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Lessons from the National Evaluation of the Rural Palliative Care Program: a synthesis of the findings and recommended next steps

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This report is part of a series of final evaluation reports on the Australian Rural Palliative Care Program (RPCP). The reports in this series are:

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

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Summary

This paper brings together the consolidated evaluation findings and the results from eight local projects in the Rural Palliative Care Program (RPCP) that were funded under the National Palliative Care Program (NPCP) through the Australian Divisions of General Practice.

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

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

- Adelaide Hills South Australia
- Eastern Goldfields (Kalgoorlie) Western Australia
- Eurobodalla (Moruya) NSW
- Mid North Coast (Coffs Harbour) NSW

- North West Tasmania (Burnie)
- Pilbara Western Australia
- South East Queensland (Kingaroy)
- West Victoria (Ararat)

The projects began in late 2003 and ran for three years. Each project started at different points and the result was eight localised versions of a rural model of palliative care aimed at extending the range and reach of services, and improving linkage, coordination and integration between disparate parts of the local system, and improving the sharing of clinical information. A national evaluation framework was used to evaluate the local projects, recognising they were taking place within a context of many closely related national and state/territory initiatives.

For palliative care patients and their carers, the projects resulted in a greater range of service options. Service providers reported that the projects were effective in increasing continuity of care due to services working together better as a team, improved communication and better information sharing. Carers' experiences show agreement that palliative care services met their needs and that appropriate support, information and advice was provided.

For providers, the projects improved working relationships and, where difficulties arose, they were attributable to structural and system integration problems related to jurisdiction and program boundaries and the resulting burdens of reporting and the complexities of information management. The rigidities and limited 'interoperability' of the systems to support the RPCP 'model' are examples of problems that are not unique to palliative care, but common to all types of programs in primary care.

The solutions that the projects managed to create were good examples of local planning, and showed ways that system 'reforms' can make progress, albeit slowly and in difficult circumstances. The time and investments required for planning have to be commensurate with the complexities of what is being managed. A long development pathway should include time for careful planning, resources, training and for testing useful tools for sharing information.

The projects themselves were judged to have made valuable contributions to local systems. There were learning opportunities and training resources created for providers. Most projects increased the range and reach of services and created more shared care opportunities.

For the wider system, the projects achieved some limited measures of structural and cultural change and some movement towards more integrated models of care for those with a life limiting

illness. This paper puts the evaluation findings in a context of the National Palliative Care Program and beyond, draws out the lessons for local and central planning and discusses how the lessons can be generalised to other primary health care settings. It finishes with a set of recommended further development steps.

Introduction

This report is a synthesis and set of lessons from the final evaluation of the Rural Palliative Care Program, one of a set of related initiatives under the National Palliative Care Program.

There are 10 reports in this evaluation series, including this executive summary:

Report Number 1	Providing Palliative Care in Rural Australia: results of a national program evaluation (a consolidated report at the project and program level)
Report Number 2	Lessons from the National Evaluation of the Rural Palliative Care Program: a synthesis of the findings and recommended next steps (a synthesis of the findings and lessons at the program and policy level)
Report Number 3	Rural Palliative Care Program: Adelaide Hills Evaluation Report
Report Number 4	Rural Palliative Care Program: Eastern Goldfields Evaluation Report
Report Number 5	Rural Palliative Care Program: Eurobodalla Evaluation Report
Report Number 6	Rural Palliative Care Program: Mid North Coast Evaluation Report
Report Number 7	Rural Palliative Care Program: North West Tasmania Evaluation Report
Report Number 8	Rural Palliative Care Program: Pilbara Evaluation Report
Report Number 9	Rural Palliative Care Program: South East Queensland Evaluation Report
Report Number 10	Rural Palliative Care Program: West Victoria Evaluation Report.

The Evaluation of the Rural Palliative Care Program

The Rural Palliative Care Program (RPCP) aimed to test a model of care developed to specifically serve a rural population[1] and was evaluated over a period of three years. The evaluation included a consolidated report as well as eight individual project level evaluations[2]. This report emphasises the lessons of the overall evaluation of the Program that was funded under the National Palliative Care Program (NPCP) through the Australian Divisions of General Practice (ADGP), now called the Australian General Practice Network (AGPN). It draws together the lessons from the local evaluations and the consolidated report, discusses the common themes and the implications for the wider system of community support; of which palliative care activity is one component.

The policy and program context

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

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[1]   Cromwell D, Senior K, Owen A, Gordon R, and Eagar K (2003) *Can the National Palliative Care Strategy be translated into a model of care that works for rural Australia? An answer from the Griffith Area Palliative Care Service (GAPS) experience.* Centre for Health Service Development, University of Wollongong
Eagar K, Owen A, Masso M and Quinsey K (2006) *The Griffith Area Palliative Care Service (GAPS): an evaluation of an Australian rural palliative care model.* Progress in Palliative Care Volume 14, Number 3, June 2006, pp. 112-119(8)
Masso M, Fildes D, Quinsey K and Matete S (2006) *GAPS revisited: evaluation of the Griffith Area Palliative Care Service 2006.* Centre for Health Service Development, University of Wollongong.
[2]   Quinsey K, Masso M, Fildes D et al (2007) *Providing Palliative Care in Rural Australia: results of a national program evaluation.* Centre for Health Service Development, University of Wollongong

Major policy reforms in Australia's health, ageing and community care sectors have occurred under the NPCP in the last five years. The Program has been built into the Australian Health Care Agreements (AHCA) 2003/04-2007/08 and through Federal budget initiatives since 2002/03, with a proportion of the resources set aside in a combined pool of $68.2m for national initiatives.

National investment under the NPCP has been focused on community awareness and carer support, education and training in primary care, improving the research capacity and information management and increasing the range and reach of palliative care services.

The eight RPCP projects operated over three years in a context of related development work in support of palliative care reform. These reforms were described through a series of aims in related National Palliative Care Program areas:

- increasing the range and reach of services (Griffith Area Palliative Care Service, Rural Palliative Care Program, case management, Indigenous needs)

- community medications (PC Medications Working Group and PBS listing of new drugs)

- assisting families and supporting the primary care workforce (the Caring Communities program, resources for respite and equipment, and community information, surveys, building national structures)

- education and training (Program of Experience in the Palliative Care Approach, a medicines handbook, palliative residential aged care, and other education and training)

- research capacity building (NHMRC and the Palliative Care Knowledge Network)

- improving performance information (performance indicators and the development of a minimum data set [MDS]).

As part of the Strengthening Cancer Care Initiative, the Australian Government announced in the 2005 Budget funding of $23.1 million over four years (2005-06 to 2008-09). This funding is being used for a Local Palliative Care Grants Program (LPCGP) that has four sub-programs, with the third round being care planning for patients who are living at home, including support for health professional to enable patients to stay at home.

With much similar local activity being supported through different but related sources of funding, there is potentially some scope for redundancy, as well as inconsistency in the methods for undertaking and understanding common activities. With a view to reducing the scope for inconsistency and redundancy, the evaluations of individual projects under the Care Planning Sub-Program, the Caring Communities Program and the Rural Palliative Care Program have all been based on a common model of evaluation that is described in a supporting publication for the national palliative care strategy[3].

A process of standardisation of the way that information is managed in an evaluation such as that carried out for the RPCP can help to build a coherent development pathway in the way that clinical information is collected and managed. There are already many clinical information systems operating, but not always successfully 'inter-operating' with each other, even within a relatively coherent sector of health activity like palliative care.

At another level there is a considerable body of work being undertaken with the aim of improving the consistency of routine reporting of clinical level data that includes the development of a program-level Minimum Data Set (MDS) and a set of performance indicators. The ways that aggregated information can be used for planning and for comparing clinical outcomes and 'benchmarking' performance in palliative care in particular, are important as part of the longer term

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[3] Eagar K, Cranny C and Fildes D (2004) *Evaluation and palliative care: a guide to the evaluation of palliative care services and programs*, Centre for Health Service Development, University of Wollongong. ISBN 0 642 82472 X
http://www.health.gov.au/palliativecare

work program proposed at the end of this paper, and for the Palliative Care Outcomes Collaboration (PCOC)[4].

In Australia, rural palliative care involves a range of specialist and primary care providers. These include public sector health services, funded by state/territory health departments, and private providers and specialists and general practitioners (GPs), funded federally. This now includes items for reimbursing GP time in care planning and patient assessment, and referral for allied health services, some of which are also now covered by Private Health Insurance.

In addition, there are non-government organisations (NGOs) which may be funded from either source, depending on their service types. As with other areas of health, the differing sources of funding create duplication and gaps, opportunities for cost-shifting, and tensions between public and private sector services and providers and the residual problems of significant program-level accountability and reporting burdens.

Palliative care has an important place as one way to focus the coordination of service provision within primary and community care, by working collectively on models of care for those who are sick enough to die[5]. The search for a common language and improved integration is also under way in the parallel reform agenda in community care, under the auspice of the Australian Government's 2004 review '*A New Strategy for Community Care – The Way Forward*'[6], which has developed ways to capture intake and assessment data in a nationally consistent way.

Who was involved?

The Rural Palliative Care Program (RPCP) had its origins in the 2002 National Palliative Care Strategy and is part of the goal to increase the range and reach of palliative care services.

There is little evidence to guide the provision of palliative care in rural areas and the research that has been done has tended to focus on identifying problems rather than providing evidence to support effective interventions. The RPCP was built around a core model that included many of these elements (shown in Table 1), based on work in Griffith, NSW, for what came to be known as the GAPS model (Griffith Area Palliative Care Service)[7].

It was anticipated that most RPCP projects would implement most elements.

Table 1   Core elements of the rural palliative care model

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

4 PCOC is a voluntary quality initiative to assist palliative care service providers to improve practice and meet the "Standards for Providing Quality Palliative Care for all Australians". See the website http://chsd.uow.edu.au/pcoc/ for more detail.
5 Dy, S and Lynn, J. (2007) *Getting services right for those sick enough to die*. British Medical Journal, 334; 511-513.
6 www.health.gov.au/communitycare thewayforward
7 Hatton I, McDonald K, Nancarrow L and Fletcher K. (2003) *The Griffith Area Palliative Care Service: a pilot project.* Australian Health Review 2003; 26(2): 11-8.

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

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

What did they do?

The projects committed significant resources to education and there was a heavy reliance on education as a mechanism for change. On the continuum from linkage through coordination to integration[8], there was a lot of local linkage. It is clear from the evaluation findings that coordination needed someone specifically designated to do the coordinating, most usually in these projects, but not necessarily, a nurse.

Formal arrangements (e.g. protocols) are a good start but are difficult to sustain, even with the funding from a project, and the same goes for the dissemination of information. It is difficult to sustain such activities without dedicated resources.

What all the eight projects managed to achieve, with varying degrees of success depending on the local circumstances, were to:

- Establish formal governance structures

- Carry out education programs

- Implement multidisciplinary care planning meetings including case conferencing and teleconferencing

- Disseminate information

- Develop formal arrangements and protocols

- Use common clinical assessment tools

In the rural palliative care setting, regular meetings of clinicians (including GPs) can be established and maintained. But the evaluation found that in rural settings a focus on communication (linkage) may be sufficient, rather than formalising decision making, care planning and review, which are indicators of a more fully integrated approach. Overcoming many (but not all) of the difficulties of

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[8] Leutz, W. (2005) *Reflections on Integrating Medical and Social Care: Five Laws Revisited*. Journal of Integrated Care, 13, 5: 3-12. October 2005.

integration may not be necessary and in particular in rural settings is likely to be beyond the scope of one program and a single coordinator role.

The overall program findings are discussed below under four themes that attempt to capture the key points from the varied experiences at the local level:

- governance
- direct care
- shared clinical information systems
- professional development and education.

Governance

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

The purpose of the governance arrangements was not only to provide an accountability framework, but also to encourage linkages and partnerships within the local project area. There was relatively little work done to develop *formal* partnerships between providers. This may have been due in part to the governing bodies providing sufficient structure and a forum for collaboration and networking. Arrangements such as memoranda of understanding and shared protocols have a part to play, but they still require individuals who are willing and prepared to put them into practice. Social relationships, networks and local champions are the more essential ingredients for sustainability and the experience of the governing bodies supported this view.[9]

Key differences in the arrangements in local settings were determined by whether they had a specialist palliative care service or not. Against this backdrop, project coordinators worked in Divisions that are funded for a series of initiatives that did not necessarily link together with local needs as understood by the public health system.

If the local perception was that the project had not come about in a planned and 'localised' way or 'from the ground up', then that could slow down the negotiations with local service providers. The original rural model in Griffith was successful to the extent it built on local community health planning in palliative care and started with an independent review and needs analysis[10].

In practice, the funding of the projects through the local Divisions of General Practice, rather than through the public health sector or community health centres, meant that the coordination and integration work in most cases was left to a busy project officer with the task of persuading busy generalist nurses that extra work for the project under the direction of the GP Division would improve the system.

In some cases there was a concern that funding had been provided to Divisions rather than local health services. Community nurses and GPs, the two key palliative care service providers in rural settings, demonstrated particular reluctance to become involved at some sites. That said, project coordinators were unanimous in their view that management via divisions gave them a level of flexibility that would not have been possible through the various state health systems.

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

[10] Hatton I, McDonald K, Nancarrow L, Fletcher K. *(*2003) op. cit..

A quote from a recent systematic review of comprehensive primary care models is consistent with the results from the RPCP evaluation:

> *"There are limitations on the extent to which Divisions can further influence service delivery at a practice or local level, without significant change that involves the rest of the health system. In the absence of commissioning or significant enhancement of their contracting role, their success and effectiveness relies largely on their engagement with and responsiveness to their members.*
>
> *The same applies to Primary Care Partnerships and Primary Health Care Networks, but even more so. Without funding levers, the most that can be expected of these structures is that they improve service coordination, especially across the range of state-funded services. With these limitations, there is a very real question about the extent to which they can engage general practice and extend service coordination across the primary care sector as a whole."* [11]

At the program rather than the project level, a key finding is that program governance arrangements need to be structurally aligned so that the program manages both individual projects and the program as a whole. With hindsight, opportunities were missed because there was no formal structure to resolve the bigger system-level problems, such as the fit with State palliative care plans and the problem of multiple reporting requirements, and to ensure that lessons learned by one project were automatically made available to other projects. This reduced the effectiveness of the program overall.

As one example of duplication, three projects implemented 'End of Life' clinical pathways simultaneously but unbeknown to each other. Coordination of this strategy might have saved local effort and enabled a more powerful joint evaluation of the impact of the three projects combined, rather than simply noting the presence of that program element within the three individual projects.

The involvement of the States in supporting the aims of the projects was mostly seen as minimal and this was not surprising as the national initiative, funded through the GP Divisions, did not easily fit with State-level priorities. This had implications for the double-reporting burdens in community health, as well as the clinical workload, and influenced what would be left behind to be picked up by subsequent rounds of State-level planning when the project ended.

Direct care

There were significant variations between projects regarding what they set out to achieve at project commencement, with some focusing on direct care more than others.

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

- the 'traditional' model (diagnosis and management by individual practitioners and referral to other practitioners where necessary);
- coordination of care by a Clinical Nurse Consultant;
- coordination of care by a formally established team; and
- visiting consultation by 'fly-in, fly-out' specialists who may or may not work with some form of local team [12].

Each project started with a different level of resources devoted to palliative care, including some elements of the rural palliative model already in place, with considerable differences in the existing

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[11] McDonald J. et al. (2006) *Systematic review of comprehensive primary health care models*. Australian Primary Health Care Research Institute, p 57.

[12] Woods D. *Models of care for rural palliative care services*. In: Proceedings of the 6th National Rural Health Conference; 2001 March; Canberra, Australia

local model within which each project sought to establish itself. Even in those localities where there were no formally established structures, processes and systems dedicated to palliative care, a service was already being provided based on the 'traditional' model of care.

So, in a context of very different organisational starting points, the program was more about moving existing service delivery towards a team-based model rather than establishing a new service model at a truly 'green field' site. As a result of the local context (usually understood as a set of service gaps), projects implemented different combinations of the RPCP model elements in different ways.

The results of the activities overall were judged to be positive. Very few patients responded that they had wasted time on health care or that their financial and personal affairs had not been addressed. In general, patients indicated a high degree of involvement in decisions about their treatment. Approximately two thirds of patients indicated that they had experienced a degree of depression in the preceding three days, indicating an area that may need further work in the future.

Carers' experiences show agreement that palliative care services are meeting their needs and that appropriate support, information and advice are being provided. However, almost half of all carers who needed it said that they did not get sufficient practical training in lifting, managing medicine or other tasks.

By all accounts, the patients and carers got quality care as a result of the projects, and this was also measurable at the organisational level in the way that the palliative standards were met. The results from the self-assessments undertaken at the beginning and end of the RPCP indicate that there was an improvement in compliance for all but two categories of standards. In those two areas (staff support standards and community network and partnerships) the standard was already being met and there was no room for improvement. By the end of the RPCP more service standards were present and to a greater degree, with a smaller number of standards rated as a high priority for attention.

The consistency of these results across the categories of standards is a positive finding, irrespective of the cause. The national palliative care standards[13] have been published since the RPCP commenced (and hence post-date the development of the projects' self-assessment tool). There is an obvious link to be made in adapting the evaluation tool to better comply with the national standards and for it to be used on an ongoing basis.

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

Shared clinical information system

Common indicators of clinical status were a key component for the focus on better patient management and all the projects found that managing patient level data with electronic information systems is difficult. There were also significant 'system-level' difficulties that contributed to the delays in setting up useful local information systems for the projects. The difficulties that arose were due to electronic systems not working well enough, a lack of agreed data standards and inconsistencies in reporting requirements, and the resulting increased burdens of data collection. None of these factors could be easily overcome at the project level.

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[13] See copies of the standards at http://www.pallcare.org.au/Portals/9/docs/publications/Standards.pdf

The genesis of the RPCP was in the work undertaken in Griffith, New South Wales, to develop a model of palliative care for a small rural community. One of the features of that work was the use of various clinical assessment tools as the basis for a common language amongst clinicians. The assumption in the RPCP remained the same - that data could be improved and used for multiple purposes and thereby it should be possible to cut down on the data collection burdens at the clinical level. Unlike in the project phase of GAPS, it did not happen that way.

The data collection tools were to be incorporated in the RPCP not as an evaluation 'add on', but as a core element of a rural palliative care model. The intention was that they would be implemented in the same way as other elements of the rural model. It was expected that, based on the results from Griffith, clinicians would come to see the tools as useful in their everyday practice. But in practice, none of the projects came near to achieving this aim of more efficient use of clinical information, with all projects ultimately collecting the clinical assessment data because they had to (for the program evaluation) rather than as an integral component of service delivery.

The use of software to collect and organise clinical information was difficult, both in the level of support required to use the system itself and in integrating its use with existing information systems, which depended on cooperation with local (and in some cases, area and state-level) service and program managers.

Within the RPCP Evaluation Toolkit[14], Tool 1.1 (Patient stage of illness data set) was by far the most resource intensive tool for sites to implement. It was not implemented for the purposes of the evaluation but as a clinical tool and as a core element of the rural palliative care model. In theory it should have been able to 'interoperate' with existing clinical information and reporting requirements, but in practice it was an 'add-on' requirement to a busy clinical workload.

On the basis of those experiences, it would be easy to conclude that the data collection requirements were too onerous and should be reduced in future programs. However, the purpose of the RPCP was not simply to improve palliative care provision in eight sites, but to test whether elements of the original GAPS model could be successfully implemented in other rural and remote communities. Evaluating those elements in a range of settings required a common approach to the collection of patient level data and the projects provided useful lessons on how difficult this is in practice.

A follow-up evaluation of the Griffith Area Palliative Care Service in 2006 found that use of the clinical assessment tools as a 'common language' was no longer in evidence.[15] This is an important finding for the future of palliative care provision in rural areas, with implications for the longer term development work being undertaken by the Palliative Care Outcomes Collaboration.

There is key point to be made here about the resources necessary to support change with adequate training. The projects did not get the expected value out of the clinical assessment tool because they did not understand its use and usefulness. If the project coordinators and the evaluators had understood this earlier and implemented better education and training strategies about the tools, then the 'common language' might have worked. And it might have got beyond a common language to also be used as a common way to assess people for care needs at the end of life.

Professional development and education

Within the theme of professional development and education, it is possible to describe the Rural Palliative Care Program as a successful exercise in continuous quality improvement in the

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[14] Eagar K, Senior K, Fildes D, Quinsey K, Owen A, Yeatman H, Gordon R and Posner N (2003) *The Rural Palliative Care Evaluation Tool Kit: A compendium of tools to aid in the evaluation of palliative care projects*. Centre for Health Service Development, University of Wollongong.
http://chsd.uow.edu.au/Publications/2003_pubs/RPC_ToolKit_FINAL.pdf

[15] Masso M, Fildes D, Quinsey K and Matete S (2006) *GAPS revisited: evaluation of the Griffith Area Palliative Care Service 2006*. Centre for Health Service Development, University of Wollongong.

palliative care sector. The use of the national (Palliative Care Australia) standards and the movement towards a common language for sharing clinical information were two strategies that the projects were able to use to improve the quality of care.

'Multidisciplinary care' for rural palliative care is essentially about doctors and nurses, and the involvement of allied health staff was problematic or, in some cases, virtually non-existent. Based on the service utilisation data collected, allied health care is only a small component of service delivery. Community nurses do the majority of the rural palliative care work and the benefits they see in the projects are for their community networking. The projects' increased focus on palliative care led to more effective relationships with other generalist services and aged care services. The cost was seen as an increasing demand on the time of already busy community nurses.

Responses to the educational needs surveys indicated a high level of 'on the job' training but also a high percentage of providers with some form of short course or formal training in palliative care. This is particularly encouraging given the 'tyranny of distance' faced by rural providers when it comes to education. The percentage of providers with no training at all declined between the first and second surveys and the work by projects to promote educational opportunities no doubt played a part in this. Professional development and education was a strong focus for all projects. The subject matter was diverse and education programs well received. The numbers participating were impressive.

Conclusions – what did we learn from the program?

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

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

The program encouraged the projects to concentrate on sustainability from project start to end. This was demonstrated in the way program elements were introduced and implemented. However, most projects expressed concerns about the ability to continue certain elements or strategies without a dedicated resource person to undertake the coordination and development role.

There is no doubt that the program enabled eight rural and remote communities to build capacity around palliative care. If the lessons learned during the program are disseminated in the sector, the program will also build capacity across the primary care and palliative care sectors more broadly.

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

The key lessons learned from the eight projects and the program overall are highlighted below and are generalisable more broadly. The overall assessment is that selected project and program elements are able to be generalised to other rural settings, but not the model or program as a whole.

Key message 1: Improving coordination in rural palliative care is hard but possible with better local planning

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

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

Key message 2: Full integration is not always desirable and can only occur in the context of much larger structural and cultural change

Structural and cultural change is necessary, though not sufficient, for improved linkage and coordination, and system-level integration is beyond the scope of any one program. Even without such larger scale change, impressive improvements in collaboration across sectors can occur with careful local planning.

Most of the projects had some focus on improving coordination with the specialist palliative care sector (i.e., between fly in fly out and networks with specialist health services, community health and private providers) and included other care providers such as GP-based practice nurses, aged care and hospice care. The projects improved public/private sector coordination and the specialist/primary sector linkages. Ongoing efforts in these directions are needed.

Key message 3: Practical local change requires investments commensurate with the level of integration that is possible and desirable

By taking into account their different starting points, and the structural limitations, the projects did not seek to achieve full integration, but recognised that "you can't integrate a square peg and round hole."[16] Linkage and coordination, information sharing and some use of a common record as part of daily practice were the main aims that were achievable.

Change management proved to be more difficult than anticipated. Future staff working on projects should have an understanding of change management issues and understand that support for change management is required at project commencement.

Key message 4: A coordinator role is necessary but not sufficient to drive change

Agencies that agree to participate in the projects need to be clear that change management cannot be simply left to a project officer to achieve. Change management needs to be led by those who are positioned to make a difference, both during the life of the project and after it ends. By itself, the project coordinator role is not enough; project activities have to be of interest to local providers, communication has to be clear and the existing demands on providers have to be respected.

What the RPCP project coordinators did was bring together key players in each locality to improve the provision of palliative care. Despite differences in format, representation and approaches, this occurred in seven projects with regular clinical meetings (regular meetings did not occur in one

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[16] Leutz W (1999), op. cit.

project). This took the form of multidisciplinary meetings with good nursing representation and quite varied involvement of other health professionals. GP participation tended to be problematic. Some sites used teleconferencing to facilitate GP participation and this worked quite well, while requiring some resources to ensure that it occurred in an efficient way. The number of EPC items claimed is not known but from other studies focusing on the uptake of these items[17], is likely to have been limited.

Key message 5: Changes occur in a complex policy context, but in the end, all integration is local

The RPCP activities occurred in parallel with other policy developments and programs. The most significant of these developments over the course of the program was the increasing recognition of the role of primary care providers and the need for better coordination between specialist health services, residential care and the primary care sector. This recognition gained momentum over the course of the projects, and the local project coordinators aligned themselves with these policy changes, adjusting their focus to include residential care facilities, hospitals and other primary care providers such as NGOs.

The eight projects employed very different models, as a result of their being tailored to their local context as well the larger policy environment. The funding initiative actively encouraged this, recognising that the ways to improve integration differ between areas and depend on their size, level and mix of existing resources, availability of local leaders, and existing relationships. There always has to be scope for this local adaptation. More recently, Walter Leutz suggested in revisiting his 'laws of integration' that an original law should have been that "*all integration is local*".

> "*On the one hand is the notion that each integration effort has to be implemented locally in a way that is consistent with the particulars of local systems and personnel. On the other is the idea that larger policies should facilitate rather than dictate the structure and pace of local action.*" [18]

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[17] Byles, J E, Young, A F and Whewy, V L, (2007) *Annual health assessments for older Australian women: uptake and equity*. <u>Australian and New Zealand Journal of Public Health</u> 31: 170-173.
[18] Leutz, W. (2005) op. cit. P.9.