



Caring Communities: a description of the 37 projects of a national palliative care program

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Centre for Health Service Development

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1 Introduction

This document is one of three sections that form the final report for the national evaluation of the Caring Communities Program (CCP), a national palliative care program funded by the Australian Government between April 2003 and May 2006. The other two sections of the report are:

- *Caring Communities: evaluation of a national palliative care program*, which contains the findings of the national evaluation; and
- *Caring Communities: deliverables report*, which addresses the deliverables in the evaluation contract.

This document supports the other two sections of the report by providing a quick-reference guide to the main evaluation questions at the project level, which were:

1. What did the project do?
2. How was the project evaluated and what outcomes were achieved?
3. What aspects of the project will continue (sustainability)?
4. What has been learned from the project (capacity building)?
5. Are the lessons useful for someone else (generalisability)?
6. Who was told about the project?

A short description of each of the 37 CCP projects appears below, along with an index that categorises projects by 'theme' according to the objectives of the program. The specific information in each description forms a useful background to the main report which brings together the learnings from the 37 projects and integrates them to arrive at some general conclusions on the findings of the evaluation. It may also be informative for palliative care service providers and others in the health sector that are considering new projects and looking for details on models and resources that have previously been tried and tested in Australian communities.

1.1 **Background to the Caring Communities Program**

The Caring Communities Program (CCP) was designed to improve the quality of palliative care in the community by assisting families, carers and health service providers to give better support to people who are dying. It had six objectives:

1. To improve the knowledge and skills of families, carers and community groups so they can better support relatives, loved ones or individuals within the community who are dying, and to support them through their bereavement.
2. To enhance community awareness of the role and benefits of palliative care in meeting the needs of people who are dying and their families.
3. To improve awareness of a broad range of health care providers to the role of palliative care as an integral part of the health care system and their role in this area.
4. To support the educational needs of the specialist palliative care workforce and primary health practitioners and enhance the skills of both groups in working collaboratively across professional boundaries.
5. To support the coordination of care for the person who is dying and their family.

6. To develop strong partnerships between palliative care service providers, other health service providers and the service system infrastructure to ensure the delivery of palliative care is geographically accessible and integrated across service delivery settings.

In October 2002 tenders were invited from organisations with an interest in improving the quality of palliative care in the community for funding of between \$50,000 and approximately \$200,000. Approximately 270 submissions were received nationally. From these applications 37 projects were funded, totalling approximately \$4.7 million over four years.

These 37 projects address several 'themes' associated with palliative care, including:

- Improving community awareness of palliative care.
- Supporting dying people and their families.
- Increasing awareness of palliative care as an integral part of the health care system.
- Delivering education to support professionals providing palliative care services.
- Creating effective partnerships between palliative care providers, other health service providers and health systems, to coordinate care for dying people.

The CCP had a broad scope, encompassing a wide range of target groups including terminally ill people and their families, carers, health professionals in primary, allied and specialist care, older Australians, children and adolescents, Aboriginal and Torres Strait Islander Australians and culturally and linguistically diverse communities.

These themes are picked up in Section 3 of this report, where projects are indexed according to their target groups and the particular objectives of the CCP they were designed to address.

2 The 37 projects of the Caring Communities Program

2.1 Australian Capital Territory

Project Name	(ACT-1) Palliative Care Education Link
Organisation	Carers ACT
Funding	\$50,000 from Feb 2004 to April 2006
Project aims <i>What did the project set out to do?</i>	The original aim of the project was to provide free education and training to service providers (other than palliative care staff) who are working with families that are receiving or may receive palliative care services. This target group includes community groups, volunteers and staff working at residential aged care facilities.
Project Delivery <i>What did the project do?</i>	<p>The original project plan committed the project to conduct 12 workshops over a 3 year period. However, due to increased demand 25 sessions were held that attracted 247 people. This training focused on palliative care grief and loss.</p> <p>As the project progressed other new initiatives occurred which were outside the original project plan. These included:</p> <ul style="list-style-type: none"> ▪ A day retreat for volunteers working in the area of bereavement. This retreat included a workshop on grief and loss theory and self care. ▪ Two seminars facilitated by a Buddhist with a focus on healing and preventing burnout. ▪ The development of a resource list of local bereavement services. ▪ The expansion of the Carers ACT resource library to include books and resources relevant to grief and loss. ▪ The development of the ACT and Region Bereavement Support Network. <p>The support network holds bi-monthly meetings attended by up to twenty organisations, including self-help organisations such as the Compassionate Friends, Solace, SIDS and Kids, National Association of Loss and Grief, educators, funeral directors, palliative care services, hospital pastoral care services, Carers ACT, and private practitioners. These meetings focus upon looking at current local services, identifying any gaps in service provision and/or opportunities to work together and provide an opportunity to share any new resources and information.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>A workshop evaluation questionnaire was distributed at the end of each training session. Of the 247 people that attended an education sessions 184 completed an evaluation form. During 2004 a follow-up evaluation was posted out to participants two months after the workshop.</p> <p>The aim of increasing participants' knowledge in supporting people who are receiving, or may be receiving, palliative care was met according to the self reports in the questionnaires of the participants. Two months after the workshop seventy-four percent of respondents to the follow-up questionnaire believed the workshop had made a difference to their work, with many reporting an increase in sensitivity and insight or understanding of families' needs. All respondents indicated that they would recommend the workshop to others working in palliative care. Some respondents believed the workshop had given them a more holistic approach to their work. From these responses it can be inferred that many participants did feel the workshop improved their skills in supporting those families</p>

Project Name (ACT-1) Palliative Care Education Link	
	receiving palliative care.
Project Sustainability <i>What aspects of the project will continue?</i>	<p>Carers ACT and the ACT Palliative Care Society have agreed to respond to future training request of this module on an 'as needs' basis. The educational resources generated by this project are now a part of both organisations' pool of resources and can be used by other staff members as necessary.</p> <p>Carers ACT will continue to give administrative support to the ACT and Region Bereavement Network into the future. Also the dissemination of information regarding services, training and activities associated with palliative care and grief and loss will continue due to the collaborative approach of this project (see project capacity building).</p>
Project Capacity Building <i>What has been learnt?</i>	<p>Capacity has been built as a result of this project from three perspectives. Firstly the collaborative approach of Carers ACT working closely with ACT Hospice and the ACT Palliative Care Society has produced a combined expertise with regard to the psychosocial issues of palliative care. Also as a result of this collaboration many other relevant service providers are working more closely together. Secondly, increasing the community's knowledge and awareness of palliative care has increased its capacity to access appropriate services and better meet the needs of people who are receiving, or maybe receiving palliative care. Thirdly, capacity has been built in the aged care sector in terms of the increased ability of staff members to better meet the needs of dying patients and their families from a palliative care approach.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>It is expected that the education resources such as hand-outs and overheads could be used in other areas as they are not location specific.</p> <p>The positive experience of Carers ACT working collaboratively with local palliative care stakeholders is certainly a model that could be replicated elsewhere in Australia. This project's success is in part a result of the fact that it has combined the expertise surrounding grief and loss with a palliative care approach.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>Awareness of the project was raised by using the following resources:</p> <ul style="list-style-type: none"> ▪ Letter and email to all residential aged care facilities in the local area. ▪ Flyer and information posted on an ACT health promotion website and the Carers ACT website. ▪ Flyer and information distributed to a health promotion email group and a HACC services email list. ▪ Various talks to local key stakeholders.

Project Name	(ACT-2) Enhancing community understanding of palliative care
Organisation	ACT Palliative Care Society
Funding	\$66,878 between May 2003 and May 2005
Project aims <i>What did the project set out to do?</i>	The activities of this project were aimed at the community, professionals and non-professionals working in palliative care. The aim was to enhance community understanding and awareness of palliative care and to improve the skills of these groups to effectively meet the needs of dying people and their families.
Project Delivery <i>What did the project do?</i>	<p>In order to meet these aims a resource kit was developed, consisting of two booklets:</p> <ul style="list-style-type: none"> ▪ Booklet 1 – Palliative care in the ACT ▪ Booklet 2 – Supporting a person who needs palliative care: a guide to family and friends <p>Booklet 1 provides general information about palliative care together with an extensive 'frequently asked questions' section. Booklet 2 provides more detailed information about palliative care.</p> <p>A range of other local information relating to palliative care in the ACT was also made available including clinical fact sheets on an 'as needs' and 'as appropriate basis'. Topics for these fact sheets included, nutrition, nausea and vomiting, skin care, breathlessness and bereavement.</p> <p>These printed resources were backed up by a community education package. This package is designed to promote community understanding and awareness of palliative care by providing information to publicise and promote the role of palliative care, the contribution of the palliative care team and ways of accessing relevant services.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>A reference group was formed to continually evaluate the structure and content of the resource kit and to determine community education needs. Once the content was decided upon a community focus group consisting of 18 people met to provide feedback on the final draft of Booklet 1.</p> <p>Feedback from this focus group led to a number of changes to the booklet aimed at enhancing its readability and content. Finally, 10 palliative care 'experts' were invited to provide feedback on the final draft of the booklet in terms of its clinical content.</p> <p>As a result of this reflective action research approach the final product is a quality, comprehensive palliative care resource developed with the greatest of care and with broad-based expert opinion.</p> <p>The education sessions that supported the resource kit were trialled on four community groups during the course of the project. Overall, positive feedback was received from all presentations and further refinements to the resource kit were made as a result of feedback from these sessions.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The resource kit has been drafted in such a way that it can be used as a stand alone resource and that sections of it can be updated/amended without a complete reprint of the whole kit.</p> <p>The community education presentation package has been intentionally designed to be flexible in format so that it can be easily adapted for different audiences.</p>

Project Name (ACT-2) Enhancing community understanding of palliative care	
Project Capacity Building <i>What has been learnt?</i>	It is hoped that these resources will build capacity for those people living in the ACT who support individuals and families affected by palliative care. The booklets make available to the local community appropriate resource materials to enable them to expand their capacity to care. This will hopefully have the effect of ensuring people can be cared for in the setting of their choice for as long as possible.
Project Generalisability <i>Are the lessons useful for someone else?</i>	By its design, the resource kit has been written for a local ACT audience. However, the community education packages, together with the clinical fact sheets, have been intentionally designed to be flexible in format so that they can be easily adapted for different audiences.
Project Dissemination <i>Who was told about the project?</i>	The process of designing the resource kit and education packages was overseen by a reference group consisting of key members of the community, palliative care service delivery and the aged care sector. These people were ambassadors for the project and promoted the resources within their relevant jurisdictions. One thousand of the resource kits were printed and these will be distributed through the ACT Palliative Care Society and other interested organisations.

Project Name	(ACT-3) Shared understandings – improving palliative care for people with dementia
Organisation	Alzheimer's Australia ACT
Funding	\$119,112 between May 2003 and August 2005
Project aims <i>What did the project set out to do?</i>	To improve the quality of palliative care services offered to people with dementia in the ACT and Southern NSW.
Project Delivery <i>What did the project do?</i>	<ul style="list-style-type: none"> ▪ Produced an education resource for health care workers and members of the community on issues surrounding palliative care and dementia. ▪ Developed an improved professional relationship between dementia care workers and other aged care workers and palliative care specialists in the ACT and Southern NSW.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The implementation of palliative and dementia education together with improving the collaborative partnerships between services has enabled people with dementia to stay within the same residential aged care facility and still receive quality end-of-life care. This will lessen the chance of a palliative care patient with dementia being admitted to the unfamiliar environment of acute care for the last days of their life.</p> <p>An independent needs assessment was conducted by the Aged Care Evaluation Unit of Greater Southern Area Health Service. This assessment revealed the need for education and training focussing on palliative care and dementia in local nursing homes.</p> <p>The project appears successful in meeting its aims and objectives and in particular with regard to bringing the issues of palliative care for people with dementia to the forefront in local aged care facilities. However, formal evaluation results are yet to be received from the independent evaluator.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The ongoing benefits of the project relate to the important information resources that have been created. The collaborative partnerships between services will also continue beyond the life of the project.</p> <p>The local ACT Hospice will continue to offer dementia/palliative care education after the end of the project and palliative care and related topics are now included in all education sessions run by Alzheimer's Australia ACT.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>A tremendous amount of capacity has been built in terms of the lessons learned from improving palliative care for people with dementia, particularly for local residential aged care facilities. The organisational partnerships created between dementia care services and palliative care services has improved the capacity of palliative care in the local area by ensuring referral between these services.</p> <p>This has been a largely under-researched area and the supportive materials created for this area of care will be invaluable resources.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	The lessons learned in this project are useful for people with dementia living with a life-limiting illness. In response to the interest generated by this project, Alzheimer's Australia is currently putting together a position paper on people with dementia and palliative care.

Project Name	(ACT-3) Shared understandings – improving palliative care for people with dementia
Project Dissemination <i>Who was told about the project?</i>	<p>A monthly Alzheimer's newsletter, <i>Sundowner Quarterly</i>, was an important resource throughout the life of the project with regard to disseminating relevant information about palliative and dementia care. Monthly dementia network meetings have also provided an important conduit to disseminate relevant information.</p> <p>A reference group consisting of key stakeholders from palliative, dementia and aged care proved to be a highly successful way of disseminating information about this project to local health professionals.</p> <p>The project officer also presented a paper at the Third International Conference of Ageing, Spirituality and Palliative Care in Adelaide in September 2004.</p>

2.2 New South Wales

Project Name	(NSW-1) Developing linkages between an Aboriginal population and a palliative care service
Organisation	Wentworth Area Health Service
Funding	\$58,000 between April 2003 and April 2005. <i>(This project was funded for one year, but was granted an extension due to difficulties in recruitment and retention of the project officer position)</i>
Project aims <i>What did the project set out to do?</i>	<p>The project aimed to create sustainable links between the Aboriginal and Torres Strait Islander population and WAHS palliative care services in order to:</p> <ul style="list-style-type: none"> • build the capacity of palliative care service to provide a culturally appropriate service and • build the capacity of the Aboriginal and Torres Strait Islander community in the area of palliative care • enhance access of these people to mainstream palliative care services.
Project Delivery <i>What did the project do?</i>	<p>Data were collected by focus groups and interviews. Five groups with existing Aboriginal forums were held in March, April and May 2004 (total 75 participants) using questions developed for Aboriginal community workers. Three groups were held with 39 Area Health Service staff, using questions developed for the purpose. In-depth interviews were conducted with three Aboriginal and Torres Strait Islander carers, using questions developed for Aboriginal carers.</p> <p>General themes were documented under Aboriginal communities, Aboriginal health workers and Area Health Service staff.</p> <p>A training package titled “Caring for the Aboriginal Palliative Care Client” was developed and include in the quarterly SWAHS western cluster palliative care education modules. This program was conducted for health workers, and evaluated using pre- and post-education questionnaires measuring participant knowledge and confidence.</p> <p>An annotated bibliography on Aboriginal and Torres Islander health was conducted and included the final report.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The project reported the following results (in the final report, p. 9):</p> <ul style="list-style-type: none"> ▪ An increase in access to palliative care services. In 2005 the service received 8 referrals compared to one Aboriginal and Torres Strait Islander person each year prior 2005. ▪ The module “Palliative Care: Care of Aboriginal People” was added into Palliative Care training and facilitated by an Aboriginal health care worker. ▪ An increase in the knowledge and understanding of palliative care service providers on how to address Aboriginal issues in palliative care (shown in the participant pre and post Aboriginal Awareness module surveys) ▪ Increased use of existing information and resources supported by an expressed understanding of how and from where information and support can be obtained.

Project Name	(NSW-1) Developing linkages between an Aboriginal population and a palliative care service
	<ul style="list-style-type: none"> ▪ There have been changes in the development of care plans to include cultural needs. ▪ Ongoing requests to attend the local Elder's Group to discuss issues such as what are palliative care and how do we access it? <p>However, the basis for drawing these conclusions is not clearly described in the final report.</p> <p>The final report did express that experiential learning and evaluation is seen as the most appropriate evaluation tools within the Aboriginal community and so used spoken informal evaluation. Therefore, the evaluation includes the perspectives of the Aboriginal Liaison Officer and the Palliative Care Clinical Nurse consultant.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>From the final report it appears that the following activities will be ongoing:</p> <ul style="list-style-type: none"> • Conducting the education module for Area Health staff working across the three modalities – aged care, inpatient and community health services. • Responding to requests for information from the local Elders Group <p>In addition, the project reported that the only way to effectively address (ongoing) issues of sustainability for improvements in Aboriginal health in general and Aboriginal palliative care is for these issues to be included in Area Health Service planning (final report, p. 12).</p>
Project Capacity Building <i>What has been learnt?</i>	<p>Useful lessons (final report p. 13):</p> <ul style="list-style-type: none"> • the need to advance the cultural awareness of health care providers by enhancing their knowledge of Aboriginal history and culture • the Aboriginal Liaison Officer must be known to, acceptable to, and trusted by the local Aboriginal community and their organisations • acknowledgement of the incongruence of Anglo-Australian approaches to palliative care with Aboriginal peoples' aspiration for self-determination, ways of communicating, and social organisation associated with caring for their sick.
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>Lessons highlighted in the final report include the need to incorporate Aboriginal cultural training in nursing curriculum in palliative care.</p> <p>The project recommended the use of the <i>National Palliative Care Indigenous Resource Kit</i>. Having the kit implemented by an Aboriginal liaison officer enhances the benefits.</p> <p>The project also recommended developing and maintaining partnerships and friendships with local organisations. The local Aboriginal community and its health care workers must know their Aboriginal Liaison Officer, must have that rapport that promotes trust and sharing.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>The project presented a paper titled "Developing linkages between an Aboriginal population and a palliative care service" at the National Palliative Care Conference, Sydney, August-September 2005.</p> <p>Details on dissemination activities were not documented. However, the project reported that sharing information on this project with local Aboriginal communities empowered them to own the project and its outcomes.</p>

Project Name	(NSW-2) Helping Communities Care: Volunteer and bereavement support networks
Organisation	Mid Western Area Health Service (MWAHS), subsequently amalgamated into the Greater Western Area Health Service (GWAHS)
Funding	\$198,000 between January 2004 and May 2006
Project aims	The project goal was to improve the capacity of communities within MWAHS to care for someone with a life threatening illness.
<i>What did the project set out to do?</i>	<p>The project objectives were to implement a model of volunteer coordination and bereavement support for rural communities, addressing the needs of people with life threatening illness, their families and carers.</p> <p>The target group was revised to exclude remote communities.</p>
Project Delivery	The project used a community development framework to guide its implementation.
<i>What did the project do?</i>	<p>A comprehensive generic model for volunteer Palliative Care and Bereavement support has been developed, after reviewing rural and remote models for bereavement support services and volunteers.</p> <p>Volunteers were recruited and trained for the three communities of Grenfell, Orange and Bathurst. Key staff were identified to advocate for and support volunteers.</p> <p>A Palliative Care and Bereavement Support Folder was produced to provide support and access to information for those bereaved. To date none of the volunteers recruited for this project have been involved in any bereavement volunteering.</p> <p>A series of documentation sets for improved management and information systems for volunteers were developed. These included: Volunteer training (1 for trainers and 1 for volunteers); Volunteer recruitment; and Volunteer coordination and ongoing management.</p>
Project Impact & Outcomes	The Evolving Evaluation Framework (a tool developed by the Western Research Institute for the Regional Health Services Project within GWAHS) was used for overall project evaluation.
<i>How was the project evaluated?</i>	There were 8 project recommendations made from the project. These are primarily recommendations to improve the volunteers systems and services and to provide ongoing support for project work.
<i>What results were achieved?</i>	<p>The project reported that the partnerships developed between GWAHS, The Cancer Council, NSW and Volunteering West have provided the cornerstone to the success of the project.</p> <p>The project reported that recruitment constraints and restructure of NSW Health limited the continuity and scope of the project.</p>
Project Sustainability	The project designed was based on a community development approach, which was planned to assist with project sustainability. However, this was ambitious and the timeframe was insufficient to support this approach.
<i>What aspects of the project will continue?</i>	There are 8 project recommendations made to assist in the sustainability of key aspects of the project. The proposal is for the WAHS to ratify these project recommendations.

Project Name	(NSW-2) Helping Communities Care: Volunteer and bereavement support networks
	<p>The project has ensured the sustainability of the resources developed by ongoing input from volunteers, local managers, patients and carers.</p> <p>Project activities will be expanded and sustained with resourcing by The Cancer Council, NSW who have funded a 2 year pilot position – A Navigator / Volunteer Coordinator. This position will provide: volunteer support and coordination within both The Cancer Council, NSW – Western Region and GWAHS; navigation assistance for people with cancer by providing information and links to service providers.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>Volunteer Central West provided the mandatory training component for the Caring Communities Volunteers. The Caring Communities Project arranged access to this training for other volunteers currently working within GWAHS.</p> <p>800 Palliative Care and Bereavement Support resources have been produced and will be provided free of charge within GWAHS.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The comprehensive generic model developed for volunteer Palliative Care and Bereavement support can be replicated within a variety of communities.</p> <p>The resources developed, such as the Palliative Care and Bereavement Support Folder can be used in other volunteer settings.</p> <p>Literature review entitled “Review of the literature and research that supports the case for volunteer and bereavement support networks” was compiled as part of the project.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>The project used a range of strategies to promote awareness of the project and disseminate results: MWAHS Staff newsletter – Mid West review; local television and local print media; presentations e.g. Chairs of local Health Councils; feedback to participants on the results of the Palliative Care Awareness survey information; meetings with stakeholders, staff and volunteers.</p> <p>Palliative Care and Bereavement Support Folder – interest and requests from external agencies such as Aged Care Facilities, Cancer Support Groups, Commonwealth Carelink Centre, Commonwealth Carer Respite Centre, The Cancer Council, NSW – Cancer Helpline.</p>

Project Name	(NSW-3) Kid's Grief: A Handbook for Group Leaders
Organisation	National Centre for Childhood Grief (NCCG)
Funding	\$90,000 between April 2003 and May 2004
Project aims	The project goal was to increase and sustain the scope of support provided by palliative care teams for dying and bereaved children and their families.
<i>What did the project set out to do?</i>	<p>The objectives were to increase:</p> <ul style="list-style-type: none"> ▪ The confidence of palliative care staff in conducting support groups for dying and bereaved children and their families. ▪ Geographical availability of counselling / support services for bereaved and dying children and their families.
Project Delivery	A manual was developed: McKissock, D. (2004) <i>Kids' Grief. A handbook for group leaders</i> . Terrigal, NSW: National Centre for Childhood Grief.
<i>What did the project do?</i>	<p>This project involved:</p> <ul style="list-style-type: none"> ▪ development of the manual content ▪ trialling and modifying the manual content ▪ producing the manual ▪ marketing and dissemination of the manual. <p>There were 2,500 copies of "Kids' Grief. A handbook for group leaders" printed for distribution. A website was developed (www.childhoodgrief.org.au), with a locked section designed to make support available to those purchasing the manual for support, including an advice question / answer section.</p> <p>On page iv of the manual is a reply form. The return of a completed form entitles the purchaser to e-mail questions and answer consultations with the National Centre for Childhood Grief (A Friend's Place) during the first twelve months of ownership.</p> <p>There was an official launch of the manual at the Terror Australis Conference in Sydney on 17/8/04 and in Melbourne on 21/8/04.</p>
Project Impact & Outcomes	Two focus groups held in Brisbane and Albury were conducted to review the manual. The project officer reported that "the focus groups provided valuable suggestions for additions to content and for refining the manual presentation to enhance user friendliness".
<i>How was the project evaluated?</i>	Subject experts conducted clinical reviews of the manual content. From this review process there were no significant changes necessary. There were changes made to the wording and some simplification of exercises.
<i>What results were achieved?</i>	<p>A feedback form was developed and sent with the manual to be returned to the author by purchasers. The project officer reports that comments from those who have already seen the book "are enthusiastic".</p> <p>This was a short project that focused on the production of the manual. Evaluation of the impact and outcomes of the manual were not part of the project. For example, the number of manuals sold, or the number of bereavement groups conducted for children from using the manual was not monitored.</p>

Project Name	
(NSW-3) Kid's Grief: A Handbook for Group Leaders	
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The project aims to be self funding with proceeds from manual sales.</p> <p>The funding obtained from sales of the manuals will be used to print more manuals. There is a project fund account set up for money from the sales, which can be accessed for printing.</p> <p>The project officer intends to design a training course for support group leaders to enhance their ability to use the manual effectively and plans to convert the course content and process into a Trainer's Manual.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>A one-day workshop was presented for another Caring Communities Program project at Mt. Olivet, Brisbane, Queensland.</p> <p>The project officer reported that the project's process included liaison with other children's services nationally and internationally, and this facilitated the development of a valuable network for mutual support and information exchange.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The manual can be used nationally and internationally. The project officer reported that interest has been shown by colleagues in Australia and overseas.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>Additional funding was given to promote the manual that included the development of a promotional flier.</p> <p>Email and postal lists developed by the project officer were used to promote the manual. Promotional material was sent to sister centres nationally and internationally.</p> <p>The manual is promoted through the www.childhoodgrief.org.au website and the www.bereavementcare.com.au website and linked to other appropriate websites.</p> <p>The manual was promoted at all Bereavement Care Centre workshops conducted in Australia and New Zealand. The project officer has received invitations to present at conferences and to conduct workshops for promotional purposes.</p>

Project Name	(NSW-4) QTY Bereavement Project
Organisation	Greater Southern Area Health Service
Funding	\$81,880 between Feb 2004 and May 2006
Project aims <i>What did the project set out to do?</i>	The aim of this project was to formalise a coordinated bereavement service for Queanbeyan, Yarrowlumla and Tallaganda (QTY) Shire areas. This is facilitated by developing strong partnerships between existing palliative care services, other health service providers, non-government organisations and community members to ensure that the delivery of bereavement services are integrated across service delivery settings. Key to this is the continual improvement of knowledge, skills and resources available to community members, nursing home staff and health professionals so they can better support those who are dying, their families, carers and the community through bereavement.
Project Delivery <i>What did the project do?</i>	<p>A steering group was formed out of a broad range of local stakeholders. Much work was undertaken in educating the steering group members about the concept of participatory action process. The steering group provided a strong sense of leadership to the project.</p> <p>A resource library of relevant bereavement and loss information was added to the special collections at three local libraries. A service directory including contact details for an extensive range of specialist and generalist services was set up through the local council's community directory.</p> <p>An education package was developed to improve the knowledge and skills of health professionals in bereavement, loss and grief using a range of formats according to the requirements of the agency.</p> <p>A bookmark, "<i>Know Someone Who is Grieving?</i>", was developed for distribution to small businesses and communities in the local area. This resource provides tips on how to respond helpfully to bereaved people and a list of relevant local resources.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The project was evaluated by the project officer. Three major components of the project were evaluated: the work of the steering group; a survey of local small businesses; and feedback from education sessions.</p> <p>A participatory action process was developed that encouraged steering group members to track processes as they evolved, reflect on the project's strengths and weaknesses and make adjustments accordingly. Detailed results from this participatory action research are not yet available but it is suggested by the project officer that whilst this was a challenging approach to evaluation it did help participants focus upon how they viewed their own contribution and participation. This resulted in lively meetings that harnessed the skills and knowledge of all steering group members.</p> <p>A survey of five questions was distributed to gauge how local businesses interacted with bereaved customers and asked what the project could do to support them in terms of information or education. Of the 97 questionnaires distributed, 78 (80.4%) were returned.</p> <p>Evaluation of the health professional education sessions was carried out through questionnaires. Results indicated considerable satisfaction with the experience. Participants also made suggestions for improvement to the sessions which have been incorporated into the education packages.</p>

Project Name (NSW-4) QTY Bereavement Project	
Project Sustainability <i>What aspects of the project will continue?</i>	Sustainability was a key component of this project and all resources developed by this project have been done so in partnership with existing resources to ensure their sustainability. A good example of this is through the development of special collections of loss and bereavement at public libraries in three local communities together with the inclusion of relevant resources in a local community directory. Both these resources will be routinely kept up to date to ensure that all information is locally relevant and current.
Project Capacity Building <i>What has been learnt?</i>	The project officer acknowledged the importance of recognising existing capacity in the community and invited the community to have input on how to build on this capacity in respect of bereavement services. In the words of the project officer "equity lies at the heart of the process...all knowledge is of equal value". This has enabled all participants to recognise and use their own knowledge and skill in contributing to the project. In this way community capacity in bereavement support is increased which will have a flow on effect in local palliative care services.
Project Generalisability <i>Are the lessons useful for someone else?</i>	All resources created by this project can be made available to other communities and can be used and adapted by them as appropriate to their local circumstances.
Project Dissemination <i>Who was told about the project?</i>	<p>The project officer presented a paper to the 7th International Conference on Grief and Bereavement in Contemporary Society in London in July 2005. Findings of the project were also presented to the National Palliative Care Conference 'New Horizons' in Sydney in 2005:</p> <p>This project was very much community focused and much effort was made by the project officer to encourage community participation and feedback at all stages of project development. As a result, awareness has been raised locally of issues pertaining to grief, loss and bereavement.</p>

Project Name	(NSW-5) Motor Neurone Disease (MND) Volunteer Visitor Pilot Project
Organisation	The Motor Neurone Disease Association of NSW Inc
Funding	\$73,000 between July 2003 and March 2006
Project aims <i>What did the project set out to do?</i>	<ul style="list-style-type: none"> ▪ Determine the benefits and efficacy of a Volunteer Visitor Program for people with Motor Neurone Disease (MND), their family and carer and the volunteers ▪ Develop and implement a volunteer recruitment strategy, MND specific education program and a training manual for MND volunteers ▪ Encourage and maintain close links between local palliative care services, MNDA NSW family support, volunteers and MND support groups ▪ Support carers in their caring roles by recruiting past carers to provide peer support in the later stages of disease and up to 6 months following bereavement.
Project Delivery <i>What did the project do?</i>	<p>Recruited, educated and supported 10 MND volunteers to provide support for people living with MND and their families in the Hunter / Newcastle / Central Coast communities.</p> <p>The education program consists of three MND specific education sessions and two sessions for MND volunteers only. Past MND carers attended the program and shared their experiences of caring.</p> <p>Following the 5 session education program, the volunteers were matched with suitable people with MND. The Role and Procedures for Volunteer Visiting was sent prior to commencing the visits. The Regional Advisor provided ongoing review of the visits and support.</p> <p>The project provided MND education to 6 palliative care volunteers to assist them to better support MND patients and their families in their communities.</p> <p>A MND Volunteer Visitor Resource Manual, Volunteer Visitor brochure and facilitators kit (power point presentations) were developed and published. A Bereavement Protocol and flyer was developed and implemented.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>An initial service provider questionnaire (December 2003) was distributed to palliative care coordinators of volunteers and MNDA NSW and identified that only two volunteers were visiting a person with MND out of 286 registered volunteers.</p> <p>Evaluations were conducted using tools designed by the project team, for the focus groups (two); education program (pre and post course); satisfaction of the volunteers, people with MND and carers with the volunteer's visits; satisfaction of the volunteers with the support they received from the Regional Advisor.</p> <p>Education program: fifteen participants, including ten MND volunteers and five palliative care volunteers in Newcastle. Evaluation demonstrated an overall increase in knowledge related to MND.</p> <p>Volunteer visits: Four (out of five) people with MND were matched up with a volunteer. Evaluation identified the potential for needs to change rapidly and for the visits to become inappropriate for the person with MND. This feedback highlighted the importance of regular contact with the Regional Advisor.</p> <p>Regional Advisor support: Positive feedback on the feeling of support from the Regional Advisor and with regular meetings of volunteers (which</p>

Project Name	(NSW-5) Motor Neurone Disease (MND) Volunteer Visitor Pilot Project
	included peer support and education) were rated highly. Bereavement support was not provided as none of the people with MND receiving visits had died.
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The project used existing MNDA NSW staff. This was a challenge but also a strength of the project with their involvement integral to the sustainability of the program. The MNDA NSW Regional Advisor in Newcastle / Hunter will continue to support the 10 MND volunteers. Funding has been provided from the MND support group in Newcastle to run the education program again in Newcastle / Hunter in 2006 and recruit more volunteers, starting April 2006. The Resource Manual will be sustained by extending its use to the MNDA Regional Advisors, palliative care coordinators of volunteers and other service providers. The resource manual was trialled with one volunteer as a self education tool. This proved to be a sustainable model of education and support. The project's final report will be used to provide information to the MNDA NSW Board and to assist with the development of the 2006-2009 Strategic Plan.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>The project has improved the capacity of the community by ensuring a skilled, supported and well-connected group of MND volunteers. The MNDA NSW family support staff have adopted the Bereavement Protocol. A new initiative from MNDA NSW was a Volunteer Education Day held on May 2005 using the resources from the project. This was developed into regular three monthly volunteer education and support gatherings for all volunteers of MNDA NSW.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>Education program and resource manual – can be used either directly or with some modifications. Resource manual can be ordered through www.mndnsw.asn.au</p> <p>Bereavement component – can be used with some modification in other communities. Bereavement flyer is available from MND Association of NSW Inc 1800 640 144</p> <p>It was recommended in the final report that MND Associations in Australia and New Zealand could replicate the project with appropriate resources and management support.</p> <p>Findings regarding volunteer visiting program:</p> <ul style="list-style-type: none"> ▪ There is a need to provide ongoing monitoring of visits and support and education for the volunteers to sustain them in their role. ▪ MND volunteers are valuable additions to the provision of care and support for people with MND earlier in the disease trajectory. ▪ Volunteers were reluctant to travel too far i.e. no more than 30 mins. <p>Findings regarding the education program: The palliative care volunteers need MND specific information and education to assist them in their role when caring for a person with MND.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>This project has used a wide range of communication strategies, including: local papers and clubs in Newcastle / Hunter / Central Coast communities; MND NSW quarterly newsletter "Forum"; Newcastle and Central Coast MND Support groups; Palliative Care Coordinators of volunteers at regular network meetings; local service providers, people living with MND, carers, past carers through focus groups; MND Special Interest E-Groups; official Launch of MND Week 2006; international and national conference papers and posters – five conferences</p>

Project Name	(NSW-6) Palliative Care Dementia Interface: Enhancing Community Capacity Project
Organisation	University of Western Sydney; Sydney West Area Health Service (Western Cluster); Blue Mountains Division of General Practice
Funding	\$176,000 between April 2003 and March 2006 (time frames changed due to staff leave issues)
Project aims <i>What did the project set out to do?</i>	The project aimed to understand the needs of key providers of care to people in the final stages of dementia, and use this information to develop, implement and evaluate a model of care to this client group. The overarching aim of the project was to build capacity to undertake care of people dying from dementia.
Project Delivery <i>What did the project do?</i>	The project used action research to identify the needs of people with severe and end stage dementia, prior to implementing a model of care designed to provide best practice palliation to this group.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Stage 1a used focus groups (6) and interviews (24) with key providers of care (family members and health service providers including 4 residential aged care facilities). Stage 1b collected data regarding pain in people with severe or end stage dementia using the Abbey Pain Scale (36 people); surveyed family members using the Satisfaction with Care in the End of Life with Dementia (SWC-EOLD) Scale (36); and conducted file audits in residential aged care facilities of residents with severe or end stage dementia (36). Stage 2 involved participatory action research. Results from Stage 1 were disseminated to residential aged care facilities involved in the data collection, and consensus on the model of care reached.</p> <p>A model of care was developed and implemented in one residential aged care facility in the greater Western Sydney area. The model of care included: education; clinical support; Family Information Booklet; pain management flowchart and use of pain assessment tools (Abbey Pain Scale and NOPPAIN); and a learning package about pain. In Stage 3 the model of care was evaluated by repeating the file audits (7); use of the SWC-EOLD Scale (7); focus groups with the residential aged care facility staff involved in the intervention (2); surveys of the area health service staff involved in the project (19); and surveys of organisations and individuals to review the Family Information Booklet.</p> <p>The results show that Area Health service specialist staff from the palliative care service are now better able to undertake care of people with severe or end stage dementia (from evaluation survey results). Residential aged care staff have improved confidence and skills (from focus groups). General practitioners were difficult to engage during the project (and not evaluated). Nurses from the residential aged care facility reported that GPs had improved their skills as a result of the project intervention.</p> <p>Details of the evaluation are outlined in the full evaluation report, which is part of the project's final report.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The major achievement of the project was to build capacity of area health service community-based staff so that people in the final stages of dementia are now accepted as appropriate for referral to palliative care services.</p> <p>Additional funding has been received from the Department of Health and Ageing Local Palliative Care Grants to launch the Family Information</p>

Project Name	(NSW-6) Palliative Care Dementia Interface: Enhancing Community Capacity Project
	Booklet, evaluate the Family Information Booklet (Round 2 Grant) and extend the project by developing pathways to improve outcomes for people with specific symptoms that are particularly difficult for nurses in residential aged care facilities to manage (Round 3 Grant).
Project Capacity Building <i>What has been learnt?</i>	<p>The project reported that residential aged care staff require ongoing clinical support and governance to sustain any changes.</p> <p>The project had planned to write best practice guidelines for dementia palliative care. These were not developed to the extent as planned as the project found that the registered nurses in residential aged care facilities do not have time to consult guidelines. Experiential learning using their own residents as case examples proved more successful than formal education sessions.</p> <p>Unexpected findings included: the number of times the project encountered people with dementia who had never been diagnosed with the condition, or who were wrongly diagnosed; the lack of access to information and support for family members throughout the dementia trajectory; residential aged care facility staff needing to access education in their own unpaid time due to inadequate education budgets in residential aged care facilities.</p> <p>The three principle success factors for the project were:</p> <ol style="list-style-type: none"> 1. support from area health management to allow nurses from palliative care and dementia care be involved in the intensive education within the RACFs, and sit on committees and working parties; 2. support and advice from the University and help in developing research and evaluation skills of area health staff; 3. goodwill of the Directors of Nursing of the residential aged care facilities where the data were collected.
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>A literature review was conducted in August 2003. New resources were developed: Family Information Booklet; poster; pain assessment and management flowchart; and self directed learning packages – pain.</p> <p>The project demonstrated that an intensive model of palliative care education implemented in residential aged care improves the skill and confidence of nurses to manage pain, and improves residents' outcomes.</p> <p>The project made eight recommendations to further developments in dementia palliative care. For example, Recommendation 2 suggests that <i>“programs similar to the Program for Experience in the Palliative Approach (PEPA) are available to staff from residential aged care facilities”</i>.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>The project was very active disseminating information throughout the project: 8 conference presentations (national and international); information presentations (9); two journal publications (plus two other papers prepared for submission); media releases; local newspaper articles (3); web page established via University of Western Sydney link; radio interview. There was widespread interest in learning how to improve care for people dying of dementia.</p>

Project Name	(NSW-7) Palliative Care Education Utilising Interactive Satellite Television Technology
Organisation	Anglican Retirement Villages
Funding	\$99,000 between May 2003 and December 2005
Project aims <i>What did the project set out to do?</i>	The goals of this project were to: educate staff in residential aged care facilities and increase their knowledge and skills; reduce transfer rate of residents in receipt of palliative care from low to high care facilities; develop a cost-effective education program that can be used in the future by remote and isolated communities; facilitate a 'shared approach' to caring for residents receiving palliative care support; and recognise that palliative care education has been lacking in long-term care settings.
Project Delivery <i>What did the project do?</i>	The project developed and screened four interactive palliative care satellite television programs targeted at personal care staff/nursing assistants working in residential aged care facilities. The topics covered: <ul style="list-style-type: none"> ▪ palliative care overview ▪ pain management ▪ death and dying, and ▪ dealing with grief & loss. <p>These four programs were supplemented by program facilitator resource material and student resource material.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	The project was externally evaluated. The outcomes assessed in the evaluation included relevant knowledge attainment of staff participating in the program and the effect of the program on facility placement outcomes for residents. <p>The education was evaluated using a set of knowledge questions developed for each of the four programs. These were based on the October 2003 Draft of Australian Palliative Care Project Competencies. Appropriate facility placement was measured by recording transfer rates among residents in receipt of palliative care.</p> <p>The evaluation findings were extremely positive from both perspectives. Staff at ARV have increased their knowledge and awareness of palliative care which has given them more confidence in caring for residents with palliative care needs. This has had the positive effect of reducing the transfer rates out of residential aged care facilities. In addition, a number of opportunities were identified for maximising the benefits of future satellite programming by instituting new work practices that address program participation rates.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	One of the key objectives of this project was to develop a cost-effective high quality palliative care education program that could be utilised in the future by remote and isolated Australian communities. The establishment and screening of all four programs via the Aged Care Channel significantly contributed to this objective being met. The Channel provides an ongoing conduit for programs to be re-screened. This re-screening of programs will help ensure staff working in residential aged care facilities across Australia continue to benefit from the programs. To date the channel has over 330 members with a projected viewing audience of over 33,000. <p>However, it is felt by the project officer that the shelf-life of these programs is approximately three to five years. This being the case the programs would eventually have to be reproduced to comply with and keep up with</p>

Project Name	(NSW-7) Palliative Care Education Utilising Interactive Satellite Television Technology
	expected legal and clinical changes within palliative care service delivery. It is likely that further funding would have to be sought to develop these programs to meet these standards.
Project Capacity Building <i>What has been learnt?</i>	Enormous capacity has been built by this project. This can be measured in the evaluation results through the reduced numbers of transfer rates out of residential aged care facilities and into specialist palliative care services as a direct result of staff in ARV becoming more knowledgeable about palliative care.
Project Generalisability <i>Are the lessons useful for someone else?</i>	Satellite television programming is an effective medium to transfer knowledge into rural and remote settings in Australia. It is also a relatively cost effective and efficient way of training at a cost of approximately \$50 per staff member. Providing the education component of the program is designed thoughtfully satellite television is generalisable to other health care settings.
Project Dissemination <i>Who was told about the project?</i>	No information available.

Project Name	(NSW-8) Study of predictors of home deaths in terminally ill cancer patients in [the former] Central Sydney Area Health Service (CSAHS) ("The home deaths project")
Organisation	Sydney Cancer Centre, Palliative Care Department, Royal Prince Alfred Hospital
Funding	\$135,000 between May 2003 and April 2006
Project aims <i>What did the project set out to do?</i>	<p>To better understand the patient-related, carer-related, disease-related and other factors that influence the place of death in a population-based sample of terminally ill cancer patients residing in CSAHS.</p> <p>The project objective was to undertake a population-based retrospective cohort study by interviewing and administering questionnaires to carers of deceased cancer patients from CSAHS. The data obtained were to be analysed to develop a multivariate model that quantified the relative risk for a home death of various identified predictors.</p>
Project Delivery <i>What did the project do?</i>	<p>Thirty-seven bereaved carers from Sydney's Inner West were interviewed about their experiences during the patient's terminal cancer illness. Participants were informal carers, all next-of-kin: 15 spouses, 14 children, three parents, three siblings, one grandchild and one cousin.</p> <p>Data was collected by face-to-face interviews using a semi-structured questionnaire, which was developed by the project. Interviews were for approximately one hour. Interviews were tape-recorded, transcribed verbatim, and thematic content analysis conducted.</p> <p>Participants were recruited from a population-based sample, rather than in a hospital-based sample. The recruitment methods ended up being more complex and resulted in a much lower response rate (< 5%) than originally planned. The final recruitment process involved accessing the records of cancer deaths held by the NSW Central Cancer Registry (CCR), contacting the GPs of these patients and asking them to contact carers.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Nine (24%) of patients had died at home and 76% (28) had contact with some kind of palliative care service. Almost two thirds (64%) of the hospital deaths were in designated palliative care wards.</p> <p>Ten recommendations arose from the carers' interview analysis:</p> <ul style="list-style-type: none"> • information on how to talk with patients about dying • pain management education and support for carers • information on available resources made know earlier • information about dying at home – what to expect / what to do – for carers and health care professionals • to consider including carers in patient management while in hospital, and provide care for them during patient admission and especially at patient death • strategies to link services and communicate a continuum of care to patients and carers. Emphasise after hours support and strategies • earlier referral to palliative care services, and increased home visits by palliative care services • bereavement services offered to all bereaved families, regardless of involvement with palliative care services • give the carers some kindness and encouragement • information should be available as a "one-stop shop" to make it easier to access all resources, including for people from a non-English speaking background.

Project Name	(NSW-8) Study of predictors of home deaths in terminally ill cancer patients in [the former] Central Sydney Area Health Service (CSAHS) ("The home deaths project")
	<p>The questionnaire developed for the carers could be used by other projects. However, it was recommended that the questionnaire is modified into separate qualitative and quantitative components.</p> <p>The final report did not include an analysis of the importance of the factors that influence place of death or analysis of the quantitative data. The project reported that they will complete this work and disseminate the results in the future.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The project was not designed to be sustainable. However, there are 10 recommendations from the project which may be addressed by the service.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>The project led to new collaborations with the NSW Central Cancer Registry (CCR). They have realised the importance of place of death and as a result have compiled their first-ever report on place of death data/reports.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>Main project lesson was that irrespective of the patients' wishes, the place of death is less important to carers than their being present at the time of death, wherever the patient is.</p> <p>The project made 10 recommendations relating to meeting carers' information & support needs and health care services issues. Carers found it hard to access information and one recommendation is that palliative care consumers need a "one stop shop" for information.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>The project has disseminated information about the methodology and the results by presenting conference papers and / or posters at national and international conferences, publishing articles in palliative care newsletters and liaising with the care support group.</p>

Project Name (NSW-9) Supporting and Educating Carers in Palliative Care	
Organisation	Carers NSW (CNSW)
Funding	\$145,634 between July 2003 and January 2006 This project was granted three extensions due to project staff leave.
Project aims <i>What did the project set out to do?</i>	The project goals were: to provide education and support to carers to enable them to better manage the demands of caring at home and to better cope with their own grieving and adjustment process once caring has ended; to improve the service provided to this group of carers by local health and community care workers.
Project Delivery <i>What did the project do?</i>	<p>Family carers in the home palliative care setting were provided with a full day program of education, support and resources. There were six full day programs conducted averaging 3 participants per program, and with a total of 15 carers attending. Recruiting carers was very difficult due to multiple factors, resulting in the target of six participants per session not achieved.</p> <p>Carers were followed up after their education day by three telegroup sessions. Each sessions lasting an hour with two facilitators present (one being a Respite Centre Coordinator). The telegroup sessions included time for socialising, airing difficulties and suggesting options for practical problems. These were not intended to be counselling sessions.</p> <p>Service and health providers were provided with a half day education program on carer needs, palliative care, loss and grief and available resources. Australian based resources were used including an interactive CD ROM and video. In addition case studies were discussed in small groups. There were 12 sessions conducted with a total of 142 participants attending mostly from the community settings.</p> <p>The project ran in conjunction with the Illawarra and Central Coast Commonwealth Carer Respite Centres (CCRC). The CCRCs were mainly responsible for recruiting carers and service providers. The CCRC staff were trained by CNSW for the telegroup sessions and were a valuable local source of knowledge of services and advocacy for carers.</p> <p>Local palliative care units were asked to assist with the training and/ or carer recruitment but declined due to workloads and other constraints.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>All groups completed pre and post course written questionnaires. For service providers a fun quiz was also used. Participant observation was used for both programs.</p> <p>Carers' education program: The delivery of education to carers via a mixed model of face-to-face and telephone support (not counselling) worked well. All carers reported improvements in dealing better with the demands of their caring role; the benefit of meeting others in similar situations; a better understanding of what palliative care is; and an improved acceptance of their own responses to the situation. All carers showed an improvement in coping ability.</p> <p>Service and health providers program: Most providers indicated that they were better informed about palliative care, loss & grief and access to resources. In addition, most reported they would deal better and had more confidence in dealing with their palliative clients, and loss & grief issues. Inviting Respite Centre staff to give a session on types of respite available was very successful. Service and health providers requested continuing education in loss & grief and palliative care.</p>

Project Name	
	<p>(NSW-9) Supporting and Educating Carers in Palliative Care</p> <p>There was increased interest by residential aged care workers in the training program. Some of the workers had had no training in basic palliative care or loss & grief.</p> <p>The project has developed a list of recommendations for: the Commonwealth Government, for NSW Health, for service providers and for Carers NSW.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The project is being sustained as Carers NSW has been successful to getting funding from the Round 2 Local Palliative Care Grants program. They will be rolling out Stage 2: supporting and educating carers in palliative care, which is an extension of the CCP project. Stage 2 will include more training to service providers focusing on pastoral care and will be provided for the South East Sydney area. The service providers program will be extended to a full day training and local specialist palliative care services will be assisting with the training sessions.</p> <p>The carers education program will consist of 3 x half day sessions, similar to the original program but with no telegroups.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>The two Commonwealth Carer Respite Centres (CCRC) involved in the project received a resource kit for continuing training of staff and carers in basic palliative care and loss & grief. They were trained by Carers NSW and obtained skills in telegroups, that is, in using the phone as a tool for group support.</p> <p>The education program for health and services raised their awareness in understanding palliative care and the accepting debriefing.</p> <p>Carer's NSW manager has joined NSW State Palliative Care Advisory committee. This has enabled the development of links with people in South East Sydney area (where Stage 2 of the project will be held).</p> <p>The staff at Carers NSW are now more aware of palliative care, as a result of hosting the project.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>Training and education materials have been sent to rural and metropolitan areas. Core educational materials on loss and grief and palliative care have been developed for the purpose of continuing basic training from Carers NSW. The training packages on loss and grief could be used for other types of service providers.</p> <p>The model of training carers hand in hand with the health and service providers was successful and could be generalised beyond the specialty of palliative care.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>The project used a range of methods to disseminate information including newspaper articles (Sydney Morning Herald, May 22, 2006), Carers NSW web site e.g. facts sheets, newsletter articles (Carers NSW and Carers in Focus), fact sheets and word of mouth.</p> <p>Carers NSW has been reporting the project findings to various committees that it sits on e.g. NSW Palliative Care Advisory Group, NSW Cancer Institute Palliative Care Oncology group.</p>

2.3 Northern Territory

Project Name	(NT-1) Greater Darwin Palliative Care Volunteer Support Project
Organisation	Northern Territory Carers Association
Funding	\$104,830 between May 2003 and March 2005
Project aims <i>What did the project set out to do?</i>	Recruit, train, coordinate and support a pool of volunteers to work with community based palliative care services in Darwin and Katherine.
Project Delivery <i>What did the project do?</i>	<p>This project began with a call for volunteers in the Darwin region, who were interested in palliative care. It received a great deal of interest and approximately 30 volunteers began their training in the first round.</p> <p>The project also aimed to modify and/or develop educational resources for training volunteers that took into account some of the issues that are particularly relevant to the Northern Territory (i.e. multicultural and Aboriginal and Torres Strait Islander populations, people isolated from their families etc). These were developed.</p> <p>The project was successful in training a large number of volunteers in the Darwin region. In fact, too many volunteers were trained and there was some frustration expressed that they didn't get the chance to do any palliative care volunteering.</p> <p>There were some problems with defining the parameters of this project, especially the role of the project officer. In some cases this person decided to be actively involved with supporting palliative patients in their homes, rather than concentrating on the role of training and supporting volunteers. This created tension about workloads and eventually led to the recruitment of a new project officer.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>There were problems with the evaluation of this project throughout. Neither of the project officers fully understood why evaluation was necessary and considered that it interfered with actually "doing things" on the project. With significant help, the project did implement an evaluation strategy and did complete all the necessary tools.</p> <p>The project used the CCP tools to evaluate the knowledge and experience of volunteers before and after training.</p> <p>It was clear that there was an experienced and committed group of volunteers in the region, many of whom were offering their services because of their experiences in caring for a dying family member or friend.</p> <p>The educational sessions appeared to be effective, with most respondents saying that the training had increased their understanding of palliative care and the needs of dying people.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>During the period of this project, a new hospice was being built at Royal Darwin Hospital. It was always intended that the volunteers' project would be transferred to the Hospice on completion and this has been the case.</p> <p>The end result of this project is that there is trained pool of volunteers that are supported by the NT government through the Hospice.</p>

Project Name (NT-1) Greater Darwin Palliative Care Volunteer Support Project	
Project Capacity Building <i>What has been learnt?</i>	<p>The project has demonstrated that there is a high level of community support and commitment to palliative care volunteering in Darwin and that this is enhanced by appropriate training. An important finding of this project was the need to assess the needs for volunteers prior to recruitment and training as the volunteers were disappointed when no opportunities were available to demonstrate the skills they had learnt.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The project generated educational materials that would be useful in other contexts. It also demonstrated the level of commitment from volunteers in the community and how this can be supported through training.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>This project put a great effort into dissemination activities including displays and posters during palliative care week, newspaper articles, radio interviews and posters.</p> <p>As a result of this, the Darwin community appeared to be quite well informed about palliative care and the role of volunteers.</p>

Project Name	(NT-2) Groote Palliative care support service
Organisation	Anglicare
Funding	\$55,000 between August 2003 and June 2005
Project aims <i>What did the project set out to do?</i>	This project was developed using the local nursing home as a focus. It aimed to develop a culturally appropriate way of delivering palliative care in Aboriginal communities and also to provide education and support for workers (both Aboriginal and non-Aboriginal) so that they could care for dying people in a way that was most appropriate to the community.
Project Delivery <i>What did the project do?</i>	<p>It is very difficult to determine what the actual impact (if any) this project had, as it was deeply embedded within an existing service. The reports provided by the service comment that the nursing home assisted with the deaths of two people, but this would appear to be something that the nursing home would do anyway.</p> <p>The reports also comment that the project staff experienced considerable barriers to implementing the project. They had a great deal of difficulty effectively engaging with the community, and found it difficult to recruit local people to act in a cultural liaison role who were prepared to talk about death and dying. The project also experienced a very high turnover of staff and each new person had to start from the beginning in developing relationships within the community.</p> <p>This project had considerable outside support, including two site visits from the NET member to assist with developing an evaluation strategy. Despite this support it is unclear if any of the project goals were met.</p> <p>There was also considerable resistance from some of the project staff to what they saw as Commonwealth pressure to report outcomes-this was due to a fundamentally different view of what the project was funded to achieve by the different parties.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	The resistance to evaluation and reporting meant that any evaluation strategies were implemented very late in the project and the opportunity to collect baseline data was lost. After the second visit by the NET member the CCP tools for Aboriginal communities were used to collect information about community awareness of palliative care, although the actual numbers are very small.
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The project is part of an existing service that will continue on Groote Eylandt because it is funded by Anglicare. There remain considerable barriers to the Anglicare service engaging effectively with the community.</p> <p>It is unclear if there are any aspects of the project that can be discussed separately from the host organisation.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>The fundamental lesson from this project is the need for clearly defined projects and to ensure that the project staff and the funding body have a shared understanding of what the project is going to achieve.</p> <p>It is also clear that high staff turnover was a considerable barrier to the project engaging effectively with the community and that strategies to support staff in remote communities should be examined.</p>

Project Name (NT-2) Groote Palliative care support service	
Project Generalisability <i>Are the lessons useful for someone else?</i>	As above-this project demonstrates key problems of implementing services in remote Aboriginal communities
Project Dissemination <i>Who was told about the project?</i>	Very limited dissemination activities were carried out. There were several attempts at fostering community discussion, but it appeared that at least on one occasion the discussion groups turned into a fishing trip. One article was prepared for the local community newspaper. Staff attended the Canberra and Adelaide workshops.

Project Name (NT-3) Territory Care	
Organisation	Northern Care Frontier Services
Funding	\$20,020 between August 2003 and August 2005
Project aims <i>What did the project set out to do?</i>	<p>This project was based at the Frontier Services nursing home in Alice Springs. It aimed to identify and work with three remote communities who used the nursing homes at Alice Springs and Tennant Creek and work with community members to find out levels of awareness of palliative care and palliative care needs.</p> <p>Through this consultation it was hoped to develop an understanding of culturally sensitive practice that could be used as the basis for education for the staff in the nursing homes that provided services for these populations. The end result was to be the development of a formal education package that would be delivered after extensive consultation with nursing home staff.</p>
Project Delivery <i>What did the project do?</i>	<p>The project officer identified three communities and held focus group discussions with each, although it is not clear from the report how many discussions were held, how many people attended and how valuable the information obtained was.</p> <p>The material obtained was developed into a new aged care curriculum which was delivered in the nursing homes, but again it is unclear how successful this activity was in terms of the number of people attending and raised levels of awareness.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The project officer was adamant that the CCP tools and other formal means of evaluation were too rigid for use in remote Aboriginal communities and that instead she was going to use a more anthropological approach of ongoing engagement with the communities. It is unclear however if the project officer spent sufficient time in any of the communities to obtain this sort of detailed and contextualised information.</p> <p>The evaluation methods are not document in any further detail in the report.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>There is no evidence from the reports that palliative care knowledge increased in any of the communities. In terms of the staff, some educational activities occurred, but the report comments that even after this training that the staff had very limited skills for the delivery of culturally appropriate palliative care.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>The problems this project experienced are the result of it being too large and from it lacking a clearly defined focus. It demonstrates the difficulties of project officers engaging with Aboriginal communities, especially when limited time is available to spend with people. It also highlights the need for Aboriginal people to be involved as project officers, so that some of the initial cultural barriers can be overcome and to ensure that communities maintain an interest in the project.</p> <p>This project also demonstrates the need to ensure the support of all key agencies prior to starting. A major barrier was hostility from some nursing home staff that were not adequately consulted with prior to the project being implemented.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>See above. Relevant for rural remote Aboriginal communities</p>

Project Name (NT-3) Territory Care	
Project Dissemination <i>Who was told about the project?</i>	There is no evidence of any dissemination activities being carried out, except for some limited discussion with community members. The project officer attended the Canberra, but not the Adelaide workshop and was not able to attend a NT workshop that was held specifically for projects to work through problems with reporting and evaluation.

Project Name	(NT-4) Palliative care education and support program
Organisation	Central Australian Division of Primary Health
Funding	\$33,000 between March 2003 and February 2005
Project aims <i>What did the project set out to do?</i>	<p>This project aimed to address gaps in palliative care education in the Alice Springs and Tennant Creek workforce. In order to achieve this, the project brought in a series of palliative care experts into the communities to deliver a series of workshops and seminars.</p> <p>The project leader also held focus groups in the communities of Alice Springs and Tennant Creek to find out what people wanted from palliative care education.</p> <p>Throughout the project, the project officer actively promoted the palliative care service.</p>
Project Delivery <i>What did the project do?</i>	All the goals of the project were achieved. The education sessions were very well attended and the level of palliative care awareness and knowledge was raised in both communities.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The education that was delivered was based on focus groups to determine needs. As a result of this it was considered to be very relevant by the staff.</p> <p>An evaluation form was developed to find out the impact and usefulness of each of the education sessions and this was used to evaluate each session.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>This project has been very successful in developing sustainability. The general level of palliative care in the workforce has been raised as well as that of the general community. As a result there is now a network who is actively involved in lobbying for palliative care in the community.</p> <p>As a result of the success of this project, on-going funding has been secured for further palliative care projects in Alice Springs.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>One key finding from this project is the need to adequately assess costs before the project is implemented. The salary of the project officer was never factored into the budget for this project, but it is clear that the project took most of his time.</p> <p>This project demonstrated the willingness of experts to share their knowledge and experience with remote practitioners and that practitioners found this education to be both useful and relevant.</p> <p>Palliative care awareness and knowledge has been increased through this project and the palliative care networks in the region have been strengthened.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	The lessons from this project are highly relevant for other regional and remote centres.

Project Name	(NT-4) Palliative care education and support program
Project Dissemination	This project has been very active in dissemination activities including displays during palliative care week, radio interviews, conference presentations and the production of a grief booklet.
<i>Who was told about the project?</i>	

2.4 Queensland

Project Name	(QLD-1) An educational strategy to increase the palliative care capacity of primary health care providers working in rural and remote areas of Australia
Organisation	Brisbane South Palliative Care Collaborative (BSPCC) conducted the project. General Practitioner Education Australia (GPEA), part of the Royal Australian College of General Practitioners (RACGP), was the fund holder.
Funding	\$122,530 between April 2003 and April 2006
Project aims <i>What did the project set out to do?</i>	The project was designed to develop, implement and evaluate an interactive educational strategy for primary health care providers in rural and remote communities. The specific objectives were: increase palliative care capacity of providers; improve palliative support for dying people and their families; improve networking between primary and specialist health care providers; improve community awareness of palliative care; develop an evaluated model to increase palliative care capacity and education of primary health care providers in rural and remote areas.
Project Delivery <i>What did the project do?</i>	<p>Four target districts were chosen, but after the project began, State funding for a similar purpose became available. As a result, education was conducted in two districts and then re-focused on Far North Queensland. The area covered by the project was extensive and included the base towns of Roma, Charleville, Mt Isa, and Normanton.</p> <p>Materials were written, including pre- and post-intervention questionnaires and a four-month follow-up questionnaire, plus the intervention format, curriculum and educational resources. The sessions were accredited by the RACGP and ACRRM so that GP participants could receive Continuing Professional Development (CPD) points. Health facilities were contacted. Resources for each site were written, and presenters recruited.</p> <p>Education was delivered, initially via 'travelling workshops' and later in one-to-one sessions, by palliative care specialists. Teams included medical officers, clinical nurse consultants and allied health professionals. Participants included therapists in aged and community care, pastoral care workers, volunteers, counsellors, ATSI health workers, allied health, nurses and doctors. A budget surplus was used to extend the project to an urban setting (the QEII Hospital Health Service District, Brisbane South).</p> <p>GPs from one town were unable to get together for a workshop, so one-to-one or one-to-two education sessions were conducted using the principles of academic detailing. This option was so well received that it was also offered elsewhere. A medical palliative care specialist contacted each GP to invite him/her to either a workshop or one-to-one session. This approach was very successful in engaging GPs during 2 ½ years, 25 education sessions were conducted, involving a total of 243 participants.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>It was originally intended that GPEA would conduct the evaluation, but this organisation was subsumed into its parent body, RACGP. The evaluation role was taken on by BSPCC and the methods had to be redesigned.</p> <p>An estimated 76% of the FTE primary medical practitioner workforce in the target areas attended education. It was not possible to calculate the reach to other health professionals. The cost per participant was \$504. Data from the questionnaires were analysed quantitatively and qualitatively. A total of 234 questionnaires were returned: 45 from medical officers and 190 from other primary health providers. Overall, there were statistically significant</p>

Project Name	(QLD-1) An educational strategy to increase the palliative care capacity of primary health care providers working in rural and remote areas of Australia
	<p>increases in palliative care skills, knowledge and practitioners' confidence in their management of palliative care patients, following education. At the four-month follow-up, 23 of the 38 respondents said they had treated one or more palliative care patients since education. Of these, 87% reported that education had a positive impact on their management of patients.</p> <p>An analysis of the findings from medical officers found that confidence in their practice with palliative care patients had increased following the intervention. There were indications that these gains were maintained at the four-month follow-up, although the poor return rate meant this was not supported statistically. Similarly, non-medical officers reported significant improvements in skills and knowledge in symptom assessment and management, developing management plans and communicating with patients and families, and these were sustained at the four-month mark.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The project management team gave high priority to obtaining funds to continue the work. Small grants were sourced for related projects such as palliative care education for 10 GPs and 31 nurses at Kingaroy, involving a workshop and networking dinner. Funding was also obtained for a weekend workshop for rural doctors and nurses attended by 32 people in Brisbane and a series of 14 workshops for 149 participants. Workshops for staff have been conducted in aged care facilities across Queensland, including Aboriginal and Torres Strait Islander communities. The project officer believes it would not have been possible to obtain these grants without the CCP project, which "cemented our reputation". The evaluation provided evidence to support new applications.</p> <p>The project team has applied for funds to employ someone on a permanent part-time basis to manage the education program. Without ongoing funding, the education sessions are not sustainable. Further education could be provided in Brisbane but this is likely to limit the number of rural and remote primary health care providers who can attend.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>A resource bag was put together for workshop participants. The education model was cost effective, had good reach and had excellent educational and clinical outcomes. Participants regularly contact the project for advice, and each time they get in touch and ask questions it builds capacity in their communities. The project officer believes the face-to-face contact with rural and remote providers is a vital part of the strategy.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The education model can be transferred to any area of health that uses a multi-disciplinary approach. The most important aspect is ensuring that the education fulfils local needs, so a needs analysis is an essential component. The project officer believes there is no point in training one group of professionals such as GPs in isolation.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>Articles appeared in several newspapers and a hospital newsletter and the project team leader was interviewed on local radio. The Governor of Queensland mentioned the project in her opening address to delegates at the Palliative Care Queensland conference, July 2004. In addition, there were several conference presentations and journal articles, publication on a website and discussion at a palliative care provider workshop.</p>

Project Name (QLD-2) Palliative Access Links (PALS) Project	
Organisation	Wide Bay Division of General Practice
Funding	\$94,000 between April 2003 and May 2005. <i>(The project originally received \$59,000 and was due for completion on 31/03/2004. Additional funding was sought for a 0.5 FTE project manager for a further 12 months to enable a graduated recruitment process, greater involvement of GPs and practice nurses and a longer evaluation period)</i>
Project aims <i>What did the project set out to do?</i>	Enhance community awareness of the role and benefits of palliative care through a network of volunteers based in workplaces, schools and the community. These volunteers, known as Palliative Access Links (PALS), are trained and resourced to provide information about palliative care services and links to other services. The PALS program targeted the general community as well as ill people and their carers.
Project Delivery <i>What did the project do?</i>	<p>Representatives from local palliative care, health and community services were appointed to a steering committee, which initially met fortnightly, then monthly. The project team carried out a community awareness survey to gauge knowledge levels at baseline. The survey and associated media activity was also intended to recruit PALS, but this was unsuccessful, so the recruitment strategy was changed. It was found that presentations to small groups were the best way to identify and inform potential PALS. A database of local palliative care organisations and resources was created.</p> <p>Three training sessions were conducted. These led to the recruitment of 40 PALS volunteers, who together have so far achieved over 700 community contacts via group presentations, individual requests, displays and information stands at workplaces and community events. A resource kit for the volunteers was developed, and additional resources have been provided as needed. Legal and risk assessment issues were addressed, and support mechanisms for the volunteers put in place. The presence of PALS in the community has led to the identification of other opportunities to promote palliative care (e.g., in workplaces, aged care facilities).</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The project was evaluated internally. A community awareness survey was conducted in July 2003 to identify baseline information. This used the NET toolkit tool 1.1. A total of 96 people were contacted by telephone, 90 completed questions 1 and 2. Of these, 78 were then posted the remaining questions, 67 returned them. Survey results indicated a lack of understanding in the community about palliative care. In March 2005 30% of the original participants were surveyed again, and palliative care knowledge had increased.</p> <p>Six local funeral directors were asked about the services they provide and their experiences with people who were dying and their families. Levels of pre-planning for death had increased in the past 10 years to around 25%. Funeral directors had observed that families appeared to experience less trauma when specialised services were available locally. General practitioners were also surveyed to assess the level of interest in developing a mentoring/support network for those dealing with palliative care patients. (No details of survey tool or numbers of participants.) GPs did not see this as a high need and it was not followed up.</p> <p>PALS education training sessions were evaluated using a feedback form designed for the purpose. There was an 88% response rate. The evaluation focused on information content and relevance, knowledge of the role of PALS and palliative care in general, and whether the training session influenced the decision to become a PAL. Participants indicated</p>

Project Name	
	<p>(QLD-2) Palliative Access Links (PALS) Project</p> <p>that they had learned a great deal from the training sessions. The delivery, quality of information and risk assessment process had an impact on whether participants decided to become PALS, and participants felt these sessions prepared them well for situations that may arise.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The resources and tools developed in this CCP project provide a base for further work. Prospects for sustaining this work are enhanced by good management practices, sensible goals and strong support from the steering committee. The project has achieved more than expected, in terms of the number of PALS trained and the number of organisations using its services. Continued baseline funding is needed in order to maintain these gains and it is unclear where these funds will be obtained.</p> <p>WBDGP has prepared a draft submission proposing that the project be expanded to other locations. They are looking at obtaining funds from DoHA (likelihood of success is unclear). The project team is also proposing to develop the training and resource package further into a form that can be used by other agencies (see Project Generalisability, below).</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>One of the first steps in establishing the PALS project was the creation of a database of palliative care service providers in the Bundaberg district and useful contacts for palliative care in Queensland and nationally. More than 150 organisations were contacted. Relevant resources were assembled and linked in a synchronised format with the database and with flow charts representing how palliative care operates in the local area. This provides an effective and efficient way of supporting the project's administration and volunteers. The training sessions for PALS resulted in recruitment of 40 volunteers and increased awareness and understanding of palliative care among participants who chose not to volunteer as PALS.</p> <p>The project has thus created an established networking framework of palliative care providers, community organisations and volunteers.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The PALS model could be used to promote palliative care in other towns and regions of Queensland and elsewhere in Australia. The project team has submitted a proposal to develop project materials into a generic 'Resource Training Package' that could be used at new project sites.</p> <p>The PALS model may also be useful in other health-related fields that could benefit from an improved flow of information between health care providers, their networks and the community.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>The most successful dissemination strategy has been public speaking presentations to small community groups by project staff. Some PALS have also taken this approach, and the project team has provided a generic introduction and speech template for the volunteers to follow if they wish. Promotional literature such as brochures, posters and flyers were developed for the project. Static displays at public events and places by the project staff and PALS, and interviews with local news media, were other dissemination strategies adopted.</p>

Project Name	(QLD-3) The Children and Young People's Bereavement Centre
Organisation	Mt Olivet Community Services
Funding	\$195,330 between July 2003 and July 2005
Project aims <i>What did the project set out to do?</i>	The Children's and Young People's Bereavement Centre (CYPBC) has three objectives: to provide accessible counselling and support to grieving children, young people and families; to raise awareness in the community (especially schools) about the needs of grieving children and young people prior to and after a death; to develop a network of social workers and counsellors in the Brisbane area in palliative care and grief work.
Project Delivery <i>What did the project do?</i>	<p>The project began in July 2003 with the appointment of a coordinator and conversion of the premises into a child-friendly space. The practice model and policy and procedures were developed. The project was advertised. The CYPBC was officially opened in September 2003. A brochure promoting the CYPBC was disseminated and volunteers were recruited and trained. Resources for parents and schools were developed or obtained, and the booklet <i>When a student is grieving – a guide for teachers</i> was distributed to 450 schools. Representatives of palliative care organisations formed a stakeholders group, which met quarterly.</p> <p>A total of 178 children and young people (aged 5-18 years) from 79 families were supported by the CYPBC in the 19 months to May 2005. Almost three-quarters of the support related to the death of a parent. Others received support following the deaths of grandparents, siblings, other parent figures or friends. Services included family group sessions, information to help parents or carers understand and respond to the child's needs, individual counselling (received by 110 children), contact with teachers, guidance officers, medical services or counsellors and referral to other services. A number of group sessions were run, including one-off specialist groups such as get-togethers during the Christmas period.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The project was evaluated externally by Encompass Family and Community in April-May 2005. The evaluation focused on whether the CYPBC had met its objectives, the quality of the services, and lessons to inform future directions. Evaluation methods included a review of progress reports and other documents relating to the operation of the project; a survey of client records (accessed by CYPBC staff only); qualitative analysis of stakeholder surveys, telephone interviews and client feedback forms; and evaluation of workshops presented by the CYPBC coordinator.</p> <p>CYPBC was found to be accessible and inclusive, with straightforward referral processes. The publicity generated to date has been exceptional. The coordinator has been successful in raising awareness – especially within schools - of children's bereavement issues and has facilitated a network of palliative care counsellors which now meets quarterly. The bereavement model employed by the CYPBC is grounded in good practice and informed by recent research, including models for quality bereavement practice. Feedback from stakeholders indicates that the principles of this model are being applied in practice, providing a service which is child-focused, inclusive, individualised, developmental and continuous and uses a variety of creative and expressive methods. CYPBC is contributing to knowledge about how to work effectively with bereaved children and young people by documenting and disseminating its model and methods.</p>
Project Sustainability <i>What aspects of</i>	The CYPBC is viable as currently staffed. Its future depends on the continuing funding and infrastructure provided by Mt Olivet Community Services. There is strong demand for the services of CYPBC, with an average of two referrals a week. Palliative care workers in specialist and

Project Name	(QLD-3) The Children and Young People's Bereavement Centre
<i>the project will continue?</i>	<p>community-based services have indicated that they value the service and believe it is needed. Improvements in referral processes, recommended in the evaluation of the project, are likely to increase demand.</p> <p>Current funding does not allow for expansion into other areas identified as promising by the project evaluators. These include succession planning, increased educational work and increased opportunities to provide specialist training to professionals. The project evaluators noted various issues for the CYPBC to address in the future, including the likely demand for response to children affected by other (non-palliative) types of family deaths and the need to link with more child-focused professional support (e.g., paediatric and youth mental health professionals for consultation).</p>
Project Capacity Building <i>What has been learnt?</i>	<p>The project has built capacity among palliative care professionals by providing specialist information on the bereavement needs of children and young people. It has achieved this by developing a network of social workers and counsellors in the Brisbane area. Meetings of this group of palliative care counsellors are facilitated by the project coordinator.</p> <p>The CYPBC has produced resources for teachers, parents and young people, presented at workshops to more than 600 people, and taken part in various collaborative ventures. The demand for education indicates a need to expand the centre's role in raising awareness of children's bereavement needs and building the community's capacity to respond.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The CYPBC uses a specific model for bereavement work with children. This model continues to be developed and refined through the work of the CYPBC. The reflective approach to practice taken by the project coordinator has identified learnings that could usefully be applied by others.</p> <p>The independent evaluators noted the project's important contribution to the body of knowledge on how to work effectively with bereaved children. They recommended that Mt Olivet support the project by making resources available to document learnings (e.g., by preparing journal articles).</p>
Project Dissemination <i>Who was told about the project?</i>	<p>Presentations were made at 21 workshops. Audiences included teachers, school guidance officers, specialists, community nurses, volunteers, counsellors, social workers, occupational therapists, carers and Masters of Counselling students.</p> <p>Other dissemination activities included distribution of 2000 brochures to hospitals, palliative care and oncology networks, schools and the public, the development and maintenance of a website, and an open day/official opening. Bulk mail outs and email networks were used to share information with professionals. Television, radio and newspaper interviews were conducted, including a segment on ABC TV which resulted in a video production featuring some of the young people who used the service. A booklet was mailed to 450 schools. The success of this dissemination strategy is reflected in the variety of referral sources to the CYPBC, including 15% by word of mouth through family friends or colleagues.</p>

Project Name	(QLD-4) Support, Education, Assessment and Monitoring (SEAM) service for regional and rural people
Organisation	GP Connections Toowoomba and Toowoomba Hospice
Funding	\$157,418 between April 2003 and July 2005
Project aims <i>What did the project set out to do?</i>	<p>SEAM was designed to: increase the palliative care support available to patients and their families; provide education for patients and their families and health professionals; assess the needs of patients and their families; increase networks between care providers to overcome communication barriers and decrease duplication of services; provide a care coordination model of delivery for palliative care; increase the role of GPs and practice nurses in the care coordination of people requiring palliative care.</p> <p>During the course of the project, the relative emphasis on the different aspects of the SEAM role changed. It was decided that the value of SEAM lay primarily in coordinating services and providing referral when needed, and in increasing awareness of palliative care among health professionals and the wider community. There was less emphasis on direct contact with patients because this role was carried out by a Palliative Outreach Nurse service initiated by Toowoomba Health just before SEAM commenced.</p>
Project Delivery <i>What did the project do?</i>	<p>The SEAM project recruited and employed a registered nurse (30 hours per week) who carried out the liaison and referral work. A project manager was sourced from within the Toowoomba Division of General Practice to take responsibility for management and administration of the project, including reporting, and also to take part in education activities. (There was a change of staff member in this role in November 2004 but the original project manager continued to provide support.)</p> <p>The SEAM nurse attended case conferences at the hospice and visited general practices to enhance the knowledge of practice staff in the area of palliative care services. The SEAM project also hosted network meetings to support the establishment of a local Darling Downs branch of Palliative Care Queensland, which held its inaugural workshop in May 2005. This branch now meets monthly. SEAM staff assisted in preparing a funding submission to the Centre for Palliative Care Research and Education for a palliative care education program for GPs and are represented, with other stakeholders, on a working party for a proposed bereavement service.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>An independent evaluation was conducted by the Centre for Rural and Remote Area Health at the University of Southern Queensland/University of Queensland. The SEAM project was evaluated at three stages, ending in August 2003, February 2004 and December 2004 respectively. Plans to use satisfaction surveys with health professionals, GPs, patients and carers were reviewed after a poor response to the pilot testing. Consistent with changes in the role of the SEAM nurse, the final evaluation design focused on service providers and was primarily qualitative (face-to-face interviews). A total of 24 interviews were conducted.</p> <p>The evaluation findings confirmed the fact that the role of the SEAM nurse had evolved from what was originally envisaged and mainly involved networking, capacity building and support of service providers, advising health professionals on patient care, and providing resources to GPs, practice nurses and some patients. This liaison and support role was highly valued by many service providers and health professionals. Some participants in the evaluation had very limited knowledge of or contact with the SEAM service, however, and it was recommended that the service be promoted more vigorously through meetings with GPs and general</p>

Project Name	(QLD-4) Support, Education, Assessment and Monitoring (SEAM) service for regional and rural people
	<p>publicity. Regular feedback from the SEAM nurse to GPs regarding client outcomes would help raise awareness of the benefits of the service. Although efforts had been made to link into health services for Aboriginal and Torres Strait Islander people, progress was slow and this would need to be continued over a longer time span than the project allowed.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The original plan for ensuring the sustainability of SEAM involved using funds generated by EPC items in GP practice through case conferencing, care plans and health assessments. While case conferencing has been implemented and uptake of this service has been excellent, the other two strategies have been less successful due to low client numbers. It proved difficult to fulfil the requirements of the HIC (now Medicare Australia) in relation to care plans and it was questionable whether care plans were clinically relevant to palliative care. Health assessments are used only with patients over 75 years of age who are not residents of aged care facilities, and most palliative care patients do not meet this description. Again, the clinical value of health assessments in palliative care was questionable.</p> <p>Nevertheless, the SEAM nurse initiated some networks among health professionals and service providers that have evolved into self-sufficient and sustainable supports for palliative care. The project team has applied for further funding from DoHA for a second phase of the SEAM service.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>New partners in palliative care networks – such as the SEAM nurse – can have an impact on the direction and structure of those networks. For example, SEAM has succeeded in making GPs more aware that a palliative approach may be appropriate for a wider range of patients than they had previously considered. This has led to GPs seeking information about palliative care. However, in order to sustain the benefits of networking and care coordination, ongoing support is needed. The educational resources developed during the project are a lasting contribution to raising awareness and understanding of palliative care. These can be adapted and updated.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The SEAM model could be applied in other regional or urban settings to revitalise or establish links between palliative care service providers and stakeholders such as GPs. The model is fully transferable to other areas of health (e.g., mental health) where patients, carers, providers and health professionals may benefit from increased knowledge about and coordination of services. The success of the SEAM model relies on the credibility of the SEAM nurse and his/her skills in networking, liaison, education and advocacy, and on ensuring public awareness of the service.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>A flyer explaining and promoting SEAM was developed and distributed through GP surgeries, the Commonwealth Carelink Centre, Centrelink offices and other relevant organisations. SEAM's affiliation with Toowoomba Hospice was an important tool in accessing the palliative care community and 'marketing' the program. Benefits of dissemination include increasing awareness of the resources developed during the project.</p>

Project Name	(QLD-5) Volunteer Palliative Care Support Network Initiative: Caring Connections
Organisation	Blue Care Brisbane Region
Funding	\$154,900 between April 2003 and November 2005
Project aims <i>What did the project set out to do?</i>	The project's goal was to enhance, develop and expand volunteer palliative care support services to meet the needs of people with a terminal illness and their carers. The specific objectives were to establish a model of interagency service delivery within which volunteers could be recruited, trained and supported; establish guidelines to ensure the provision of uniform, quality volunteer support services; develop resources, including training materials, for volunteers; expand the scope of volunteer activity (e.g., to include complementary therapies); offer volunteer services that support ill people to remain at home and maintain their independence.
Project Delivery <i>What did the project do?</i>	<p>A steering committee was established and a project officer recruited. They set up a reference group that met regularly between February and December 2004. Volunteer coordinators of all the partner organisations were interviewed to collect data on the existing services and identify gaps. The project officer established a network of contacts with organisations providing palliative care and compiled a database of services and resources in the Brisbane area. A literature review was conducted and the findings from the consultation process were summarised. As a result of this preliminary work, a model for service delivery was created and the new service, Caring Connections, was launched on 23 February 2005.</p> <p>Supporting documentation for the new service included guidelines for the utilisation of volunteers in palliative care; a manual of policies and procedures; and a volunteer handbook. Standards of training were developed, reviewed, refined, tested and evaluated. Volunteers were recruited via advertising, articles in the local press and posters. Support mechanisms were put in place, including monthly support meetings.</p> <p>At the conclusion of the pilot on 31 August 2005, there had been 54 enquiries, and 14 of these had become clients. Referrals were received from a wide range of sources, including within Blue Care Brisbane Region, hospitals, community health and social workers. A total of 98 enquiries had been received from potential volunteers, and of these 42 were taken through selection and recruitment. Three groups of recruits were trained, although none of these groups were conducted with the full set of Caring Connections training modules, and 25 volunteers completed training. (A fourth group was trained in December 2005, using the full set of materials.)</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>An internal evaluation, designed by the project officer and project manager with external advice, was conducted between August and October 2005.</p> <p>Satisfaction surveys were planned and tools developed for the purpose. Due to the small numbers of clients and active volunteers, however, it was decided that qualitative methods would be more appropriate and informative. Interview schedules were created and interviews conducted with seven clients and four active volunteers. Transcripts of the interviews indicated high levels of satisfaction among clients and volunteers. It was recommended that the service be re-evaluated in June 2006.</p>
Project Sustainability <i>What aspects of</i>	Blue Care had agreed to continue funding the service until June 2006 but this was discontinued in November 2005. Managers who supported the service left and new policies mean that money from bequests and donations is no longer available. If new funding sources cannot be found, the service will disappear and the volunteers will be absorbed back into the

Project Name	(QLD-5) Volunteer Palliative Care Support Network Initiative: Caring Connections
<i>the project will continue?</i>	<p>general volunteer pool for Blue Care, without the support of the a palliative care volunteer coordinator. The project team has sought sponsorship from large organisations and approached clubs and community groups for donations. They have also applied for HACC funding.</p> <p>Another threat to the sustainability of the service is the cost of petrol, which means volunteers are decreasing the distance they are willing to travel and are more likely to seek reimbursement for transporting clients. Caring Connections will not be able to continue reimbursing transport expenses if it does not obtain funding. There are also plans to streamline Blue Care volunteer services with uniform policies and procedures. Blue Care does not reimburse volunteers for transport expenses.</p>
Project Capacity Building <i>What has been learnt?</i>	<p>The publicity associated with the volunteer recruitment drive helped raise community awareness of palliative care and bring community members together to support each other. Capacity in palliative care was built through the development of resources and the provision of training for volunteers. Networking opportunities were created through the cooperation of the partner organisations in supporting Caring Connections. The resource kit included a list of local services.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The project developed a best-practice model for managing palliative care volunteers, along with evaluation tools and documentation, policies and procedures, training materials and a volunteer handbook. These resources update those by Gallash (1996, Murray Institute of TAFE). The resource kit covers legal issues, duty of care, infection control and other issues not addressed in previous work. Other organisations have used the Caring Connections model in applications for new services.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>While the volunteer recruitment strategies were very successful (ads and articles in local newspapers, posters), the project was less successful in catching the attention of potential clients and medical staff than hoped. A flier was written to advertise the service, but there were difficulties with hospital bureaucracy in getting these distributed. The project officer was not authorised to contact the media or potential sponsors directly as publicity activities were handled by the Blue Care head office. Due to a major reorganisation of Blue Care management in the Brisbane region, the head office staff were not active in publicising Caring Connections.</p> <p>The project officer proposed dissemination activities such as creating a website and putting the service in the telephone book, but this was not done because the project managers (wrongly) believed they would be able to save the funds for use after the project had finished.</p> <p>After receiving large numbers of inappropriate referrals for people with severe disabilities, the project officer changed the wording of the flier to make the eligibility criteria clearer (from “progressive illness with ... no known cure” to “terminal illness”). This resulted in more appropriate referrals, and a larger proportion of those referred became clients.</p>

2.5 South Australia

Project Name	(SA-1) Establishing the care-worker role in palliative care – education, support and integration with palliative care teams
Organisation	Royal District Nursing Service of SA Inc
Funding	\$199,273 between March 2003 and February 2006
Project aims <i>What did the project set out to do?</i>	The project aimed to develop trial and evaluate a self directed learning package for use by care workers to improve their knowledge and skills for delivering care to clients with a life-limiting illness.
Project Delivery <i>What did the project do?</i>	A project management group was set up to oversee the project. A literature review was conducted to investigate the role and education needs of care workers providing palliative care in the home setting. Interviews and focus groups were held with clients receiving palliative care, carers, care workers, allied health professionals and care coordinators to help determine the role of care workers in palliative care. A self-directed learning package was developed consisting of guidelines, a case study, four elements, evaluation forms and further readings.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The initial self-directed learning package was trialled with a pilot group with a limited number of care workers. The feedback from this pilot study was then used to refine the package for a second trial to a wider audience of 100 participants. Of these 53 completed the package. A pre and post questionnaire was developed to identify any increased knowledge after completing the package. Evaluation of the content, format and support of the package was also carried out. Also the amount of time participants took to complete the package was also evaluated (average time being 40hrs).</p> <p>Overall, 81% of respondents responded positively to the package and 88% indicated that the package was useful, beneficial and user friendly. The pre and post questionnaire revealed that participants significantly increased their knowledge, skill self-assessment and confidence as a result of completing the package.</p> <p>None of the evaluation data indicated that the self-directed learning package or the evaluation needed to be amended.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	The self-directed learning package is a sustainable resource. However, the cost of producing the package (approximately \$100) could be prohibitive for potential users.
Project Capacity Building <i>What has been learnt?</i>	The development of this package was supported by a wide variety of stakeholders. Through their consultation and collaboration a useful tool has been developed to support care workers in the community. The information within the package will build the capacity of all care workers who deliver care to clients with a life-limiting illness.
Project Generalisability <i>Are the lessons</i>	The project target group initially focused on SA care workers in the form of focus groups and initial testing of the resource but this was later extended to a national testing group to ensure the resources were transferable. The self-directed learning package is a valuable tool that can be adapted for use in the home for carers, a useful resource tool for staff in Aged Care

Project Name	(SA-1) Establishing the care-worker role in palliative care – education, support and integration with palliative care teams
<i>useful for someone else?</i>	Facilities and for care workers. With further refinement this package could be an appropriate module in an elective in the Diploma of Nursing.
Project Dissemination <i>Who was told about the project?</i>	Information relating to the project was disseminated using a variety of mechanisms. A presentation was delivered to three palliative care program forum workshops and at a Palliative Care Conference in SA. Various newsletters and industry magazines were also used to advertise the project.

Project Name	(SA-2) Kangaroo Island Palliative Care Project
Organisation	Kangaroo Island Health Service
Funding	\$55,000 between July 2003 and June 2005
Project aims <i>What did the project set out to do?</i>	<p>The project had four main aims:</p> <ol style="list-style-type: none"> 1. To develop and provide appropriate palliative care information and education opportunities to the Kangaroo Island community and its health professionals. 2. To set up a Volunteer Support program that will provide long term practical and emotional assistance for people who are dying either at home or in an institutional setting. This would complement professional services already available. 3. To up-skill Kangaroo Island Health Service staff in palliative care. 4. To develop a collaborative network of support between off Island specialist palliative care services, health professionals on Kangaroo Island, volunteer supports and the community.
Project Delivery <i>What did the project do?</i>	<p>A collaborative network of off-island palliative care services, volunteer networks and professional organisations was developed both within South Australia and nationally. This provided a platform to commence and develop networks of support and information gathering. This process was invaluable in gaining an understanding of the practicalities of managing a volunteer service and in setting up the necessary resources required to implement a sustainable service.</p> <p>Palliative care community education and awareness sessions were held in main towns on Kangaroo Island. These sessions were repeated for health service staff and were well received and attended. These meetings generated interest for people in the community to become involved in palliative care volunteering.</p> <p>As a result of these initiatives twelve palliative care volunteers were recruited. Their training was supplemented with a volunteer handbook, a volunteer program manual and an orientation handbook. All of these resources were created by the project and included relevant information about managing a volunteer care service, protocols, policies, management structures and legal responsibilities.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The community and professional education sessions were evaluated using a survey designed by the project coordinator. The response rate from the community sessions was good (30 completed surveys from 33 attendees). Respondents stated that the sessions were well presented and informative. Only 8 of the 20 professionals who attended the professional education sessions completed an evaluation survey. However, all who responded declared that the sessions were useful and informative.</p> <p>Eighteen prospective volunteers attended the comprehensive volunteer training program that included 6 sessions on varying topics related to volunteering and palliative care. All sessions were well attended and well received by trainees.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The ongoing support and training of palliative care volunteers will be sustainable and supported by the Kangaroo Island Health Service with a 0.1 FTE position made available to coordinate activities. The program manual and resource book are invaluable resources which can be used by the health service in the future.</p>

Project Name (SA-2) Kangaroo Island Palliative Care Project	
Project Capacity Building <i>What has been learnt?</i>	<p>One of the biggest achievements of this project has been the development of a vision for palliative care on Kangaroo Island. This has been achieved in part as a result of the great support networks that have been developed along the way between the community, professional staff, carers, volunteers and off-island specialists.</p> <p>Also the protocols and procedures for volunteering developed by the project have been adopted by Kangaroo Island Health Service.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>The volunteer handbook and procedure manual is relevant to other organisations that have a volunteer component to their service delivery.</p> <p>Although these resources have a South Australian focus the information available is extremely thorough and includes a useful resources page of relevant websites and contact people. An electronic version of these resources is available from Kangaroo Island Health Service.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>The palliative care information and education sessions were advertised in the local press and placed in three local school newsletters. Flyers were also used to advertise the project.</p> <p>In terms of generating follow-up information requests the most successful way of disseminating information locally was through presentations to local service providers or agencies.</p> <p>The project was also presented at the 7th Biennial Rural Palliative Care Conference in Adelaide in May 2004.</p>

Project Name	(SA-3) Partnering with Rural Communities to Improve Access and Education in Palliative Care
Organisation	University of South Australia, Whyalla Campus
Funding	\$155,000 from March 2003 to May 2005
Project aims <i>What did the project set out to do?</i>	<p>The project had three main aims:</p> <ul style="list-style-type: none"> ▪ To improve community awareness of palliative care services. ▪ To enhance the knowledge and skills of caregivers in order to help them better cope, and to provide better care for loved ones. ▪ To increase knowledge and awareness of palliative care services amongst health professionals.
Project Delivery <i>What did the project do?</i>	<p>Each objective of this project was carried out in rural/remote areas of South Australia (Wakefield, Mid North, Eyre and Northern and Far Western Regions).</p> <p>The project carried out:</p> <ul style="list-style-type: none"> ▪ Seven community education sessions tailored to the local community in the targeted areas. Topics included the palliative care approach, referral processes, activities of daily living, bereavement support and pain and symptom management. ▪ Thirty volunteers and carers attended three focus groups. These sessions were held to help determine their needs. ▪ Seven health information sessions targeted at health professionals working in palliative care. ▪ 75 individuals who were involved with caring for a person with a life limiting condition were interviewed. These people came from a variety of backgrounds including clients, caregivers, health professionals, volunteers and pastoral care. Interviews provided the project team with the opportunity to link people with appropriate services and to help answer their questions in relation to palliative care.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The community education sessions were evaluated with a questionnaire and results indicated that the majority of respondents were satisfied with the information provided. Many respondents expressed an interest in attending future similar sessions.</p> <p>The results of the interviews were entered into a qualitative data management package and recurring themes and phrases were identified. From these themes gaps in service delivery were identified. The focus groups also identified gaps in service delivery.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>It is very difficult to measure the sustainability of this project as the major aims were to raise knowledge and awareness of palliative care at the level of community, carer and health professional. Whilst it appears that the project created a greater awareness of what palliative care services are on offer and linked carers with appropriate support networks it is difficult to determine whether this knowledge will stay in the community.</p> <p>Positively, the project has received funding in the Local Palliative Care Grants Program for providing pastoral care and support in these same target areas.</p>

Project Name	
(SA-3) Partnering with Rural Communities to Improve Access and Education in Palliative Care	
Project Capacity Building <i>What has been learnt?</i>	<p>Although it is difficult to measure it appears that capacity has been built in remote areas of SA with regard to knowledge and awareness of the palliative approach. One of the major achievements of this project was getting four of the seven South Australian Regional Health Services working to a common goal. These regions continue to be supportive of the project activities and have an increased understanding of palliative care services available within their jurisdictions. As a result of the networks created between these regional health services there is more open communication and linking between them which has created a greater awareness of palliative care.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>Certainly this model of improving community awareness of palliative care is generalisable to other regional/rural area in Australia. It is clear that in order to sustain these learnings it is essential to have the involvement and support of local area health services. Equally important is gaining an understanding of what the communities' needs and expectations are of palliative care.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>During the life of the project it is estimated that 1,500 individuals have been involved in the project through information sessions, and community partnerships and engagement. Information relating to project activities was disseminated through a project website within the web pages of the University of South Australia. The project was also showcased on the front page of the University website in June/July 04. Other dissemination activities included television, radio, local newspapers, flyers, posters and various newsletters. It is difficult however to determine which method was most successful as no formal evaluation was undertaken.</p> <p>Conference papers were delivered at the following conferences or workshops:</p> <ul style="list-style-type: none"> ▪ Biennial Rural Palliative Care Conference in May 2004 ▪ Ageing, Spirituality and Palliative Care Conference in September 2004 ▪ SA Regional Engagement Forum in June 2005. ▪ 8th National Rural Health Conference in March 2005 ▪ Inaugural Rural Health Services Forum in 2005

Project Name (SA-4) Shared bereavement care in the west	
Organisation	Western Palliative Care Service, The Queen Elizabeth Hospital, Adelaide
Funding	\$199,084 between March 2003 and May 2006
Project aims <i>What did the project set out to do?</i>	To increase collaboration between specialist palliative care providers and primary health providers, Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse (CALD) organisations/agencies to ensure there is coordinated and culturally appropriate bereavement care in the western region of Adelaide.
Project Delivery <i>What did the project do?</i>	<ul style="list-style-type: none"> ▪ A comprehensive literature review was undertaken to gain information on the specific effect of culture on the need for bereavement. ▪ Three steering groups were formed to represent peak bodies and key organisations from each community. These three groups were merged into one large group half way through the funding period. ▪ Focus groups and interviews were held with health workers, community members, carers and Aboriginal elders to help define the bereavement needs of Aboriginal and CALD groups in the western community of Adelaide. ▪ Palliative care education sessions were held for relevant agencies and community/carers groups. ▪ Cultural competency training was held for health workers at Queen Elizabeth Hospital. ▪ A database of key workers and services within Aboriginal and ethnic organisations was compiled for local palliative care workers. ▪ Community working groups developed culturally and linguistically diverse protocols for the Italian, Vietnamese and Aboriginal communities. The protocols were developed specifically for mainstream palliative care workers and primary health care workers. ▪ Aboriginal elders painted a banner for the palliative care unit at the Queen Elizabeth Hospital and this artwork was used on promotional materials. The artwork is a symbol of reconciliation to show Aboriginal patients and communities that they are welcome at the palliative care unit at the hospital. ▪ A pamphlet was created for the local Aboriginal community providing a simple explanation of palliative care and the options for care in terminal illness. ▪ A process of engagement was developed with local Aboriginal health bodies for other mainstream health organisations.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The evaluation methodology for this project covered the levels of the consumer, provider and the system. At a consumer level community awareness was evaluated in each of the three communities (Aboriginal, Italian and Vietnamese) using Tool 1.5 and Tool 1.6 (modified for urban communities). From the perspective of providers Tool 2.5 was used to assess the level of palliative care awareness amongst health professional working directly with the Vietnamese and Italian communities. Evaluation of the local palliative care system was conducted using Tool 3.1.</p> <p>Overall, the consumer evaluation revealed a general lack of knowledge of palliative and bereavement care within each of the communities. This was identified as a barrier for accessing relevant services. From the perspective of providers there was an increased understanding of palliative</p>

Project Name	(SA-4) Shared bereavement care in the west
	<p>care and greater awareness of resources available in the community as a result of the palliative care education sessions. The cultural protocols developed for the CALD community together with the cultural diversity training were both received in a positive light. The evaluation results of the cultural awareness training targeted at Aboriginal health workers were extremely positive and described by one participant as “the best in-service I have been to because I really felt it came from the heart”.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>Considerable effort was made in building relationships with key bodies and stakeholders in each community. It is hoped that these links will continue into the future. In particular, the working group of palliative care and Aboriginal peak bodies is still meeting, focusing on the needs of Aboriginal palliative care. Also a database of key workers and services within Aboriginal and ethnic organisations will continue to be made available. The CALD cultural protocols have been made available on the Queen Elizabeth Hospital website and in the Interns Handbook 2006 and the Aboriginal cultural protocols will be incorporated into the SA Palliative Care Companion Resources. From the perspective of the Western Adelaide Palliative Care Service referral forms have been amended to include cultural identity of the client and primary carer and the internal bereavement form now includes cultural identity.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>It is crucial for mainstream health workers to be culturally competent and to work in partnership with Aboriginal and multicultural services. Only when these workers understand the unique needs of these communities will access to these services improve for these groups. Key to this goal is to build strong relationships between mainstream palliative care peak bodies and services with key Aboriginal and multicultural stakeholders.</p> <p>Equally important is the need to educate the Aboriginal, Italian and Vietnamese community about palliative care and bereavement services in order to build their capacity to access more culturally appropriate services.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The Aboriginal and CALD protocols developed by this project have been adopted by mainstream health providers working with patients/families from these communities. Also this information has been included in the SA Companion Book of the Providing Culturally Appropriate Palliative Care for Indigenous Australians Resource Kit. The model of engagement used in this project for liaising with the Aboriginal community could be adapted for use with other Aboriginal and Torres Strait Islander communities in Australia.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>Various methods were employed to disseminate information about this project both in written and oral form. With regards to the Aboriginal and Torres Strait Islander community an oral presentation was made to the Full Council of Aboriginal Elders. Also there were regular network meetings with key stakeholders of the three communities.</p> <p>A Department intranet site was developed for Aboriginal issues and various cultural resources were made available. Relevant information was disseminated through the hospital newsletter and a peer reviewed journal article has been drafted for submission.</p>

2.6 Tasmania

Project Name	(TAS-1) Collaborative Palliative Care in Rural Communities
Organisation	Tasmania Palliative Care Service
Funding	\$200,000 between April 2003 and March 2006
Project aims <i>What did the project set out to do?</i>	The project aimed to develop a collaborative approach between specialist and primary palliative care providers in rural communities in Tasmania; develop and implement strategies to support primary care practice; develop an ongoing partnership of monitoring and analysis to assist client focused care, service planning and development; and implement a mentoring strategy to strengthen networks beyond the life of the project.
Project Delivery <i>What did the project do?</i>	<p>Very little progress was made in the first 18 months, primarily due to the ambitious scope of the project, inadequate staffing and the impact of a state-wide review of palliative care services. A dedicated project officer commenced in January 2005 and the CCP project became part of the Review Implementation Project, a three-year project to address the recommendations from the state-wide review, including the development of a collaborative model of service delivery. The CCP project plan was amended and a new Steering Committee formed to oversee both projects.</p> <p>The initial focus of the project was in the North West of the State due to work that had already commenced to facilitate working relationships between specialist and primary care providers as part of a Rural Palliative Care project commenced in 2004 by the local Division of General Practice. An initial literature review was undertaken and a service delivery model with four levels of care – primary care, consultation/liaison, shared care and specialist care – developed, outlining the roles and responsibilities of providers. State-wide standards and clinical protocols for referral, intake, admission, allocation and intervention were developed, together with a consistent approach to assessing client needs and care planning. A Guide to Collaborative Practice for primary care providers was developed and is intended for distribution to approximately 800 providers.</p> <p>Clinical tools were trialled within specialist community teams, endorsed after review of the results, and implemented state-wide. This included the development of a Psychosocial Assessment Form. The client information database was amended to standardise data collection and facilitate ongoing monitoring of collaborative practice.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Evaluation was primarily based on information from interviews, focus groups, questionnaires, documentation audit and direct feedback through attendance at meetings. Three tools were used from the CCP Evaluation Tool Kit. The Palliative Care Providers Tool (2.1) was completed by staff from the three community based palliative care teams early in the project and because the results indicated that team members were confident and knowledgeable about providing palliative care was not repeated later. The Health Professionals not Working in Palliative Care Tool (2.5) was used in a series of primary care provider focus groups at project commencement, in collaboration with the North West Rural Palliative Care project, and disseminated to 20 participants from various disciplines. The results indicated that most had only a general knowledge of palliative care but were confident most of the time in caring for the dying person and were sufficiently supported in undertaking that role.</p> <p>Feedback on the key themes in Tool 2.5 was again ascertained in 2005 through a process of consultation, which indicated that primary care</p>

Project Name	
(TAS-1) Collaborative Palliative Care in Rural Communities	<p>providers had a greater understanding of palliative care and the services available in their area, and the relationships between the specialist and primary care providers. Tool 2.5 was later modified to meet the need of specific sites in the process of implementing a clinical assessment scale in primary care. The Palliative Care Service Self-assessment Tool (3.1) was completed by staff from the specialist palliative care service who rated the service's structures as supportive, except for bereavement support and education and professional development.</p> <p>Monthly audit of the clinical assessment scale (part of the Clinical Assessment Toolkit) demonstrated approximately 50% compliance and highlighted gaps in assessment processes. Feedback was provided to managers regarding the need for in-service education and monitoring.</p> <p>A tool was developed to assess client satisfaction and identify caregiver stressors and given to new clients on registration with the service. By project completion three completed forms had been returned.</p> <p>As a result of the project's activities the service has developed and enhanced its processes for providing advice, support and education. The service delivery model has helped to define the roles and responsibilities of specialist and primary care providers. Since the project commenced the proportion of clients accessing the community palliative care service throughout the State has shown a consistent and sustained increase. Greater awareness of the role of the specialist service has resulted in more referrals from primary care providers. The number of out-of-hours contacts from primary health care providers has also increased.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The service delivery model has been endorsed by key stakeholders and will be implemented across the state. The clinical tools developed as a result of this project will be made available throughout Tasmania and further education provided to primary care providers regarding their use. Formal networks between primary and specialist providers (with an emphasis on rural areas) will be sustained by recently appointed area palliative care managers. Work will continue to evaluate and refine the various materials developed during the project – a draft care plan, the clinical assessment toolkit, and the Guide to Collaborative Practice.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>The project has fostered collaboration between specialist and primary care service providers, with identification of the roles and responsibilities of each. The model provides a framework for the specialist palliative care service to support primary care providers with advice, information, resources and education.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The model of service delivery provides a framework for primary care and specialist palliative care service providers to work together. The model and other resource tools are likely to be useful for other palliative care services</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>The project has focused on disseminating information about the project throughout Tasmania, with newsletter articles, presentations and attendance at local service meetings, rather than disseminating the results of the project elsewhere.</p>

Project Name	(TAS-2) Empowering the Southern Midlands Community through Information and Integration
Organisation	Department of Health and Human Services - Midlands Multi Purpose Health Centre
Funding	\$68,380 between April 2003 and December 2004
Project aims <i>What did the project set out to do?</i>	The project aims to increase the knowledge base of health professionals, key community agencies and the residents of the Southern Midlands Municipality regarding Palliative Care issues, across the continuum of care.
Project Delivery <i>What did the project do?</i>	<ul style="list-style-type: none"> ▪ Provided palliative care in-service training to all staff at the Midlands Multi-Purpose Centre. In addition to this registered nurses received training on the Oncology Ward and Hospice Whittle Ward at the Royal Hobart Hospital. ▪ Promoted understanding of the concept of Palliative Care for service providers and members of local communities through local advertising in newsletters, local radio and through a locally held community forum. ▪ Selected, trained and coordinated nine volunteers to provide support to clients in their own homes, specialist units and the local hospital. ▪ Provided a small, local equipment store of care items allowing a quick response to identified needs for the client and safety for the carer. ▪ Created positive linkages and sharing of resources with the local specialist palliative care service and the Hospice Care Association.
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The major achievements of this project have been the continued commitment from the locally based health care staff in the planning and development of the local palliative care service. Also the creation of a palliative care volunteer service has been very successful and has already developed other benefits for the community.</p> <p>Community awareness of palliative care was assessed prior to the community forums and then reassessed three months later. The evaluation form was based on Tool 1.5 from the Caring Communities Evaluation Toolkit. Overall participants' knowledge of palliative care had significantly increased after the forum.</p> <p>Staff awareness/knowledge/attitudes of palliative care was similarly assessed before and after training sessions using Tool 2.1. A separate assessment form was designed locally specifically for employees of the Midlands Multi Purpose Health Centre.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The project has generated a lot of interest with regard to palliative care in the local community. However, should the numbers of people in palliative care increase dramatically it is doubtful whether the current level of staff resources could keep up with demand. Currently there are only two community nurses available who work Monday to Friday with weekends and public holidays off. Currently after-hours work is compensated with time off in-lieu which will further challenge available resources.</p> <p>Also there is the issue relating to wear and tear and use by dates for the items in the equipment store. Replacement and upkeep of these items will require additional funding.</p>

Project Name (TAS-2) Empowering the Southern Midlands Community through Information and Integration	
Project Capacity Building <i>What has been learnt?</i>	Capacity has been raised with training of relevant staff and community members in issues relating to palliative care service provision. 86% of people trained expressed an interest for further involvement in the project.
Project Generalisability <i>Are the lessons useful for someone else?</i>	This service model could be replicated in other rural health care facilities provided that funds are available for staff education costs and the purchase of equipment.
Project Dissemination <i>Who was told about the project?</i>	The biggest impact in terms of raising awareness about the project came from appearances on local radio and targeted mail outs of information leaflets.

2.7 Victoria

Project Name	(VIC-1) A best-practice support model for life-threatening illness in the workplace
Organisation	Palliative Care Victoria (PCV) and Creative Ministries Network
Funding	\$191,761 between August 2003 and May 2006 (<i>The start of this project was postponed six months due to delays in recruiting a project officer.</i>)
Project aims <i>What did the project set out to do?</i>	The project aimed to develop a model of support for employees affected by life-threatening illness, either themselves or as a carer. The model was also designed to support managers and colleagues in dealing with issues such as the need for time off, coping with the changing situation as the illness progresses, and grieving. It was developed in collaboration with employees and employers. As an important community site, the workplace was seen as an appropriate place to disseminate the 'palliative approach'.
Project Delivery <i>What did the project do?</i>	<p>A literature review was carried out. This demonstrated the lack of scholarly study around workplace support for people with life-threatening illnesses and for their carers. It identified relevant Canadian legislation that warrants further investigation for the Australian context.</p> <p>The project partner, Creative Ministries Network, provided insights about occupational health and safety issues relevant to palliative care, and also highlighted the importance of focusing on employers' needs and issues. Employer and employee organisations assisted in researching the existing framework of legislation, policies and strategies that support workplaces and employees to deal with issues arising from life-threatening illness.</p> <p>Thirty people were interviewed, including 10 who had been diagnosed with life-threatening illness. Interviews were conducted in industries such as hospitality and service, freight, education, agricultural science, medical transport, legal services, construction and health care. Qualitative analysis revealed that work was an important source of identity for Australians, providing independence and a sense of self. Illness is feared because it may bring loss of identity, self-worth and belonging. Four elements of support are needed: economic (practical), emotional (empathy, trust), information (to help people cope) and appraisal (feedback).</p> <p>The support model was created, with input from the project's Reference Group, plus 15 workplaces and about 22 palliative care providers (members of PCV). The model addresses training needs, the development of mechanisms to overcome barriers between work and family, and the implementation of support at different stages of the illness (including bereavement) by people in various roles within the workplace.</p> <p>A number of policies, strategies and resources were also developed: Occupational Health and Safety Guidelines for Grief and Loss at Work; Occupational Health and Safety Guidelines for Life-threatening Illness at Work; A workplace assessment checklist; A pooled sick leave scheme; Tough questions for managers of an ill employee; Tough questions for managers of an employed carer; Information about the Compassionate Employer Awards auspiced by the Compassionate Friends Inc. Victoria.</p>
Project Impact & Outcomes <i>How was the project</i>	Some of the performance indicators in the funding application were not completed within the time and budget of the project. No pilot testing of workplace model was possible, so there was no training provided and no evaluation of the model's effectiveness. Nevertheless, an evaluation was carried out by a final-year social work student who undertook a placement

Project Name	(VIC-1) A best-practice support model for life-threatening illness in the workplace
<i>evaluated?</i>	at PCV, during which time she was supervised by the project officer.
<i>What results were achieved?</i>	
Project Sustainability	The prospects for sustainability are low. The project officer's contract period has ended and she has moved on to seek another job. It does not appear that PCV will continue this work.
<i>What aspects of the project will continue?</i>	The project has recommended the creation of a pilot three-year Health and Safety Workplace (Life-threatening Illness) consultancy position. This would provide a direct service to industry, telephone advisory line and a training program in practitioner roles. Such a consultancy would require further funding from sources such as DoHA.
Project Capacity Building	The project produced a set of resources (see list above) which will be published and may also be made available on the PCV website. Relationships have been built and maintained through the consultation process (e.g., between PCV and the Victorian Chamber of Commerce and Industry).
<i>What has been learnt?</i>	A number of recommendations from the project are designed to promote capacity building. These include commissioning a study on the costs to business of life-threatening illness in Australia, which would provide basic information on the costs and benefits of providing support to ill employees and employed carers. Other recommendations deal with a review of relevant legislation, consultation with small business, and reviews of insurance and superannuation.
Project Generalisability	The model is designed for all types of businesses – small, medium and large – but it has not been piloted. Pilot testing and evaluation would identify opportunities to use the model in various settings and also highlight potential barriers to generalisability.
<i>Are the lessons useful for someone else?</i>	The project recommends that palliative care providers be encouraged to develop services appropriate to the needs of businesses with ill employees or employed carers.
Project Dissemination	In addition to the wide consultation undertaken during the project, a great many dissemination activities were achieved. These included four conference presentations (including one international conference), two peer-reviewed journal articles, an article in the <i>Australian Financial Review</i> newspaper, articles in palliative care sector and industry newsletters, submission of an abstract to the CareSearch website, two employer/industry workshops and numerous other presentations to students, community groups, local government and health professionals.
<i>Who was told about the project?</i>	

Project Name	(VIC-2) Building rural community capacity through volunteering
Organisation	Hume Regional Palliative Care.
Funding	\$207,692 between April 2003 and March 2005 (<i>includes \$183,942 from CCP and \$23,750 from other sources plus in-kind support from Hume Regional Palliative Care regional office</i>)
Project aims <i>What did the project set out to do?</i>	Stream 1 - Strengthen supports to rural palliative care volunteers Stream 2 - Encourage community involvement in a public-health approach to palliative care. An additional objective was to strengthen partnerships between palliative care volunteer services, providers, communities and health services.
Project Delivery <i>What did the project do?</i>	<p>Stream 1 involved increasing communication with the 17 health service agencies which auspice palliative care volunteer services in the region, developing protocols to enhance links between services and volunteers. Coordinators of Volunteers (CoV) were given management training. Data were gathered on their roles and activities in order to identify the level of funding required to support paid CoV positions. Delivery of volunteer training by palliative care staff and community professionals was trialed and evaluated. A workshop on submission writing was held to build the capacity of the auspice agencies to seek funding for volunteer services.</p> <p>Stream 2 began with a regional forum on the public health approach to palliative care, delivered to 72 participants including CoV, volunteers and palliative care regional staff. This was followed by a workshop providing training in health promoting palliative care. From the pool of trained volunteers and staff, a regional Health Promotion Resource Team (HPRT) was formed. Using guidelines developed in partnership with La Trobe Palliative Care Unit and seed funding via the CCP project, the HPRT assisted or mentored 25 regional initiatives that explored issues surrounding death, dying, loss and care. The funding ranged from less than \$100 to more than \$2000 (a total of \$12,250 was provided for 24 of these 'mini projects'). Examples of projects included a performance event and art exhibition, a reflective space at a cemetery, death education via World Café events and memory boxes. Partnerships were encouraged between palliative care services and community groups, e.g., businesses, schools, health centres, churches, youth services, complementary therapists, artists and craftspeople.</p> <p>Community professionals attended a 'train the trainers' session on how to facilitate adult bereavement seminars, which are designed to break down myths and encourage people to view it as a normal part of life. Resources and guidelines were given to providers who were encouraged to develop partnerships with the community in planning health promoting activities.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Stream 1 was evaluated by Jigsaw Research (Wangaratta). Data were collected through two written surveys of CoV and interviews with 10 managers of auspice agencies. Two reports were provided. Local ownership, recruitment, training and management of palliative care volunteers enables rural communities to provide an accessible palliative care service. To be sustainable, rural palliative care volunteer services need funded management and coordination, and regional guidance and protocols to link them with services and best-practice education.</p> <p>Stream 2 was evaluated by La Trobe University Palliative Care Unit. This involved a focus group and telephone interviews with HPRT members, an interview with the project officer and telephone interviews with 19 recipients of grants. The formation of a regional HPRT can contribute to greater community understanding of palliative care and the support needs</p>

Project Name	(VIC-2) Building rural community capacity through volunteering
	<p>of palliative care clients and families. The HPRT strategy relies on team members to incorporate their responsibilities with their usual work or volunteer roles. Accessible education for health professionals, use of the Big 7 Checklist and simplified funding guidelines also contributed to success. Seed funds enable community groups to identify needs and form partnerships, providing a starting point for access to funding sources.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The findings informed service planning in the region. Funded coordination of palliative care volunteers has been identified as a regional priority. The project improved communication between services and volunteers, helping provide a supportive framework for palliative care services.</p> <p>The HPRT strategy was a cost-effective way to deliver a public health approach to palliative care. Sustainability for the 'mini projects' will depend on the partnerships formed, their impact on the community and the possibility of alternative funding. By providing seed funds, regions can gather evidence on the effectiveness of strategies, to help make future submissions for sponsorship by philanthropic or corporate organisations. Regional palliative care services require designated resources for health promotion (from Australian and State Governments) in order to provide these small community grants. To sustain the benefits of the CCP project, the HRPC team has resourced a position to provide guidance and support to volunteer services and carry out community development activities.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>Capacity building was achieved by enhancing supports around volunteers through training and monitoring the workloads of volunteer coordinators, regional protocols linking volunteer auspice agencies closely with palliative care services, and enlisting local professionals in the delivery of volunteer training. The second stream of the project built local capacity in palliative care by training providers and volunteers in the public health approach to palliative care, involving trained people in establishing a Health Promoting Regional Team (HPRT) and, through the HPRT, providing small grants to community groups for activities to champion health-promoting palliative care. These activities built community capacity by initiating or strengthening cooperation between diverse groups and agencies.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The project demonstrates the value of including a volunteer service and community development role within specialist local palliative care teams. The findings are a resource for other rural regions in Victoria and elsewhere in Australia which seek to develop coordinated volunteer services across regions and implement public health approaches to palliative care.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>Articles in palliative care newsletters; letters, guidelines and findings posted to stakeholders; two abstracts submitted to a national conference; findings used to inform Department for Human Services regional palliative care consortium planning group and state and regional representatives from the Department for Victorian Communities; journal article; health promotion activity and volunteer services featured in local media; web site.</p>

Project Name	(VIC-3) Experiential palliative care program for general practitioners
Organisation	Mornington Peninsula Division of General Practice (MPDGP)
Funding	\$150,087 between April 2003 and April 2006 (plus \$14,200 in-kind from stakeholders Peninsula Hospice, Royal District Nursing Service (RDNS), MPDGP and Peninsula Health)
Project aims <i>What did the project set out to do?</i>	The project's goals were to promote greater understanding of palliative care and to improve integration of care for patients, family and carers. The specific objectives were: improve symptom management and psycho-social support of patients; improve understanding of GPs of how the 'triangle of care' functions in their region; enhance knowledge and skills in symptom management; improve networking and communication with specialist providers; improve understanding by providers of the challenges and constraints on GPs providing palliative care to their patients; increase opportunities for patients to be cared for in their setting of choice.
Project Delivery <i>What did the project do?</i>	<p>The steering committee designed a survey for GPs based on questions from each organisation. This was sent to all GPs in the region (260) with a response rate of 17%. The results provided an insight into current referral patterns and highlighted three challenges that needed to be addressed by the attachment program, namely: change in referral patterns to Peninsula Hospice instead of RDNS; increase GPs' understanding of the breadth of services available; encourage earlier referral.</p> <p>The survey results informed the design of the clinical attachment program, which was then developed into a Continuing Professional Development (CPD) activity for GPs. The project manager negotiated with the RACGP to have 48 CPD points awarded and to reduce the amount of paperwork for GPs who wanted to claim CPD points. This provided an incentive for GPs to take part. Evaluation - pre- and post-attachment questionnaires including case scenarios - was built into the design of the attachments.</p> <p>GPs were sent a written invitation to take part, and a waiting list was established. One GP volunteered to be a 'test pilot' and improvements were made to the program based on feedback. An administration officer developed a database which captured information on the evaluations; tracked GP participation, completion and payment; and generated letters to participating GPs and agencies confirming rosters and providing details of attachments. This enabled much administrative work to be automated.</p> <p>A total of 60 GPs completed attachments with local palliative care service providers. These consisted of four half-days over 2-6 weeks which GPs spent with the RDNS, the inpatient unit, the community care service and on consultant visits. They were given preliminary reading and opportunities to reflect and comment after each visit. One central point of referral – a telephone number for the Assessment Officer at Peninsula Hospice - was agreed with GPs. An important aspect of this new referral system is the multi-disciplinary case conference, which GPs attend by teleconference.</p> <p>Four one-off events also took place during the project: a training event to launch the project; an aged care weekend, with information on end-of-life planning; 'Palliative Care in Aged Care', an event that looked at ways to enable patients to remain in their place of choice (which may be an aged care facility); a palliative care 'hypothetical' for GPs who had taken part.</p>
Project Impact & Outcomes	The main source of data for the evaluation was the pre- and post-attachment questionnaires completed by GPs. There was a 100%

Project Name	(VIC-3) Experiential palliative care program for general practitioners
<p><i>How was the project evaluated?</i></p> <p><i>What results were achieved?</i></p>	<p>response rate because payment to the GPs was contingent on the return of these questionnaires to both the MPDGP and the host agency. Analysis of the questionnaires demonstrated changes in GPs' knowledge and attitudes following the attachments. GPs were more confident about their initial referrals and about pain management and the overall management of their patients. They had greater awareness and understanding of the available support services and referral pathways.</p> <p>Data from the participating agencies were used to track any changes in referral patterns by GPs. It was apparent from these statistics that there had been a change over the life of the project: more GPs were tending to refer earlier and to use the agreed central referral pathway.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>Although providers are happy to continue providing clinical attachments, this cannot happen without funds to enable GPs to take time out from their practices. The project manager believes that demand had peaked by the end of the project, although if funds were available the attachments could continue at a rate of, say, five per year. The GP population in the Mornington Peninsula area is very stable so the benefits of the project will not dissipate quickly through staff turnover as in some other rural areas. A special interest group for GPs has been established. They will meet three or four times a year for case discussions etc. Information about palliative care will continue to be put into the DGP newsletter.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>The evaluation indicates that GPs' referral patterns are changing and they are passing on their knowledge to nurses, practice managers, other GPs.</p> <p>The MPDGP has been able to build on the CCP project. Feedback from providers, inpatient units and GPs highlighted the lack of support available for palliative care in aged care facilities. This led to a successful submission for a new grant, which will be used to employ a palliative care nurse to go into aged care facilities and build capacity. The role will involve liaising with GPs who have a palliative care caseload and it is hoped the new project will draw on the expertise of some GPs who did attachments.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The model of clinical attachments can be used in other areas for palliative care and for other health fields. In order to make the model work, certain requirements must be met: recognition that GPs run a business; good relationships with providers, understanding how providers and GPs can help each other; excellent organisation and management; meeting expectations by providing standard content (in consultation with providers) and some tailoring (ensuring specific caseload questions are addressed).</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>The project was publicised mainly through the MPDGP's website and newsletter, and the annual report to members. An article appeared in the hospice newsletter. Presentations at the CCP national workshop and the regional workshop in Melbourne led to fruitful discussions with other organisations also trying to engage GPs in palliative care training. Another promotion strategy was to meet local MPs to tell them how the grant money had been used successfully in the community. This resulted in an article in the Frankston Bulletin, published by the local Federal MP and circulated to all households in the electorate and other Federal MPs.</p>

Project Name	(VIC-4) Improving consumer and health professional access to comprehensive, accessible, evidence-based online information
Organisation	La Trobe University
Funding	\$180,151 between June 2003 and May 2006
Project aims <i>What did the project set out to do?</i>	The project aimed to improve the Palliative Care Victoria (PCV) website to provide online access to information for the general public (including patients, carers, and prospective volunteers), health professionals (particularly GPs and community nurses) and those working in the field of palliative care.
Project Delivery <i>What did the project do?</i>	<p>During the pre-development stage, literature on the development of a credible and effective palliative care website was reviewed. This was updated throughout the project. Two expert panels (health professionals and consumers) were established and they, with the project officer, conducted a gap analysis of the information available to Victorian consumers, carers and health professionals. A six-month survey of PCV website users was conducted.</p> <p>Beta site development involved the adaptation of evidence-based information, website design and construction, and appraisal by the expert panels and an external, international expert. Once the beta site was established on the La Trobe University server the expert panels evaluated the 'look and feel' of the site and focus groups were conducted with consumers. The site was presented to the Board and special interest groups of PCV and feedback obtained. All feedback was tracked to ensure it was incorporated into the website. Links were tested and a readability study conducted to check that the site could be understood by audiences.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Evaluation was carried out at each stage of project development (pre-development, beta site development, beta testing, launch/sustainability). Lessons learned at each stage guided the development and implementation of the next stages. This formative evaluation design included user-based, expert-based and design-based elements.</p> <p>Data on the use of the PCV website were gathered from visitors to the old site, the expert panels and people who work in palliative care. This user-based evaluation led to the inclusion of a third portal for the 'palliative care community', which includes prospective and current volunteers and carers, in addition to the 'health professional' and 'general public' target groups. Experts in palliative care were invited to examine the materials written or adapted for the site. Expert opinion was also sought from webmasters of other sites. A readability assessment was conducted using the Flesch Reading Ease and Flesch-Kincaid Grade Level formula to ensure that the writing style was pitched at the appropriate level for the audience. The web design, structure and content were evaluated against the accessibility guidelines and standards set by the World Wide Web Consortium (W3C).</p> <p>The processes of conducting the project were not evaluated, but the project officer highlighted some challenges. In particular, review of the draft materials by the expert panels and other experts – who were all volunteers with many other commitments - resulted in a continuous and unpredictable flow of feedback, which did not necessarily correspond to data collection timeslots. This feedback had to be carefully documented to ensure it was all followed up and reworked drafts submitted to the research team for review. As a result of this time-consuming collaboration process, the beta site was not ready for testing until January 2006.</p>

Project Name	(VIC-4) Improving consumer and health professional access to comprehensive, accessible, evidence-based online information
	<p>A satisfaction survey has been built into the 'live' website. In addition, the functionality of the website will be monitored through statistical analysis of site visitors (hit rates, navigation and points of access and exit).</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The 'live' website was launched at the start of Palliative Care Week on 22 May 2006. The Board of PCV has agreed to set up an editorial subcommittee, and special interest groups of PCV have undertaken to conduct regular surveillance of the site and recommend changes where needed. It remains to be seen whether this will be viable, however, as many of these organisations are run by extremely busy volunteers. The project officer has moved on to another role but is planning to visit PCV in her own time to try to establish a system for maintaining the website.</p> <p>The developers of the website (at La Trobe University) developed processes, web scripts and a plug in to hand over the website to PCV. The relationship with the volunteer PCV webmaster has direct implications for sustainability. The volunteer, who had hosted and maintained the old PCV website, was not told about the plans to develop a new site until the project was underway. Although the new site has now been handed over to the volunteer webmaster, some important issues remain unclear, such as how to ensure good communication. The volunteer does not use the same software as the website builders, and there is a risk that changes to the site will eventually make it "break down".</p> <p>When the DHS reorganised palliative care services in Victoria into regional consortia, the need for a proper communication strategy was recognised and the new PCV website was identified as a potential vehicle. Funding was provided to PCV to develop the website for use by the regional consortia. Fortunately, the site was designed so that discussion groups and pod casting could be added. This may, however, mean there is a need to move away from control of the site by the volunteer webmaster.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>The website provides a tool to build professional awareness and understanding of palliative care. It could be a useful link from providers' own websites, which tend to be more focused on the services they can provide. The PCV site can be used strategically, to provide more content and information about palliative care than would otherwise be possible for these organisations. The site is targeted somewhere between information giving and education. It provides information but also access to resources that will educate. Several of the other Victorian CCP projects are featured on the website, contextualised within current themes in palliative care.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The methods of developing the website are well documented in the final project report and can be used for similar evidence-based online resources for other community organisations. The website provides resources from across Australia, with an emphasis on Victoria since it is the PCV site. Each state could add its own materials or the site could be developed further into a truly national palliative care website.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>The official launch took place on 22 May 2006 at the start of Palliative Care Week. Media releases were prepared for the event. Promotion until that time was largely through professional networks of the stakeholders. The site will generate its own audience through the careful selection of key words for search engines.</p>

Project Name	(VIC-5) Living and Dying in Style
Organisation	South West Healthcare, Warrnambool
Funding	\$223,546 between March 2003 and March 2006
Project aims <i>What did the project set out to do?</i>	Advance Care Planning (ACP) is “a process involving conversations with people to help them make, and preferably document, decisions concerning their future health care”. The goal was to make these conversations a part of routine care on admission to palliative care or a residential aged care facility in rural and remote communities. Objectives were: to establish an acceptable and sustainable program of end-of-life care planning; to encourage patients to take part to ensure their wishes are known and can be enforced; to have the documentation accepted by health agencies.
Project Delivery <i>What did the project do?</i>	<p>Reference groups were established in the regional centres (Warrnambool, Hamilton and Portland). A steering committee was set up, and included the project officer (0.5 EFT) and medical officer (4 hrs/wk). Documentation was prepared, and the project was promoted to allied health staff, nurses, medical practitioners and the management and executive of agencies.</p> <p>The ACP framework was based on the Respecting Patient Choices (RPC) program run by Austin Health, Melbourne. In August 2003, the director of RPC and his staff presented a two-day workshop in Warrnambool to 30 key people. The project officer, medical practitioner and three others were then given additional training to become trainers. These trainers presented seven more two-day workshops attended by 200 staff, who became ACP consultants. The project officer travelled throughout the region to support and update the ACP consultants, ensure that the integrity of the system was maintained, provide encouragement and evaluate progress.</p> <p>Before beginning an ACP conversation, a consultant assesses the person’s capacity to take part. (A process for dealing with incompetent patients was developed by Austin Health and additional training was provided to some consultants.) Conversations may begin with a question, e.g., ‘Have you ever discussed your thoughts about future medical treatment?’ Consultants were encouraged to have a series of short discussions guiding people through the issues, culminating in completion of documents, which were filed in a distinctive ‘green sleeve’ in the patient’s medical history. Documents may include Enduring Power of Attorney (Medical Treatment), a Statement of Choices, a Refusal of Treatment Certificate, a discussion record, life review and family tree.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The evaluation was conducted internally. Training programs were evaluated using a questionnaire. Some (limited) changes were made to the program as a result. Surveys were sent to ACP consultants at three months after the first training session; during the last year of the project; and in the last month of the project. These gathered information on activity levels, the value of the training, documents and support, and sustainability issues. Most of the ACP practice was carried out by just over 50% of those trained. Consultants described the benefits (e.g., improved communication among family members) and difficulties (e.g., finding an appropriate time to initiate ACP discussions) of the framework. Surveys were also sent to 79 GPs (response rate 38%) assessing their understanding of ACP and the relevant legislation. Most indicated they would respect a patient’s documented wishes. As a result of the survey, education on ACP was provided through the Otway Division of General Practice newsletter and talks by the project officer at DGP meetings and functions.</p> <p>Five patients and one carer were interviewed about their experiences of ACP. Feedback was mostly positive. All patients were glad to have the</p>

Project Name	(VIC-5) Living and Dying in Style
	<p>opportunity to document their choices and were confident these would be respected. Review of the palliative care programs showed that ACP had been implemented in 66% of cases at Warrnambool and less in the other two regional centres. A document audit demonstrated that most choices were followed, with the exception of site of death for a few people.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>Austin Health holds the Australian licence to the ACP framework and has funding until June 2006 to expand the program nationally, and has applied for further funding. A Memorandum of Understanding (MoU) making South West Healthcare a licensee has been drafted. This would require a project manager with ongoing funding from South West Healthcare, which is not available. Instead, the project officer is continuing her (previous) role as regional palliative care nurse consultant, adding ACP to the position statement. Training and support for ACP consultants can be covered as part of her duties, funded from the regional palliative care program.</p> <p>Executive support in agencies can be threatened by senior staff turnover. One strategy has been to find a 'clinical champion' for ACP at each site. Training courses are continuing, but participants are charged for catering and consumables - a cost of \$65. This includes a copy of the ACP manual and a large laminated poster. This arrangement is likely to work as long as a compromise can be reached on the requirements of the MoU. It would be preferable to have a position funded part-time to promote ACP and maintain quality, inform consultants of changes and provide support. There is a risk to sustainability if the current project officer leaves her job.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>The project demonstrated that routine ACP in palliative and aged care enhances the quality of end-of-life care. Most people do not want the dying phase of their lives extended, and wishes that have been documented are generally respected. The project trained about 200 ACP consultants and more than half of them were engaged in conducting ACP. Training and other materials were adapted, where possible, to meet local needs.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>Organisations that wish to use the RPC framework must sign a licence agreement with Austin Health. General information and resources for ACP are available from the Office of the Public Advocate and state palliative care organisations. Although the original target population was palliative care patients and elderly people admitted to residential aged care, the project was extended to cater for frail aged people living in the community. ACP training was made available to practice nurses, community health staff and the case managers of Community Aged Care Packages.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>Initial visits were made to the agencies to ensure understanding of the concept. The project was promoted to GPs through visits to 16 practices, information in the Otway DGP newsletter and documents made available on Medical Director (software for GPs). Posters, badges and certificates for ACP consultants and introductory pamphlets were distributed. A paper was presented at a state palliative care conference. Letters were sent to legal practices. Articles appeared in newspapers and there was an interview on local radio. The project officer and medical practitioner gave talks at 23 community and 17 health care professionals meetings. ACP consultants were sent newsletters every three months.</p>

2.8 Western Australia

Project Name	(WA-1) Accessing palliative care in Kimberley remote Aboriginal communities
Organisation	West Australian Country Health Service
Funding	\$64,000 between June 2003 and December 2005
Project aims <i>What did the project set out to do?</i>	<p>This project was based in Broome WA, but the focus was on remote Aboriginal communities in the Kimberley.</p> <p>The aim of the project was to enhance awareness and understanding of palliative care in the communities that had services delivered to them by the West Australian Country Health Service. The project also aimed to work with local community institutions such as nursing homes, clinics and community government councils to develop a network of local support systems and to develop partnerships with these agencies.</p>
Project Delivery <i>What did the project do?</i>	<p>Despite the remoteness of these communities, which made access and communication extremely difficult the aims of the project were achieved. There is a raised understanding and awareness and knowledge in the communities and good support networks have been established.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The project officer designed instruments that are part of the CCP tool kit and she used these instruments as the basis for her evaluation, at the community level, at the level of health workers in the community and in terms of outside agencies delivering services to the community.</p> <p>The evaluation process was useful, a baseline was collected so it was possible to monitor increasing awareness of palliative care in all key groups.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	<p>The service has been absorbed into the community palliative care program, which means that it will continue after funding has ceased.</p> <p>The project has also achieved renewed funding as a result of the CCP project to develop two new projects that build upon the key discoveries of the project:</p> <ol style="list-style-type: none"> 1. Project to enhance Aboriginal health worker training in palliative care. 2. Project to enhance Carer knowledge and awareness of palliative care.
Project Capacity Building <i>What has been learnt?</i>	<p>Much has been learnt about the difficulties of working with remote Aboriginal communities and associated factors such as high staff turnover.</p> <p>This project has demonstrated how important it is to obtain baseline information and how evaluation can be used to monitor the progress of the project in order to provide feedback to communities and staff.</p> <p>The project has demonstrated that it is possible to raise awareness of palliative care in remote Aboriginal communities, despite considerable barriers due to remoteness and communication.</p>

Project Name	(WA-1) Accessing palliative care in Kimberley remote Aboriginal communities
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The project has provided valuable lessons about the importance of taking time to develop relationships of trust and respect. It has also demonstrated the importance of building flexibility into the project so that it can change to respond to community needs.</p> <p>The project has demonstrated the success of effective consultation with key stakeholder and the importance of developing and maintaining networks and developing lists of key contacts.</p> <p>Finally the importance of acknowledging success through rigorous evaluation has been highlighted in this project.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>The project was engaged in extensive dissemination activities including:</p> <ul style="list-style-type: none"> ▪ Presentation at the Australian Health Outcomes Conference 2004. ▪ Production of a DVD explaining palliative care for remote Aboriginal communities ▪ Radio interviews during palliative care week ▪ Ads on local TV stations ▪ Radio ads ▪ Culturally appropriate flyers ▪ Presentation at State Aboriginal health workers conference ▪ Article in palliative care WA magazine

Project Name	(WA-2) Fitzroy Valley Palliative Care Service
Organisation	Nindilingarri Cultural Health Service Inc
Funding	\$57,890 between March 2003 and October 2005
Project aims <i>What did the project set out to do?</i>	To develop a strategy for palliative care services and to raise awareness of palliative care in Fitzroy Valley that is sensitive to the cultural needs of the Aboriginal and Torres Strait Islander people living in this remote area. This strategy will include the provision of a palliative care room at a local hospital.
Project Delivery <i>What did the project do?</i>	<p>A steering committee of local stakeholders was formed in order to plan how the goals and aims of this project could be delivered in a culturally sensitive way in order to ensure that the project is accepted by the local Aboriginal and Torres Strait Islander population. Participants on this steering committee represented all four language groups of Fitzroy Valley.</p> <p>A room in the local Fitzroy Valley Hospital was identified as appropriate for the needs of palliative care clients. This room was refurbished and Aboriginal artwork was installed. It also has external access from a veranda enabling extended family to visit freely without having to gain access via a reception area and nursing staff.</p> <p>The project officer liaised with the regional palliative care coordinator in Broome to ensure that she was aware that a suitable palliative care room was available in Fitzroy Valley and that they could start taking referrals.</p> <p>A brochure was developed to explain the role of palliative care in Fitzroy Valley.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The final report from this project was a three-page document, with no details of evaluation methods or findings.</p> <p>Therefore, formal evaluation findings from this project are not available and there is little evidence to suggest that any evaluation methods were employed. However, anecdotal evidence indicates that the palliative care service has been well received by the local people who have accessed it and they are enthusiastic about the service continuing into the future.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	A palliative care room will continue to be available at Fitzroy Valley Hospital. The staff and doctors at the hospital will continue to take referrals from the local palliative care coordinator.
Project Capacity Building <i>What has been learnt?</i>	The palliative care room at Fitzroy Valley Hospital has improved the capacity of caring for local palliative care patients in a culturally sensitive way.

Project Name (WA-2) Fitzroy Valley Palliative Care Service	
Project Generalisability <i>Are the lessons useful for someone else?</i>	One of the key lessons from this project is that it takes time to link Aboriginal and Torres Strait Islander communities with existing health services.
Project Dissemination <i>Who was told about the project?</i>	The project officer presented a poster at the National Palliative Care Conference in Sydney in August 2005.

Project Name	(WA-3) Kalgoorlie-Boulder Palliative Care Coordination Project
Organisation	Silver Chain Nursing Association
Funding	\$198,966 between May 2003 and September 2005
Project aims <i>What did the project set out to do?</i>	Provide coordination, education, cultural awareness and indigenous liaison and interpretation to support the development of an integrated and cooperative palliative care service and enhance the delivery of palliative care to Kalgoorlie-Boulder, and surrounding areas, of Western Australia
Project Delivery <i>What did the project do?</i>	<p>Project delivery focused on Kalgoorlie-Boulder and involved simultaneous development of a multidisciplinary clinical team and associated procedures; an advisory group to oversight the project and develop partnerships between service providers; education programs for health professionals and volunteers; and strategies to raise community awareness and engagement with Aboriginal and Torres Strait Islander groups. The project coordinator not only managed the project but functioned as the coordinator for the palliative care service being established, including the provision of some direct clinical care.</p> <p>The clinical team met fortnightly for case conferences, informal education and to coordinate service delivery. Difficulty in gaining GP attendance for case conferences was overcome by linking the GPs in by phone. Good support from the local division of general practice was enhanced by additional funding under the Rural Palliative Care (RPC) Program. The Palliative Care Therapeutic Guidelines were adopted as a guide to practice. The development of local protocols was considered but not pursued. State Government funding was obtained to provide domiciliary palliative care nursing, including an after hours service, to support the project. Existing client home files were used to record home visits. The PalCIS software was used as the basis for a clinical information system towards the end of the project but proved difficult to implement and a common system across all service providers was not established. A team of volunteers was trained to provide respite care, social support and transport. Volunteers were trained in simple hand and foot massage. Clients were supported if they chose to use complementary therapies.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Over the two years of the project 79 referrals were received. Of these 12 (15%) were Aboriginal and Torres Strait Islander clients who constitute 6% of the local population. 17% of clients died at home, 19% in a nursing home, 57% in the local hospital and 6% in Perth.</p> <p>Satisfaction surveys were conducted annually. Although the numbers were small the results indicated a high degree of satisfaction with the service by clients and carers.</p> <p>Once the optimal mode of delivery had been established attendance at education sessions was encouraging with positive feedback from participants.</p>
Project Sustainability <i>What aspects of the project will continue?</i>	The project benefited from additional funding from the RPC Program to enhance GP involvement in the palliative care service. The advisory group for the project has continued beyond the life of the project, in part due to support from the associated RPC project. The coordinator position was seen as critical to ongoing maintenance of the service and a business case for ongoing funding of the position was developed and submitted to the regional health authority. The funding has been secured and the coordinator position established.

Project Name	
(WA-3) Kalgoorlie-Boulder Palliative Care Coordination Project	
Project Capacity Building <i>What has been learnt?</i>	<p>The rapid turnover of the local population (30% per annum) presents enormous difficulty in building capacity. This impacted on the project in several ways, including the high turnover of personnel on the advisory committee, changes in Silver Chain management and difficulty in retaining volunteers.</p> <p>Numerous attempts to employ an Aboriginal and Torres Strait Islander liaison officer for the project were unsuccessful, resulting in the establishment of an arrangement with the local Emotional and Social Wellbeing Centre (ESWC) whereby the manager of that service provided Aboriginal and Torres Strait Islander liaison support when required and acted as a mentor to the project coordinator in understanding Aboriginal and Torres Strait Islander issues. This arrangement worked well and was subsequently extended to all GPs in the region with the establishment of a memorandum of understanding between the ESWC and the division of general practice.</p> <p>The original education plan for the project focused on sending health care providers to Perth for training. However, it proved to be more beneficial and practical to purchase and deliver specialist education programs in Kalgoorlie. Education programs spread over a number of weeks proved more acceptable than (say) one three-day block.</p>
Project Generalisability <i>Are the lessons useful for someone else?</i>	<p>Many of the features of this project are similar to the work done in Griffith, NSW, and other rural towns e.g. Albany, WA. The results indicate that a model of palliative care based on a multidisciplinary team that meets on a regular basis, with good support from GPs and other health care providers, is suitable for communities of a comparable size. The work done in engaging the local Aboriginal and Torres Strait Islander community, particularly the use of a formal arrangement with an Aboriginal and Torres Strait Islander organisation to provide support and liaison, provides useful lessons for communities with a sizeable Aboriginal and Torres Strait Islander population.</p>
Project Dissemination <i>Who was told about the project?</i>	<p>The project coordinator in consultation with the advisory committee used the marketing and public relations resources of Silver Chain to assist in the preparation and placement of stories in the local print media and radio. A permanent advertisement appeared in the Kalgoorlie Miner. A graphic designer was used to create a logo, pamphlets and business cards for the palliative care service. Dissemination activities included articles in the division of GPs newsletter, WA Palliative Care newsletter and information booths at health related events. Presentations at community groups proved to be more useful than organising community forums specifically to raise awareness of palliative care. The project was presented at the WA State Palliative Care Conference in September 2004.</p>

Project Name	(WA-4) Learn Now, Live Well
Organisation	Hollywood Private Hospital, Perth
Funding	\$162,870 between April 2003 and March 2006
Project aims <i>What did the project set out to do?</i>	The aim was to provide education and support to caregivers of patients with a life threatening illness so that they can more confidently provide care in the community. The program was specifically designed to better prepare caregivers prior to discharge but also included a community component. The project aimed to reduce unplanned readmissions for individuals requiring palliative care, increase the duration of their time spent at home, provide caregivers with practical skills in caring for someone at home and develop collaborative relationships between health providers within and external to Hollywood Private Hospital.
Project Delivery <i>What did the project do?</i>	<p>A structured education program was developed with six modules – pain, the physical side of caring, communication, knowing your medicines, nutrition and exercise, and symptom control. The modules were pilot tested and the results used to refine the modules, in consultation with a Project Reference Group and with input from five consumers. Development of the program was informed by a literature review and resulted in a program that was about providing support for carers as much as it was about education.</p> <p>The modules were delivered over a two week period at Hollywood Hospital and also combined into three larger sessions for provision in the community. The community-based component initially involved one provider (Silver Chain Hospice Care Service) but was extended to include four other organisations that requested the program be offered to their clients.</p> <p>The program was promoted with a combination of advertising, information sessions for staff, a radio interview, activities during Palliative Care Week and Carers' Week and presentations at conferences.</p> <p>The program was strongly supported by Hollywood Private Hospital, including the provision of office space, computers, meeting rooms and assistance of staff with advertising and financial management. The program was greatly assisted by having a stable and supportive project team over the course of the project.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>The program was evaluated by a university-based research team, a strategy that proved to be very successful. Participants in the evaluation had to be 18 years of age or older and be able to speak and read English. Questionnaires were developed based on the content of each module and tested in the pilot phase. To assess effectiveness data were collected at three points in time – immediately prior to each education session, immediately after each session and four weeks after an education session.</p> <p>In addition, semi-structured interviews were conducted with five carers who had attended one or more modules. Interviews were conducted with key informants from other organisations to capture data on project implementation. Seven staff and the project coordinator were also interviewed.</p> <p>Initial recruitment to the program was low but various strategies were identified to overcome this and by project end 205 carers had participated.</p> <p>Carers provided positive feedback and indicated that, after attending the</p>

Project Name	(WA-4) Learn Now, Live Well
	<p>program, they were more confident about taking their patient home to die. Carer knowledge scores for each module indicated that participants increased their knowledge following the education session, compared to their prior knowledge. Knowledge scores four weeks after the education sessions declined, but remained higher than scores prior to education. Responses to the community-based program were similar to those for the program offered in Hollywood Private Hospital.</p> <p>The organisations that adopted the program felt that the program was positively received and was a success in their organisation. Responses from staff were consistent with the feedback from carers.</p> <p>Changes in unplanned readmissions and time spent at home were not included in the evaluation.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>The project coordinator set up an educators support group that continues to maintain regular contact. Additional funding has been obtained to develop a 'train the trainer' package to facilitate dissemination of the program. Sustainability of the program is dependent on the availability of ongoing funding for the program facilitator and respite care to allow carers to attend the program.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>Involvement of an external university-based evaluator assisted project staff to develop their own research skills.</p> <p>Various resources were developed during the course of the project, including a package of PowerPoint slides for each module, a manual and questionnaires to evaluate each module.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The project developed an educational package that can be delivered as a stand alone program. The package is suitable for small organisations without the resources to develop their own education materials. The role of the facilitator delivering the education was seen as critical to the success of the Learn Now, Live Well program. Care should be taken when replicating the program elsewhere to ensure that the program is delivered by a facilitator with appropriate skills.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>Dissemination has included presentations at state and national conferences and publications in nursing journals. The results of the evaluation will be submitted to a peer reviewed journal for publication.</p>

Project Name	(WA-5) South West Perth Collaborative Community Care Project
Organisation	Murdoch Community Hospice (in collaboration with Silver Chain Hospice Care Service)
Funding	\$130,000 between July 2003 and June 2005
Project aims <i>What did the project set out to do?</i>	Improve the continuity of care for patients and families; increase awareness of and educate the family GP in contemporary practice; improve the quality of care provided to patients/families at home and in the hospice; avoid potential inappropriate admissions to the hospice; play a role in education for the community-based palliative care service.
Project Delivery <i>What did the project do?</i>	<p>The focus was the use of various strategies to improve links between the inpatient hospice service and the community-based palliative care service, run by separate organisations. This included introduction of Admission Assessment Tool to identify those considered most appropriate for hospice admission, sharing of home-based clinical notes with hospice staff and opportunities for GPs to undertake a clinical attachment at the hospice.</p> <p>Clinical meetings between staff in the hospice and community-based teams and data from the Admission Assessment Tool identified a need for social worker involvement with community clients. This supported a previous finding by Silver Chain that a social worker was needed to augment the work of their domiciliary nursing team. The part-time hospice social worker was employed part-time to work with the community team.</p>
Project Impact & Outcomes <i>How was the project evaluated?</i> <i>What results were achieved?</i>	<p>Evaluation consisted of a review of the Admission Assessment Tool, a patient/carer satisfaction survey, staff satisfaction survey, a review of the sharing of home files and a review of discharges from the hospice. A Social Worker Pilot Project (to augment the community palliative care service with the introduction of a social worker position) commenced during the CCP project (due in part to the lessons learnt from the CCP project) and this was evaluated using anecdotal comments from nursing staff and the social worker.</p> <p>Due to illness of a key stakeholder and the early resignation of the project coordinator some aspects of the project were not achieved. These included: home visits by hospice medical staff, development of comprehensive palliative care management plans and protocols for hospice staff to visit patients at home post-discharge.</p> <p>The methodology used for the evaluation did not lend itself to identifying whether inappropriate admissions to the hospice had been avoided. However, the Admission Assessment Tool did contribute to improved admission processes and facilitated staff from the two organisations 'talking the same language'. Attendance by staff from the hospice and community palliative care teams at each other's regular clinical meetings (commenced in part prior to the project starting) became a regular occurrence. Clinical attachments (for a minimum of 48 hours of direct contact hours) were taken up by only four GPs but each provided positive feedback on the experience.</p> <p>The review of hospice discharges resulted in the distribution of a document to hospice staff highlighting the educational needs of patients and carers to be considered when planning and implementing a discharge.</p> <p>Feedback from nursing staff regarding the Social Worker Pilot Project was positive and resulted in Silver Chain employing a social worker for each of their community-based palliative care teams in Perth. Feedback from</p>

Project Name	(WA-5) South West Perth Collaborative Community Care Project
	<p>hospice nursing staff about having a patient's home file available on admission to the hospice was positive. Feedback from community-based nursing staff was less positive.</p> <p>The staff satisfaction survey (based on two group discussions with the hospice and community-based teams) identified that there was a good relationship between clinical staff of the organisations, although it was not clear to what extent this was due to the project. Negotiating an admission to the hospice was easier because of the Admission Assessment Tool. Satisfaction surveys were completed by 15 patients and 12 carers. The surveys focused on the relationship between the hospice and community-based teams, and on admission and discharge processes. Feedback was generally very positive.</p>
<p>Project Sustainability</p> <p><i>What aspects of the project will continue?</i></p>	<p>Certain features of the project such as joint clinical team meetings and use of the Admission Assessment Tool have become part of day-to-day practice. Inclusion of a social worker in the community-based palliative care team, although strictly speaking not part of the project, has also been established. Sharing of home files with hospice staff is seen as a welcome change and it is anticipated that the practice will continue, with ongoing refinement of the policy and process. There is the potential for those parts of the project that were not achieved to be undertaken in the future. Continuation of clinical attachments by GPs will be dependent on the availability of funding. Both organisations will give consideration to using the client satisfaction survey as an ongoing quality assurance tool.</p>
<p>Project Capacity Building</p> <p><i>What has been learnt?</i></p>	<p>The project was critically dependent on the leadership of the Medical Director of the Hospice, particularly for features of the project that relied on medical input, and the incumbent's absence for much of the project due to unforeseen circumstances impacted the project adversely. The hospice had little capacity to provide any other medical input to the project.</p> <p>The Admission Assessment Tool was considered to be a useful tool and the intention is that its use will continue, with further refinement to eliminate some redundancy. A Medical Learning Guide was developed primarily for the use of GPs undertaking clinical attachments at the hospice but the Guide is also suitable for doctors with other backgrounds.</p>
<p>Project Generalisability</p> <p><i>Are the lessons useful for someone else?</i></p>	<p>The results of the project provide support for using some quite specific strategies to improve the links between hospice-based and community-based clinical teams e.g. joint clinical meetings between the two teams, sharing of home files and use of tools to develop a 'common language'.</p>
<p>Project Dissemination</p> <p><i>Who was told about the project?</i></p>	<p>Dissemination was limited to raising awareness about the project within the two organisations involved and the recruitment of GPs to participate in clinical attachments at the hospice.</p>

3 The CCP projects indexed by theme

Table 1 below provides an index of the CCP projects. Table 2 is a matrix identifying themes addressed by each project indicated. These themes are based on the target groups and objectives of the CCP and are not mutually exclusive, so any one project may appear under several headings (e.g., rural and remote, indigenous Australians and older Australians).

Table 1 *Numbered list of Caring Communities Program projects*

No	Title
ACT-1	Education Link – PC
ACT-2	Enhancing Community Understanding of Palliative Care
ACT-3	Shared Understandings Improving Palliative Care for People with Dementia
NSW-1	Developing linkages between an Indigenous population and a palliative care service
NSW-2	Helping Communities Care: Volunteer and bereavement support networks
NSW-3	Kids Grief: a handbook for group leaders
NSW-4	QTY bereavement project
NSW-5	Motor Neurone Disease Volunteer Visitor Pilot Program
NSW-6	Palliative care dementia interface: enhancing community capacity
NSW-7	Palliative care education utilising interactive satellite television technology
NSW-8	Study to predict home death
NSW-9	Supporting and educating carers in palliative care
NT-1	Greater Darwin Palliative Care Volunteer Support Project
NT-2	Groote Palliative Care Support Service
NT-3	Northern Care Frontier Services
NT-4	Visiting Specialist Program, Central Australia
QLD-1	An educational strategy to increase the palliative care capacity of primary health care providers working in rural and remote areas of Queensland
QLD-2	Bundaberg Palliative Access Link (PAL) Project
QLD-3	Community Bereavement Support Service Children, Adolescents and the Families
QLD-4	SEAM: A support, education, assessment and monitoring service for regional and rural people
QLD-5	Volunteer Palliative Care Support Network Initiative
SA-1	Establishing the care-worker role in palliative care-education, support and integration with palliative care teams
SA-2	Kangaroo Island palliative care project
SA-3	Partnering with rural communities to improve access and education in palliative care
SA-4	Shared bereavement care in the west
TAS-1	Collaborative Palliative Care in Rural Communities
TAS-2	Empowering the Southern Midlands community through information and integration
VIC-1	Best Practice Support Model for Terminal Illness in the Workplace
VIC-2	Building rural community capacity through volunteering
VIC-3	Experiential Palliative Care Program for General Practitioners
VIC-4	Improving consumer and health professional access to comprehensive, accessible, user-

No	Title
	friendly evidence-based online information
VIC-5	Living and Dying in Style
WA-1	Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities
WA-2	Fitzroy Valley Palliative Care Service
WA-3	Kalgoorlie-Boulder Palliative Care Coordination Project
WA-4	Learn Now, Live Well: An Educational Program For Patients And Care-Givers Living With And Affected By Life Threatening Illness
WA-5	South West Perth Collaborative Community Palliative Care Project

Table 2 CCP projects indexed by theme

	Target Groups										Strategies						Location				
	Aboriginal people	Aged/Community Care workers	Bereaved people	Carers	Children / adolescents	Community	CALD communities	Health professionals	Older people	Palliative care patients	Volunteers	Awareness raising	Coordination of care	Direct service delivery	Education	Information	Research	Aged care facilities	Rural and remote	Schools	Workplaces
ACT-1							x							x							
ACT-2						x					x					x					
ACT-3								x							x						
NSW-1	x					x		x							x	x			x		
NSW-2			x	x		x				x	x	x	x	x					x		
NSW-3			x		x	x		x					x	x	x					x	
NSW-4			x	x		x		x		x				x	x						
NSW-5			x	x						x	x	x	x	x							
NSW-6		x		x				x	x	x			x		x			x			
NSW-7															x			x			
NSW-8			x	x													x				
NSW-9		x	x	x				x					x		x	x					
NT-1				x		x									x						
NT-2	x					x										x				x	
NT-3	x					x			x									x	x		
NT-4								x						x						x	
QLD-1								x							x			x			
QLD-2			x			x						x									
QLD-3			x		x	x		x					x	x						x	
QLD-4								x					x							x	
QLD-5										x				x							
SA-1		x													x			x			
SA-2				x							x				x					x	
SA-3				x							x				x					x	
SA-4	x						x	x				x		x	x	x					
TAS-1								x		x										x	
TAS-2							x														

	Target Groups											Strategies					Location				
	Aboriginal people	Aged/Community Care workers	Bereaved people	Carers	Children / adolescents	Community	CALD communities	Health professionals	Older people	Palliative care patients	Volunteers	Awareness raising	Coordination of care	Direct service delivery	Education	Information	Research	Aged care facilities	Rural and remote	Schools	Workplaces
VIC-1			x	x		x				x		x				x	x				x
VIC-2						x				x	x		x						x		
VIC-3								x						x					x		
VIC-4				x		x		x								x					
VIC-5		x						x					x	x						x	
WA-1	x								x			x								x	
WA-2	x						x	x			x	x								x	
WA-3		x		x				x				x								x	
WA-4				x					x												
WA-5		x		x				x	x			x									