.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project submission was developed in response to the increasing request for specialist palliative care in the acute care settings. The project aimed to support the smooth and appropriate transition between settings of care for people with life limited illness and their families and carers, through developing and trialling a framework in regional / rural acute care environment of Albury/Wodonga.</p>
<b>Project planning and development</b>	<p>The project appointed a part time project officer (community development worker) and part time project nurse (clinical nurse consultant) in August and September 2006. These positions were advertised two and three times respectively, leading to a subsequent delay in recruitment.</p> <p>A detailed project management plan was developed which included a stakeholder management and communication plan, plus a risk management plan. However, it took time to understand and scope the project as those involved in the application development were not accessible.</p> <p>There was one Memorandum of Understanding that covered the eight health providers: Northeast Health Wangaratta; Ovens and King Community Health Service; Goulburn Valley Hospice Care Service Inc; Goulburn Valley Health; Wodonga Regional Health Service; Benalla and District Memorial Hospital; Numurkah District Health Service; Seymour and District Memorial Hospital.</p> <p>Overall project management was provided by the executive sponsor (Executive Director of Patient Services), who presented bi-monthly status reports to the Hume Palliative Care Consortia. A Project Reference Group (PRG), chaired by the executive sponsor, provided support and advice to the project. The project reported that 'despite changing PRG membership due to personnel changes, the role of PRG became clearer over time, and the group was a valuable resource in holding a bigger picture, outside of separate organisational issues and interests'.</p> <p>In addition, a Palliative Care Working Party (PCWP) organisational working group was reformed with the project as one of the members (with other members from acute and community services, including specialist palliative care). The PCWP undertook quality improvement activities and promoted the palliative approach to care within the hospital.</p> <p>A Sustainability Strategies Group (SSG) was formed where input and advice was provided</p>



<b>Project title</b>	<b>VIC-8 - A framework for supporting a patient / family centred palliative approach in a regional rural acute care setting</b>
	<p>for a specific period through formal meetings, and was found to be extremely valuable in refining the framework and trial activities.</p> <p>An ethics application was approved by the Human Research Ethics Committee to cover any potential involvement of past consumers.</p>
<p><b>Delivery</b></p> <p><i>What did the project do, create, change?</i></p>	<p>The Strengthening Palliative Care in a Regional Rural Acute Care Setting Project was a multi staged action learning project which developed, trialled and established a framework for guiding palliative care development in a regional and rural setting.</p> <p>Project exploration and development stage: Activities undertaken during this stage were aimed at developing an understanding of the situation and identification of issues and opportunities (obtained through stakeholder interviews and focus groups, literature search and site visits).</p> <p>A project launch was conducted using a hypothetical, as a way of bringing together a range of different stakeholders in one place at one time. The evening was cafe style, and facilitated by a local well-known comedian / actor, John Walker. Forty people attended, including participation from Commonwealth, regional, cross-border and local services, and carers and past consumers. The launch provided opportunities for education, dissemination and needs identification.</p> <p>Framework development and activities stage: Findings from the project exploration and development phase were used to develop the initial framework.</p> <p>Sustainability review and plan stage: A sustainability review was undertaken by the Sustainability Strategies Group (SSG), who produced a Sustainability Strategies Options Paper that identified sustainability issues and options for informing the next stage of framework development. The project found that access to this resource provided a key infrastructural link and support for the project.</p> <p>Framework refinement and trial stage: The framework was primarily informed by input from PRF, SSG and PCWP groups; information gathered during the consultation and research phase; and reference to the Palliative Care Australia guides for planning, service development and the palliative care standards.</p> <p>The framework's purpose was to provide a foundation for informing and supporting palliative care development. It renamed as a Strengthening Palliative Care Framework, and consisted of three key components, with corresponding key objectives and key activities.</p> <ul style="list-style-type: none"> <li>▪ Component 1 - Planning and service development with the key activities being the development of a palliative care planning framework, and policy.</li> <li>▪ Component 2 - Service provision and care coordination with key activities consisting of participation in the organisation's palliative care working party and case audit tool development.</li> <li>▪ Component 3 - Community and public health initiatives (health promotion) involved the coordination of community 'Four funerals in One Day' (play) planning group, and Dying to Know (Pilotlight) books.</li> </ul> <p>The project team participated in organisational and community activities in order to trial each component of the framework including the development of a palliative care policy; participation in the organisation's palliative care working party; and coordination of a cross-border community education initiative.</p> <p>Evaluation stage: Evaluation, review and further development of these activities were undertaken through the Plan-Do-Study-Act (PDSA) cycles.</p> <p>Dissemination stage: Dissemination of project experiences and findings was also a deliberate strategy in the final phase of the project. The aim of this strategy was to share information and further develop relationships with ongoing potential partners in service development and delivery in this regional rural area.</p>
<p><b>Evaluation methods</b></p>	<p>This project undertook a multi-staged action learning approach to understanding the situation and developing the framework - focusing on system level change. The project reported that direct patient outcomes would be limited at this stage, until a foundation and</p>

<b>Project title</b>	<b>VIC-8 - A framework for supporting a patient / family centred palliative approach in a regional rural acute care setting</b>
<p><i>How was the project evaluated?</i></p>	<p>increased capacity were in place to influence and manage ongoing improvements to care.</p> <p>For each of the three components of the framework, key activities were trialled using the PDSA cycles and reviewed against the key objectives / key learning goals. Therefore, evaluation and review processes were conducted in relation to the specific activities trialled, such as the case audit tool, the community play, or the palliative care week promotions.</p> <p>The project team developed its own evaluation tools and used the organisations planning tools. A survey was distributed at the closure of the project to invite comment regarding the impact of participating in activities overall.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The final report stated that the overall impact of the project had included anecdotal feedback from key participants reporting a raised profile of palliative care within the hospital and community, and increased awareness, understanding and knowledge of health care providers. A survey was developed to elicit further information on these areas and to assist in understanding which project-related activities were useful.</p> <p>The results of the survey, completed by 11 respondents, indicated that:</p> <ul style="list-style-type: none"> <li>• Organisational and palliative care knowledge increased through working at the interface of executive, quality, education, primary and specialist care provision and community. Of the 11 survey respondents 91% identified an increase in awareness and 82% an increase in knowledge (“increase” ranged from slightly to greatly increased).</li> <li>• Increased profile of palliative care, as identified by 80% (n=10) survey respondents.</li> </ul> <p>The activities most frequently identified as assisting increases in understanding, knowledge and profile were participation in the Project Reference Group and the Palliative Care Working Party; Dying to Know book; project presence; and education / in-services.</p> <p>The project reported that the community cross-border palliative care planning group and delivery of a play resulted in firstly expanded partnerships including local government, TAFE, media, support group and regional palliative care, carers’ and cancer organisations; secondly increased community knowledge (of 54 survey respondents 61% learnt new information and 85% indicated they were more reported to talk about death); and thirdly financial resources and goodwill for continued activities.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>This project was very focused on ensuring that aspects of the project would continue.</p> <p>Two key activities undertaken to ensure this were the formation of the Sustainability Strategies Group with the resulting Sustainability Strategies Options Paper (discussed in the delivery section) and the development of criteria for activities to be undertaken.</p> <p>Criteria were developed and then applied when deciding on activities to be undertaken as part of the project. The criteria included assessing if the activity would be sustainable, integrated, build capacity, encourage partnership development and generalisable to other sites. This criteria was expanded to include additional explanations: Sustainability would be an outcome of the criteria; caution to be used when talking of integration of palliative care, with the focus for this purpose being integration into the processes and structures of the organisation; relationship building precedes effective partnership development; capacity building can not be underestimated, and arises through a range of formal and informal activities and interactions; and being generalisable is critical, given the nature and purpose of a project.</p> <p>Many other sustainability strategies were implemented in this project:</p> <ul style="list-style-type: none"> <li>▪ Working with existing organisational programs and staff such as the Quality Manager, so that the project fits in with the Accreditation and quality improvement program</li> <li>▪ Developing a palliative care policy for the organisation</li> <li>▪ Reforming a palliative care working party where the project was a member, rather than the leader</li> <li>▪ Using or modifying existing organisational tools and resources such as the case audit tool and the Quality Improvement Planning and Reporting tool</li> <li>▪ Reviewing the project activities and goals with the revised Hume Region Palliative Care Consortia Plan to ensure consistency with the regional directions.</li> </ul> <p>The overarching principle was to facilitate system level change, working in collaboration</p>

<b>Project title</b>	<b>VIC-8 - A framework for supporting a patient / family centred palliative approach in a regional rural acute care setting</b>
	<p>with existing services and systems so that the framework and key activities will be ongoing when the project ends. The planning model/framework developed, based on the Palliative Care Standards and Palliative Care Australia guides, and is now embedded in the organisation as the palliative care policy. This policy aims to inform and guide future palliative care planning, service development and public health / community initiatives to ensure more accessible and equitable service delivery for people in the local area.</p> <p>The project nurse continues in her permanent nursing role in the hospital, and hence continuing influence through project learnings and outcomes.</p>
<b>Recommendations</b>	<p>Those recommendations provided by the project are listed as follows.</p> <p>For the Wodonga Regional Health Service:</p> <ol style="list-style-type: none"> <li>1. Palliative care policy is used to underpin future developments in palliative care.</li> <li>2. Plans be made for clinical governance arrangements (Palliative Care Working Party reporting to Quality and Risk Committee) and palliative care quality improvement activities to be sustained.</li> <li>3. Health promotion and palliative care partnership continue to be supported and developed.</li> <li>4. Partnerships with key internal and external stakeholders be continued and instigated as opportunities arise, with attention to inclusion of people with influence and connection to decision making at organisational, local, regional and state levels.</li> <li>5. Services provided by the Hume Palliative Care Consultancy Team as a resource and support team be optimised.</li> <li>6. Albury-Wodonga Health integration takes into consideration the relevant provision of palliative care to the population of Albury, Wodonga and surrounding areas.</li> </ol> <p>For the Hume Region:</p> <ol style="list-style-type: none"> <li>1. Learnings from the current Hume Region projects, the Network of Victorian DoHA-funded Projects and this project be shared at the Victorian Consortia Managers forum for consideration on ways to move forward.</li> <li>2. Learnings from this project be related through the State Strengthening Palliative Care in Victoria through Health Promotion Projects' Advisory Group to relevant stakeholders and decision makers.</li> </ol> <p>For the Victorian Department of Human Services:</p> <ol style="list-style-type: none"> <li>1. Findings from this project and the Network of Victorian DoHA-funded Projects are included in the current departmental reviews.</li> <li>2. Funding for developmental / capacity building positions be acknowledged and funded recurrently, separate to service provision roles and funding.</li> </ol> <p>For the Australian Department of Health and Ageing:</p> <ol style="list-style-type: none"> <li>1. Resourcing of an independent national evaluation and support team be continued in future funding rounds.</li> <li>2. Resourcing for state networks be reviewed and supported.</li> </ol>

## WA Project Summaries June 2009

<b>Project title</b>	WA-1 - The Renal Palliative Care Initiative, "Finishing up?... Maybe soon..." Project
<b>Keywords</b>	Local, remote, community care, primary care, ATSI
<b>Host organisation</b>	Kimberley Aboriginal Medical Service Council
<b>Partner organisations</b>	Kimberley Aboriginal Medical Services Corporation, Western Australia Country Health Services (WACHS) – Kimberley, Kimberley Palliative Care Service, and the Western Australia Cancer and Palliative Care Network.
<b>Project funding</b>	\$256,148.20 incl. GST
<b>Project timeframe</b>	31 May 2006 to 31 March 2009
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> The project sought to integrate a palliative approach into the care planning for people with a non malignant disease, that is, End Stage Renal Disease (ESRD).</p> <p><i>Aims:</i></p> <ul style="list-style-type: none"> <li>▪ To increase the patients' understanding of Chronic Kidney Disease (CKD) and the CKD pathway so informed decisions can be made by the patient and their family.</li> <li>▪ To ensure the provision of renal care in the Kimberley is culturally appropriate for indigenous patients.</li> <li>▪ To improve the coordination of care and care outcomes through a multidisciplinary team approach.</li> <li>▪ To decrease unnecessary hospital admissions and crisis management.</li> <li>▪ To create a seamless transfer between health providers for renal patients.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project sought to improve care planning for people with End Stage Renal Disease (ESRD), the vast majority of whom are Aboriginal. A key aspect is the introduction of the concept of 'supportive' (i.e. palliative) care for people with renal disease, allowing them to make decisions earlier on about their treatment options, in particular acknowledging that many clients wish to 'return to country' to die.</p>
<b>Project planning and development</b>	<p>A sound project planning and governance arrangement was adopted at the start of the project, including the establishment of a reference group which comprised the key stakeholders of local services as well as related services based in Perth. Membership included the local renal GP, Kimberley Satellite Dialysis Centre manager, Director of Nursing from the Broome hospital, WA Cancer and Palliative care network representative, Kimberley Palliative Care coordinator, as well as the visiting palliative care consultant and nephrologist who were based in Perth.</p> <p>Engagement between related services was planned to be achieved through the development of Memoranda of Understanding, however it was not clear from the project reports whether these eventuated. The reference group did, however, provide input into the initial project plan, which was comprehensive and ambitious. Many of the reference group members were also signatories to a business case which had been developed to establish a regional renal service, and it was expected that the key activities of the project would underpin the processes of that new service.</p> <p>Soon after the project commenced the palliative care services in the region were reduced due to staff shortages, and reference group meetings were less successful. Contact with members was maintained through email, and the provision of regular project updates. The project officer started working in close collaboration with staff at the Ord Valley Aboriginal Health Service in Kununurra, who assisted in developing and trialling resources in close consultation with community members. In addition, the Advisory Group for the proposed Kimberley Renal Service had commenced and included many of the same members of the project reference group; consequently, and appropriately, the project officer used this group as an ongoing source of advice and support for the project. The project received ethics approval from the Western Australian Aboriginal Health Information and Ethics Committee.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	As noted above, the project had an ambitious plan, and sought to develop tools and resources that would underpin the development of the proposed new Kimberley Renal Support Service. The first activities undertaken by the project officer, an experienced renal clinician, was a skills development program which provided her with project management

<b>Project title</b>	<b>WA-1 - The Renal Palliative Care Initiative, “Finishing up?... Maybe soon...” Project</b>
	<p>and palliative care expertise. A literature review was undertaken to identify issues, resources and policies or procedures which could be taken into account in the development of an ESRD palliative approach.</p> <p>The outcome of this search was that very little was available, necessitating the development of an entire renal resource package which included information about kidney disease as well as palliative approach, in a culturally appropriate medium. Mechanisms were also developed to make staff aware of new policies and procedures, including the provision of training and orientation materials, as well as inclusion of elements into position descriptions for the new service.</p> <p>A number of culturally appropriate kidney educational resources were developed to support care planning including posters, booklets, a brochure around kidney disease awareness prevention and treatment options. These were developed in close conjunction with members of the indigenous communities, presented in language and style which were readily accessible and understandable by Aboriginal health workers as well as clients and their families.</p> <p>A number of communication tools were developed which were incorporated into patient medical records, including a CKD sticker, CKD summary form, health service transfer form, case conference form and family meeting form.</p> <p>Health staff were also provided with resources to assist in their understanding of the issues associated with and management of patients with CKD, as well as facilitating clearer communication with patients and their families about the condition. These included a CKD protocol, kidney disease pathway poster, kidney disease care planning poster, palliative approach poster and palliative approach PowerPoint presentation.</p> <p>Progress on a number of aspects of the project was impeded at times due to the limited availability of palliative services within the region, and also due to the different administrative arrangements for the dialysis service, which was run by the Broome Regional Aboriginal Medical Service, and the project which was auspiced by the Kimberley Aboriginal Medical Service (KAMS). The new Kimberley Renal Support Service was established just prior to the project’s completion and is administered by KAMS, and it is anticipated that the project activities will be embedded into the new service.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>A comprehensive evaluation strategy was developed for the project activities, including evaluation of training programs to staff; client and family/carer experiences; and broader stakeholder feedback. As noted above, the development of resources utilised a process of ongoing evaluation and engagement by end-user representatives. However, formal evaluation of the project activities did not occur as they were designed to be implemented within the constructs of the new Kimberley Renal Support Service, which commenced just prior to the project’s completion. The resources and processes developed during the project will be embedded into the new service, and the project officer advised during the exit interview that the process of evaluation will be ongoing within this context.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>This project is an Australian-first, focusing on palliative support to indigenous clients with End Stage Renal Disease (ESRD). The achievements of the project are significant, especially when the geographical, cultural, resource and political contexts and constraints of its delivery are taken into consideration. The major outcomes of the project were the development and delivery of culturally appropriate educational resources and establishing systems so people can stay within the region for their treatment, instead of being transferred to Perth. As noted above, the resources and processes developed during the project are being embedded into the newly created Kimberley Renal Service, and therefore formal evaluations will be ongoing as the service becomes more established.</p> <p>Aboriginal people with ESRD and their families have benefitted from a range of aspects of the project. Direct clinical support was provided to approximately 135 clients and their families, the majority being in the vast East Kimberley region. In addition, these individuals and their broader communities benefitted from the community engagement of the project and resource development, which resulted in an increased level of understanding of kidney disease, the kidney disease pathway, and care and management for patients and their families.</p> <p>Prior to the project there were limited options for people with ESRD. There was no culturally appropriate care available in the region – and there was no recognition of the</p>



Project title	WA-1 - The Renal Palliative Care Initiative, "Finishing up?... Maybe soon..." Project
	<p>importance of family/kinship/country. Communication with patients and families were poor and in many cases patients were often transferred to Perth without the family being aware. As a result of the project, there are now more options available to patients in the region, and the services are more culturally appropriate due to the introduction of family meetings, and development of culturally appropriate educational resources. The final report noted that communication between patients, families and service providers has also improved through the use of the newly developed medical record forms, which have also made transitions between services smoother for patients.</p> <p>A brochure about the new renal service was developed as part of the project, which outlined the role of the service and how the kidney care team can support patients and their families. In another first, the brochure also introduces the subject of specialist palliative care which may be required as the disease progresses. The brochures have been provided to families as a talking point at the visiting nephrologists' clinics, Ord Valley Aboriginal Health Service clinic and CKD family meetings. Verbal feedback from patients, their families and staff has been positive.</p> <p>Service providers, health workers and clinicians have also benefitted from the resources and systems introduced by the project, and this is expected to increase over time as the new renal service becomes more established. The process of engagement with providers in the development of educational materials and new systems have assisted in increasing the level of understanding about chronic kidney disease (CKD) and the kidney disease pathway, the importance of providing a multidisciplinary approach to providing care, and the implications for service delivery to clients and their families. The final report notes that the resources provide a universal language in understanding kidney disease, and both indigenous and non-indigenous general community and health staff have found the resources helpful in learning about kidney disease. Given this is the first project of its kind to examine and develop resources for providing a palliative approach to CKD, there has been strong interest from other communities in Western Australia and the Northern Territory, and the resources are now incorporated as part of the learning materials for student Aboriginal health workers through the KAMSC health school.</p> <p>The project also developed a training package, which has yet to be trialled. It is expected that, when finalised, the package will be incorporated into an orientation package for staff working in the new Kimberley renal service.</p> <p>The kidney education posters, booklets and pamphlets, which have incorporated the palliative approach, are reported to be having significant impact. Prior to the project, there was no education or culturally appropriate resources for Aboriginal clients, and people did not seek out information once diagnosis of renal disease had been made. The project officer reported that following their involvement in the project, they subsequently had clients and family members contacting the service providers for more information – which is a significant change.</p> <p>Although initially developed for the Aboriginal patient and their family, over time the project has found that the resources have been universally accepted as learning aids for Aboriginal health workers, nurses, doctors and allied health staff. The final report notes that the tools have slowly increased regional awareness of kidney disease and in turn improved access to care. This is shown through the increasing numbers of patients attending their clinic for follow up and an increase in numbers being referred to the specialist renal clinics throughout the region.</p> <p>A number of resources were commenced, but due to time constraints were not finalised. These include a cultural flow chart, which outlines the issues which need to be taken into account when caring for an indigenous person with renal disease, and an advanced care planning tool, to document patients' treatment choices and end of life wishes. These items will continue to be developed as the renal service becomes established.</p> <p>The initial project plan included the recruitment of an Aboriginal health worker to take a lead role in the project, directed by the project manager. However, retention proved difficult, and the project manager effectively ran the project full-time. A strategic partnership was formed with the Ord Valley Aboriginal Health Service (OVAHS), which facilitated the inclusion of cultural input into all of the development of resources, and also enabled them to be trialled through the OVAHS clinic. Consequently, the reach of the project was enhanced, with a greater than anticipated impact on clients and providers in the East Kimberley region.</p>



<b>Project title</b>	WA-1 - The Renal Palliative Care Initiative, “Finishing up?... Maybe soon...” Project
	<p>The project maintained a strong engagement with key stakeholders, through the initial project planning and later with the Kimberley Renal Advisory Group in the development of the new renal service. The final report notes that this has enhanced communication and collaboration between the regional service providers and the Royal Perth Hospital, as well as between renal and palliative care services.</p> <p>The final report notes there appears to be an improvement in the follow-up for those clients with CKD, and in its management.</p> <p>As noted above, the project and the dialysis service were managed by different Aboriginal medical services, which impacted on the engagement of staff and implementation of outcomes. During the project period a review of the Broome Aboriginal Medical Service (BRAMS) was undertaken, as a prelude to decisions regarding the future funding of the Kimberley Renal Support Service. The review resulted in the decision being made to allocate responsibility of the new service to the Kimberley Aboriginal Medical Service Council (KAMSC). The final report suggests that this decision was an indication of the positive contribution of the project, the outcomes of which could be readily incorporated into the operations of the new service.</p>
<b>Sustainability</b>  <i>What aspects of the project will continue?</i>	<p>The Kimberley Renal Support Service (KRSS) commenced prior to the completion of the project. Auspiced by the KAMSC, the aim of the service is to provide education and support to regional health staff around the prevention, screening, care and management for those with chronic kidney disease and community dialysis. The project was timed to ensure that the palliative approach, and the resources and systems developed to support it, is integrated into all aspects of this new service as it develops.</p> <p>At the time of reporting, the KRSS has incorporated the multidisciplinary case conferencing for clients developed by the project, and commenced two-monthly monthly case conferencing meetings and education sessions with the visiting palliative care consultant from Perth.</p>
<b>Recommendations</b>	The project did not make any recommendations regarding the project processes as the final report noted that all processes developed have been incorporated into the new Kimberley Renal Support Service.

<b>Project title</b>	<b>WA-2 - Midwest Aged and Indigenous Palliative Care Planning Project</b>
<b>Keywords</b>	Local, regional, RACF, community care, primary care, ATSI
<b>Host organisation</b>	WA Country Health Service trading as Midwest Murchison Health Region
<b>Partner organisations</b>	Nazareth House Nursing Home (Catholic Healthcare); Geraldton Nursing Home (Moran Health); Midwest Division of General Practice; and Geraldton Regional Aboriginal Medical Service
<b>Project funding</b>	\$170,299.80 incl. GST
<b>Project timeframe</b>	April 2006 to May 2008
<b>Project aims</b> <i>What did the project set out to do?</i>	<p><i>Purpose:</i> To develop processes that will facilitate the smooth transition of palliative clients from acute care to residential aged care facilities (RACFs). This will include discharge planning guidelines, carer information packs and an information DVD explaining the palliative journey in the context of the rural setting and cultural needs.</p> <p><i>Aims:</i> Enhance the delivery of quality palliative care to clients who reside in RACFs and Indigenous people within Geraldton area through the following five objectives</p> <ul style="list-style-type: none"> <li>▪ Develop a care pathway/s to promote a seamless transfer of palliative clients between care settings particularly at the discharge point.</li> <li>▪ Develop specific processes that will meet the needs of local Aboriginal patients.</li> <li>▪ Facilitate training for staff to deliver culturally appropriate palliative care to Aboriginal clients within RACFs.</li> <li>▪ Develop localised carer information packs and promotional information.</li> <li>▪ Facilitate networking among other care planning project organisations funded under the Local Palliative Care Grants program in Western Australia.</li> </ul> <p><i>How project aims relate to goals of the sub-program:</i> The project aimed to enhance interface between acute care and RACFs for those residents with palliative care needs. A key impetus for the project was the number of aged care clients being sent to acute care facilities, essentially to die. The project set out to develop transfer tools, protocols and procedures, as well as education to RACF and acute hospital staff. In addition, the project targeted Aboriginal communities, and aimed to provide community and carer support and education, as well as cultural awareness training (and implications for palliative care) for the RACFs in the local area.</p>
<b>Project planning and development</b>	<p>The project was well established with an advisory group which included senior representatives of key stakeholders from the RACFs and services, private and public hospitals, Aboriginal medical service, general practitioners network and community palliative care services, and was chaired by Director of Population Health, Western Australia Country Health Service (WACHS). The group was heavily involved in steering the project and decision-making, with members being signatories to Memoranda of Understanding with WACHS. The project manager was advised by WACHS management that ethics approval was not required, as no individual personal details were being collected during the project.</p> <p>A subsidiary Aboriginal advisory group, comprising clients, carers and survivors of life-limiting illnesses was convened by Geraldton Region Aboriginal Medical Service (GRAMS) to inform the project activities targeting Aboriginal communities.</p> <p>The project was extremely ambitious, seeking to address a great number of issues across a broad geographic region, with a relatively modest budget. The project plan was reviewed when the project officer commenced in October 2006, and significant time was spent identifying priority actions and refining the work program. The extent to which it achieved its original objectives was affected as a result.</p>
<b>Delivery</b> <i>What did the project do, create, change?</i>	<p>The project was directed at Aboriginal communities and residents of RACFs in the Geraldton / Greenough region of Western Australia. The activities focused on improving transition pathways, education and support to those with palliative care needs, and targeted members of the Aboriginal and general community, as well as health and aged care providers.</p> <p>A number of activities were undertaken to address the needs of the local Aboriginal clients with palliative care needs, working in partnership with the Geraldton Regional Aboriginal Medical Service (GRAMS). The project was active in supporting the development of the</p>

Project title	WA-2 - Midwest Aged and Indigenous Palliative Care Planning Project
	<p>Indigenous Women's Cancer Support Group, part of the work being undertaken by a local Aboriginal Health Promotion Scholarship student. In addition, a "Guide to Aboriginal Culturally Appropriate Care Geraldton RACFs" was developed for use as an induction tool for RACF staff and carer volunteers as an introduction to local cultural information that could positively enhance their caring skills. The document is linked to the national resource 'Providing Culturally Appropriate Palliative Care to Indigenous Australians – Resource Kit'. And finally, an Aboriginal Carer's Training Package was developed, based on two existing resources designed for Aboriginal adult education. The <i>Learn Now Live Well</i> and the National Respite Centre's <i>Caring for Our Mob</i> programs were combined and tailored to the specific needs of the Aboriginal people of Geraldton.</p> <p>The project also sought to develop a number of information products, including a DVD and a brochure, to target the broader Aboriginal community, and provide support to carers of people with palliative care needs. The final report notes that due to funding constraints, these remain in draft form only.</p> <p>Improving the transition of clients between health and RACFs was another focus of the project. A 'transition audit' was undertaken in January 2007 to assess the main issues, including barriers to supporting palliative care provision in RACFs. As a result, the 'Just in Case Medications Program' was developed to address the lack of suitable treatment options available for pain symptoms or other minor medical conditions, that often lead to a resident's transfer to hospital. The Program included the development of a policy and guide for storage of essential palliative care medications in RACFs.</p> <p>Another issue identified during the audit was the need for support to guide decision making about palliative care. The Palliative Approach Pathway was developed to assist medical staff and care workers understand when palliative care can be introduced to a terminally ill patient, such as in the early stages of diagnosis.</p> <p>Halfway through the project, additional funding was provided by the Department of Health and Ageing to host and coordinate networking meetings for itself and the Renal Palliative Care Initiative, "Finishing up?... Maybe soon..." Project (WA-1) based in Broome.</p> <p>The project officer gained important skills in submission writing, as she sought funding from various organisations to enhance the project, including agencies such as WA Health and WA Lotteries. The final report notes that the project officer was successful in securing a number of grants, including for a Carer's Picnic and Recognition event during Carers Week, sponsorship of catering for two Carer training sessions and for information and gift bags for the participants of the National Respite Carer's 'Caring for our People' training program.</p>
<p><b>Evaluation methods</b></p> <p><i>How was the project evaluated?</i></p>	<p>The project evaluation plan underwent significant refinement following the revision of the project plan, which in turn meant the focus of the project would be to develop resources and strategies only; funding was not available for implementation.</p> <p>A Transition Audit was conducted at the outset of the project and provided baseline data on issues relating to transfers of clients between care facilities, the findings of which was used to plan project activities.</p> <p>Subsequent evaluation strategies comprised mainly anecdotal feedback from stakeholders. Advisory Group members were provided with a survey to look at the system level impacts and outcomes (Tool 8 from <i>The Caring Communities Evaluation Tool Kit</i>, developed by CHSD), as well as a survey following the piloting of the carer's training which was developed.</p> <p>Data regarding clients was not collected. The final report notes that 'as there was no implementation of resources, tools or policy reforms there was no evaluation able to be conducted on their effectiveness or impact'.</p>
<p><b>Impact &amp; outcomes</b></p> <p><i>What results were achieved?</i></p>	<p>The main activity which directly involved clients and carers was the project's support of the establishment of the Indigenous Women's Cancer Support Group (IWCSG). The project officer assisted with administrative tasks, such as organising meetings, encouraging membership, grant writing, developing the mission statement, objective setting and reporting. In addition, assistance was also provided to gather relevant information, host a 'welcome' event, and group facilitation. The IWCSG gatherings were informal meetings held fortnightly at which general discussion revealed many issues regarding palliative care and Aboriginal access to health services.</p>

Project title	WA-2 - Midwest Aged and Indigenous Palliative Care Planning Project
	<p>Formal evaluation of IWCSG members and carer training participants was unsuccessful, with a poor return of surveys. The final report suggests that a more productive approach would have been for an Aboriginal person to conduct the surveys verbally with each person. Despite this, the report states that the capacity for Aboriginal people to access palliative services has been increased with the establishment and development of the volunteer support group. It goes on to say it is likely that the initiative has created direct access to information and support that Aboriginal people were previously reluctant to pursue.</p> <p>A major focus of the project was to increase awareness by Aboriginal people of the services and supports available to them, given the disparity in the numbers of Aboriginal people utilising palliative services in comparison to the non-Aboriginal population. The project set out to develop a number of resources which could be made available through the Geraldton Regional Aboriginal Medical Service (GRAMS) as well as other community services. A significant amount of work was spent on developing a multi-purpose DVD resource which included information on mainstream palliative care services to the community, stories of Aboriginal people who had experienced cancer and palliative care and provide information on Aboriginal culture for care service providers, to provide better understanding of care for Aboriginal palliative patients. The project applied to four different funding sources to secure funding for its production, without success, so the DVD remains in draft only. An information file and brochure for Aboriginal carers was also developed in consultation with GRAMS and community representatives. Similarly, it remains in draft form due to insufficient funds for production and distribution.</p> <p>The project sought to provide support and education to Aboriginal carers through the development of an Aboriginal Carers training package. The package was based on a combination of two existing training programs, and tailored to meet the needs of Geraldton Aboriginal people. Palliative care issues were incorporated into the training, to promote the services and options available to people in their community. The training was delivered twice, once as a trial in April 2008, and again as a full-day training in May 2008. Anecdotal feedback was positive, with the participants indicating they had gained valuable information.</p> <p>A number of activities were undertaken to better enable staff of RACFs to support Aboriginal people, and those with palliative care needs. A key outcome was the development of a “<i>Guide to Aboriginal Culturally Appropriate Care Geraldton RACFs</i>”, which was compiled using information gathered from interviews, forums and meetings with the community and service providers across the region. The document is linked to the resource ‘<i>Providing Culturally Appropriate Palliative Care to Indigenous Australians – Resource Kit</i>’. The aim of the <i>Guide</i> is to offer RACF staff an alternative source of training in the form of an introduction and checklist of appropriate Aboriginal cultural care, and includes references to a national literature source accessible across Australia. The guide was distributed to two local high care facilities and one low care facility in Geraldton.</p> <p>The final report notes that project funding was not sufficient to conduct training, and therefore the focus shifted to facilitating access to information and relevant training courses, and distributing this to local aged care, palliative care and relevant health services. Alternative options to access training were investigated, including costs associated with establishing a tele-centre, however at the time of the project’s completion no local facility had progressed the option.</p> <p>At the outset of the project a process was undertaken to identify systemic issues affecting the care of RACF residents with palliative care needs, particularly in regard to the relationship with the Geraldton Hospital. A transition audit was undertaken in consultation with the project advisory group and key stakeholders, resulting in the identification of 15 issues which could be addressed to improve the transition pathway, with the major issues being around the quality of the paperwork exchanged between care settings, and communication with general practitioners regarding their patients’ transfer to, or discharge from, hospital. A number of strategies were attempted to address these issues, including the development of a ‘yellow envelope’ which would enable hospital and RACF staff to clearly identify when patients were deemed to be palliative, and which included essential information such as their medical summary, family contact details, advance care directive (if any), and medication regime.</p> <p>The ‘Just in Case Medications Program’ was also developed to address the lack of suitable treatment available in the RACF for treatment of pain symptoms or other minor medical conditions that often resulted in residents’ transfer to hospital. The program included the development of a policy and guide for storage of essential palliative care medications in</p>

Project title	WA-2 - Midwest Aged and Indigenous Palliative Care Planning Project
	<p>RACFs. The final report notes that this program received significant support of the Midwest General Practitioner Network's Aged Care Panel, as general practitioners and pharmacists often received calls after-hours for the replacement of scripts. While the protocols and guidelines were developed, the program was not able to be implemented during the time of the project. The final report notes that there was an expectation that the Aged Care Panel of the GP Network would be able to progress the implementation of the Program, however at the time of reporting it appeared that funding for the Panel had been discontinued.</p> <p>The project did not achieve the outcomes anticipated at the outset due to the broad range of initiatives it was aiming to conduct within the two-year timeframe and funding. Consequently, the impact has been limited, and the project officer spent considerable time seeking (unsuccessfully) alternative funding to fully develop and deliver on the objectives of the project. That said, however, there is a sense by the project staff involved that there has been benefits arising from the project in terms of community development and network building between services and in particular with the Aboriginal population, and capacity building of the project officer in terms of submission writing, stakeholder relations, cultural consideration, community engagement, event management and project management.</p>
<p><b>Sustainability</b></p> <p><i>What aspects of the project will continue?</i></p>	<p>A major outcome of the project has been the ability of the IWCSG to secure additional funding for a two-year period. The IWCSG model was developed to be as uncomplicated as possible to ensure its sustainability within the Aboriginal community. The final report notes that the model can also be adapted for use by other community, gender and culturally diverse groups.</p> <p>As noted above, a number of resources have been produced as part of this project, which remain in draft form. These include the brochure, information file and training package for Aboriginal carers, and the multi purpose DVD resource which provides information on mainstream palliative care services to the community, stories of Aboriginal people who had experienced cancer and palliative care and provide information on Aboriginal culture for care service providers, to provide better understanding of care for Aboriginal palliative patient; and the resources developed to assist with the transition processes between RACFs and hospital, such as the 'yellow envelope' and the Just in Case Medication Program. Should additional funding be sourced, these resources will be able to be more fully developed, disseminated, and implemented.</p>
<p><b>Recommendations</b></p>	<p>The recommendations provided by the project are listed as follows.</p> <ol style="list-style-type: none"> <li>1. That future project submissions include the appropriate components for the development, production, distribution, training and evaluation of resources, tools, guidelines and policy reforms.</li> <li>2. That funding bodies embrace the benefits of community development and capacity building approaches, particularly when a minority population is involved and fund accordingly.</li> </ol>

## Appendix A Care Planning Sub-Program projects

Code	Host organisation	Project title
NSW-1	Calvary Health Care Sydney Ltd	Collaboration in trust and care: A transition model of palliative care to residential aged care
NSW-2	Feros Care Ltd	Northern Rivers Primary Palliation Response Project
NSW-3	Catholic Care of the Aged	Hunter Palliative Aged Care Collaborative Framework
NSW-4	H N McLean Memorial Retirement Village Pty Ltd	Northern New England Palliative Care Planning Project
NSW-5	Hunter New England Area Health Service	Bingara and Warialda Palliative Care Planning Project
NSW-6	Catholic Health Care Services Ltd	Catholic Healthcare – Palliative Care Plan Development
NSW-7	Mid North Coast (NSW) Division of General Practice Ltd	Mid North Coast Integrated Network Palliative Care project
NSW-8	Intereach Inc. NSW (formerly Regional Social Development Group)	Rural and Remote Palliative Care Planning Model
NSW-9	Riverina Division of General Practice and Primary Health Ltd	Rural Community Palliative Care Packages and Education
NSW-10	University of Western Sydney	Decision making frameworks in advanced dementia: links to improved care
NT-1	Top End Division of General Practice	Top End Palliative Care Planning
QLD-1	Blue Care	Fraser Coast Palliative Care Project
QLD-2	Queen Elizabeth II Health Service District	End of Life Care Pathways Project
QLD-3	Canossa Services	Collaborative approach to the planning and delivery of palliative care services for end-of-life care at Canossa Services in Oxley and in the South West Brisbane Community
QLD-4	Spiritus Care Services (formerly St Luke's Nursing Service)	Bayside Palliative Care Carers Support Group and Bayside Care4U
QLD-5	The Prince Charles Hospital	Hospital to Home: Palliation for Sick Hearts
QLD-6	The University of Queensland	Palliative Care Discharge Planning Project
SA-1	Daw House Hospice Foundation Inc	Case conferencing and care planning: an exploratory study
SA-2	Mid North Regional Health Service Inc	Mid North Palliative Care Referral and Care Planning Project
SA-3	Northern Yorke Peninsula Health Service Inc	Yorke Peninsula Palliative Care Planning Project
SA-4	Palliative Care Council of SA Inc	Metro Acute Palliative Care Resource (MAPCARE)
SA-5	South East Regional Health Service Inc	Linking palliative care services and generalist providers in the South East of South Australia
TAS-1	Tasmania Department of Health and Human Services	Multidisciplinary palliative care plans for specialist and primary care providers of palliative care and consumers
VIC-1	Ballarat Health Services	Listen up! Hearing all the voices in caring for palliative patients in a regional / rural setting
VIC-2	Melbourne Citymission Inc	Being smarter – a partnership model of palliative care
VIC-3	Monash University, School of Primary Care	What happens after dark? Improving after-hours palliative care planning in urban and rural Victoria, for patients, their carers and health professionals
VIC-4	Mornington Peninsula Division of General Practice Inc	I.M.P.A.C.T (Improved Management Palliative Aged Care Treatment)



<b>Code</b>	<b>Host organisation</b>	<b>Project title</b>
VIC-5	Palliative Care Victoria	Way to Go project – creating partnerships to enhance access to palliative care
VIC-6	Peter MacCallum Cancer Centre	Improving palliative care services for adolescents and young adults with cancer
VIC-7	Royal Children's Hospital	A national approach to referral and care planning in paediatric palliative care
VIC-8	Wodonga Regional Health Service	A framework for supporting a patient / family centred palliative approach in a regional rural acute care setting
WA-1	Kimberley Aboriginal Medical Services Council Inc	The Renal Palliative Care Initiative, 'Finishing up?...Maybe soon...' Project
WA-2	Geraldton Palliative Care Service, WA Country Health Service trading as Midwest Murchison Health region	Midwest Aged and Indigenous Palliative Care Planning' Project