RURAL AND REMOTE
PALLIATIVE CARE
PLANNING MODEL

FINAL REPORT

A Project funded under
The Care Planning Sub-Program
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By the
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Authors: Julianne Whyte
Project Managers: Mark Stephens, Maz McCalman,
Evaluators: Julianne Whyte

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The Department of Health and Ageing, Palliative Care branch, also needs to be acknowledged for having the insight to fund this important research which will add to the body of knowledge about the way in which we care for the dying in rural communities.

It goes without saying that the people that need the greatest recognition and thanks are the many patients, families and carers that were referred to the project and became part of the research. These people gave of their time so generously and cared about making a difference for others, based on their own experiences. It was a privilege to work alongside these families as they struggled with a fragmented health care system, and their own illness and death of those they loved. It is important that the lessons learnt make a difference, and can influence policy and funding initiatives for people living in rural and remote communities.

Intereach NSW Inc
PO Box 501
Deniliquin. NSW 2510
Phone:(03) 5881 1855
Fax: (03)5881 5440
Website:
www.intereach.com.au

What they said……….

" We didn't know we had a choice. We didn't know what questions to ask. We didn't know what would come next – how many good days, how many bad ones. What to do on the bad days." Ruth

"Mum died peacefully at home, with her daughters , son and grandchildren with her. We *knew what to expect from the dying process and we were supported to care for Mum who was dying (of end stage dementia) for as long as we could."*

"Things didn't turn out as planned. She was so peaceful and her death was not unexpected. We had an emergency care plan, and had advanced care directives in place. But when she died, we rang the GP and the GP told us to ring the police and the ambulance……..When the police and ambulance arrived, Mum was taken to the hospital and announced dead. It was awful. We felt she was taken from us. We couldn't say good bye the way we had planned".

"What we loved was talking about what it would be like when Mum died. We planned memory boxes, scrap booking, even made a DVD with pictures and her favourite music". …….We are now planting a tree in her special place in the garden – she told us where to put it too. That is where we will be able to talk to her when she is gone. We sit there now and can feel her presence".

"I hate having this cancer. It is robbing me of my life with my children. I have to get the most time I can. It has to be good….the time I have left……I'm OK about dying. I just don't want it to happen". Linda

"Please don't stop the program. We didn't know any of this. The nurses came once or twice a week, but did not talk about the little things that troubled us, or prepared us for what dying may look like. …..We loved being able to talk about Mum's death…it has taken some of the mystery away".

"They did it so gently and over a couple of months. They let us talk about how frightened we were. We knew who to ring and what to expect…….Some things were not pretty, but we knew they were normal. It took the fear away…. Others need to access this carers advice and support". Janice

"We didn't know what the doctors meant when they said that they could continue to treat Dad. We thought that it meant that each time he got sick they would treat him and he would get better. His cancer was still in the pelvis area. It hadn't spread yet – or so we thought…… No one told us that Dad could die from this." *Michelle*

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APPENDICES:

Part B – Key Messages for Decision Makers

A model of care planning suitable for people requiring palliative care in rural and remote communities needs to be flexible, multidimensional, multidisciplinary, incorporate both the biological and psychological care aspects, be sensitive to the specific needs and population trends of each community, be sustainable, be equitable and available to all people living with an eventually fatal (terminal) condition[1].

Applying a one size fits all approach to the provision of palliative care will only further alienate many rural and remote communities and their people. The model that needs to be developed has to be mindful of the larger client capture areas in rural areas, smaller populations, poorer reported health, lower life expectancy, fewer specialist and primary health care professionals and a very complex community care system. Rural and remote populations have many other factors that influence prosperity and economic stability such as drought, natural disasters, availability of resources and subsequent population migration and population changes. These conditions can affect demand for infrastructure and services and employment, as seen in many mining and irrigation communities [2].

This action research project -Rural and Remote Palliative Care Planning Model, has enabled us to trial and developed a new model of care that will address many of the identified gaps and challenges in providing palliative care, reduce the inequalities in service provision in many rural and remote communities, is affordable and accessible and ensures that Palliative Care is provided within the framework and standards as set out by Palliative Care Australia and is available to all Australians in rural communities that need it.

A comprehensive literature review was conducted to provide the evidence base to underpin this new model. This model was trialled in 32 rural communities, reaching 350 clients, and provided a range of services such as specialist social work case

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[1] PCA (2008) Glossary of Terms

[2] AIHW (2007)2nd Ed. Regional, Rural and Remote Health: a study on mortality.

management; common intake, assessment and consent processes that incorporate the patient, the family and care giver/s as the unit of care and provided a flexible brokerage of equipment and services. A rigorous evaluation of the trial indicated that the model provided significant benefits for patients, their family members, care giver/s, service providers and the broader health system.

This new model of care – PallCare Packages- operates similarly to the ComPacks model in generalist community care services. Key elements of this new model include:

1. Specialist social work case management
2. Common intake, assessment and consent processes that incorporates the unit ofv care being the patient, the family and care giver/s
3. Flexible brokerage of equipment and services
4. Development of partnerships between key service providers and stakeholders in each community
5. Multidisciplinary care planning
6. Continuity of care and seamless referral processes
7. Psychosocial support for the patient, carer and family, including grief and loss / bereavement information and support
8. Home Notes
9. Carer support and information, , available 24 hours, seven days a week,
10. Professional support, education and supervision

It is recommended that this new model – PallCare Packages – be comprehensively rolled out across rural towns and communities across the Riverina Murray region and South West New South Wales. An evaluation plan incorporating key elements of the Centre for Health Service Development Evaluation Framework will determine the generalisability and sustainability of the model and its suitability for rolling out to all rural communities across Australia.

Patients that are dying are not just dying

They are also living

Whether or not they have the opportunity

To live this final human experience

To the fullest – each in their own way

Is influenced in great measure

By those that take care of them.

Browning & Lewis 1972 taken from Queensland Palliative Care

Part C: EXECUTIVE SUMMARY

Context:

Across the Riverina Murray region, Palliative Care is provided by primary health care workers including General Practitioners, community nurses, local hospitals and aged care facilities. Specialist palliative care services, primarily being Clinical Nurse Consultants (CNC) and a Clinical Nurse Specialist (CNS) are located at Albury, Deniliquin, Griffith, Young and Wagga. Albury also has a public 12 bed Palliative Care facility, servicing the whole area, and Calvary Health Service in Wagga has a private combined acute and palliative care ward with on site family accommodation. Palliative Care Medical Specialists fly in monthly to both Albury and Wagga from Sydney for consultations, home visits and education. There are Palliative Care volunteers in most major regional centres, and a few smaller rural communities, where the volunteer coordinator role has been funded through the local community nurses.

Many community services, including the Commonwealth Respite and CareLink Centre are provided by Intereach NSW Inc formerly the Regional Social Development Group. The Riverina Murray Commonwealth Respite and Carelink Service (CRCC) provides a 24 hour, seven day per week, range of support services and information for carers across the Riverina Murray region, including carers of people requiring palliative care.

In 2006 Intereach was successful in obtaining $247,000 from the Commonwealth Department of Health and Ageing, Care Planning Sub Program of the Local Palliative Grants round, to develop an evidence based model of care planning for people requiring palliative care in rural and remote communities. The Riverina Division of General Practice and Primary Health Care (RDGP), who had also received a Care Planning Grant in 2006, and the CRCC, entered a service agreement to provide case management and flexible brokerage of services for people requiring palliative care, their carers and family members, referred to the RDGP project.

The submission was based on findings from earlier work undertaken by the CRCC, that carers supporting people at home or in their own community requiring palliative care face considerable challenges in finding the right mix of services, information, psychosocial support and timely access to such services. Based on this evidence, and the collaborative partnership established with the RDGP, Intereach, through the CRCC, embarked on both the action research project, incorporating the evaluations and learning's of the research into the RDGP Palliative Care project. The RDGP project provided the opportunity to trial the model within 32 rural and remote communities, with 350 people and across three health clusters.

Approach:

The research project commenced with a broad literature review in order to examine the complex issues involved in providing an integrated and evidence based model of care planning. Providing complex care planning for any population group requires a multidimensional approach, involving many tiers of both public and private service coordination. Including in that mix are people and their care giver/s and families who are facing the end of their lives, required the research to examine aspects of psychosocial care planning, legal and financial support, and adequacy of carer support for palliative and end of life care. This was so the model would be responsive to the needs of people requiring palliative care, their families and carers, and to allow people real choices as to where they wanted to be cared for or where to die.

An action research model, using phenomenological qualitative data, was decided as the best approach. This was so that as new information was gathered, interventions could be initiated and trialled. This methodology allowed us to be critically reflective and constantly evaluate processes, assessment tools, communication pathways, information provision and carer support for each patient, their families and care giver/s.

The evaluation process included semi structured informal interviews, focus group discussion, surveys, questionnaires, telephone interviews, and discussions with key stakeholders across the Riverina Murray.

Results:

The results of the project indicated that a flexible packaged approach to care, that includes:

- access to medical care planning, at both the primary and specialist health care level,
- access to specialised allied health care professionals such as palliative care trained social workers, counsellors, occupational therapists and dieticians
- community care services that understand the needs of people requiring palliative care and is flexible, and has a broad eligibility criteria, and
- access to flexible brokerage for the rental or purchase of equipment and services, such as personal care, social support and domestic assistance

\- provides a very effective and potentially sustainable model of care.

The main objective of the project, **being to develop and implement a flexible model of service delivery that meets the needs of each palliative patient, their carer giver/s and family, in their local community,** was met. Flexible packages of integrated care planning and case management – PallCare Packages, was provided to over 150 patients across the rural and remote communities of the Riverina. Including the primary care giver/s in the total number of people supported and provided with care, then over 350 people received supportive care and services.

The second objective, **to improve collaboration between services involved in providing care** was also met, though has to be seen as an ongoing process. Communication difficulties were a main concern in improving collaboration and information sharing, both in the electronic form and regarding role delineation. However by the completion of the project, these issues had resolved enough to provide an effective, integrated service with clear role delineation, improved coordination, reduced duplication, and improved responsiveness to patient and care needs, to be achieved.

Discussions and Conclusions:

Evaluations with patients, their care giver/s and family members as well as clinical and community based stake holders have shown that this model of care planning and case management provides the right mix of support and care that is flexible and responsive to the unique needs of people requiring palliative and end of life care.

The key strategies and interventions that are integral to this new model of **PallCare Packages** are:

1. Specialist social work case management
2. Common intake, assessment and consent processes that incorporates the unit of care being the patient, the family and care giver/s
3. Flexible brokerage of equipment and services
4. Development of partnerships between key service providers and stakeholders in each community
5. Multidisciplinary care planning
6. Continuity of care and seamless referral processes
7. Psychosocial support, for the patient, care giver/s and family, including grief and loss / bereavement information and support
8. Home Notes
9. Carer support and information, available 24 hours, seven days a week
10. Professional support, education and supervision

The model developed **- Pall Care Packages**, is integrated and evidence based, addresses the clinical and psychosocial needs of people living in rural and remote communities, is supportive and responsive to the needs of primary health care providers in these communities, is affordable and provides timely access to appropriate services and equipment and effectively integrates change management processes and strategies.

The model also delivered on the many standards that intersected across community and primary health care such as Palliative Care Australia Standards, EQuIP, Case Management of Australia Standards and Home and Community Care Standards.

Part D: MAIN REPORT

Context:

Approximately six million people live in what is loosely called rural Australia [3]. Populations in rural areas are challenged by many external factors such as drought, environmental disasters, availability of resources, population shifts due to work and educational availability, shortages in health and allied health professionals across all communities, travel requiring long distances to access health care and other services and challenges related to communication access both within and between regions. However, not all rural communities experience disadvantage.

Intereach NSW Inc is a rural, community based charitable organisation with over 30 years experience providing a range of community services within the Riverina Murray region. This region encompasses a population in excess of 250,000 people across southern and western NSW. The region covers 28 LGAs in the area bounded by the snowy mountains to the east, west to the South Australian border, south along the Murray River and the Victorian border and north to the centre of NSW.

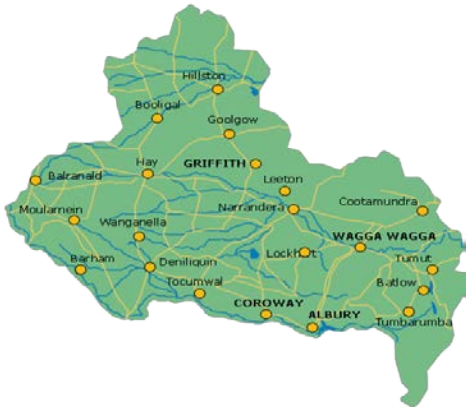

Figure 1 Riverina Murray Region

Intereach, as part of their suite of programs, auspices the Riverina Murray Commonwealth Respite and Carelink Service (CRCC), which provides a 24 hour, seven day per week, range of support services and information for caregiver/s across the Riverina Murray region, including caregiver/s of people requiring palliative care. Intereach works in partnership and collaboration with a range of community and health related organisations, state government bodies, as well as local universities and the Divisions of General Practice.

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[3] AIHW; 2007 Regional Rural and Remote Health, Study on Mortality. 2nd Ed.

From offices in Deniliquin, Albury, Baronga and Wagga Wagga, Intereach provides services to families, carers and care recipients across rural and remote communities in the region.

Background

Whilst Intereach has not specifically been involved in providing services to people requiring palliative care, the Carer Respite and Carelink Centre provides a range of support and brokerage services to eligible carers, of which carers of people requiring palliative care form a sub group of all target groups [4]. In 2005 the CRCC was funded by the Commonwealth to provide brokered support and equipment to carers of people requiring palliative care. This funding was not ongoing, however the comments from carers receiving such assistance showed the valuable nature of such support.

Palliative Care Australia commissioned a report on carers of people requiring palliative care, called the 'Hardest Thing We Have Ever Done, '[5] and other research (Wiley 1998, Hudson 2003, Wilkes and White 2005, Russell 2008) has identified that the ability and feasibility of caring for a person requiring palliative care and end of life care, particularly, was dependent on the availability and willingness of a committed primary care giver. The standards developed by Palliative Care Australia see the patient, their family and caregiver/s as a 'unit of care' [6]. Based on this research and the CRCC's own experience, it was decided to source additional funding to continue providing care planning, case management and flexible brokerage for care giver/s of people requiring palliative care in rural and remote communities.

At the same time the GAPs project (Griffith Area Palliative Care Project) was nearing completion, and the results of their evaluation formed part of the decision to apply for funding to research a suitable model of care planning that supported the patient, family

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[4] Commonwealth Respite and Carelink Centre Guidelines 2005

[5] Palliative Care Australia. 2004 : The Hardest Thing We Have Ever Done, The social impact of caring for the terminally ill people in Australia.

[6] Palliative Care Australia. 2004 Standards for providing quality palliative care for all Australians.

and care giver/s as a unit of care across rural and remote communities. It was thought that the scope of the project could then be incorporated into the management and general service coordination of the CRCC.

Method

An action research methodology was chosen as the best model for working with people requiring palliative care and their families and care giver/s. Action research has been described by Brink (2000) as a strategy that brings about social change through action – or through developing and improving practice and at the same time generating and testing theory. Action research is a way of doing research and working on solving a problem at the same time. Action research is also participatory, as it encourages active participation of the people whom the researcher intends to assist. In this way it was intended to empower the people involved in the project, including the planning and implementation of the project and hopefully encouraging participants to 'own' any solutions that emerge. It was hoped that the process as well as the research would generate meaningful organisational change at both the macro and micro level.

Another important strategy of the research involved studying the human experience through the descriptions of the patients and carers involved. This is called phenomenology research and is concerned with the 'lived experiences" and is used to interpret the experience/s or what meaning the experiences had for the patients, care giver/s and family members. This was done through informal semi structured interviews and ongoing conversations with patients and their families and care giver/s throughout the project and was used to inform critical reflection and changes made to interventions that affected these people directly.

Previous work by Kate Senior and David Perkins (2005)[7] identified that researching palliative care services was different to other mainstream services for a number of reasons. These being:

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[7] Senior,K. & Perkins, D. (2005) What are the challenges for Evaluating a Palliatives Care Service? Australian Journal of Primary Health. Vol 11, No3.

- that the service objective is to improve quality of life, not to effect a cure
- service providers may have conflicting objectives from that of the care giver/s and or the patient
- the provision of palliative care is a shared responsibility between paid care providers, family care giver/s, specialist and primary health care providers
- palliative care patients have more immediate needs, due to time (life) limitations, and changes to phases of care
- the effectiveness of the service is measured by the experience of the patient, the family and caregiver/s.

Based on this information, using only quantitative research and evaluation methods would not have provided the information needed to understand what makes an effective model based on the experience of those that received support or assistance from the project. For this reason quantitative and phenomenological data was decided as equally important to determining an appropriate model of care.

A base line survey, using the PCA Evaluation Tool Kit [8] was conducted in conjunction with the RDGP Palliative Care Project Manager, of patients, care giver/s, service providers and key stakeholders. CRCC satisfaction questionnaires were also examined to ascertain the level of satisfaction of carers with the 24 hour CRCC emergency service.

A thematic analysis of the available literature on palliative care formed the basis of the research questions.

Evaluation of the overall project intention and the interventions chosen was conducted continuously in cycles throughout the project. Tools developed by the University of Wollongong, Centre for Health Service Development and the NET[9] team formed the basis of evaluation. Working parties were established to examine specific tools or interventions and a quality management approach taken, using PDSA cycles to critically

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[8] University of Wollongong.(2004) Centre for Health Service Development :Palliative Care Evaluation Tool Kit.

[9] National Evaluation Team. University of Wollongong

reflect on their effects or system impacts. Information or changes to the project developed from these cycles was reported to the Steering Committee for discussion and endorsement.

Project Implementation

On July 10th 2006 Intereach appointed a Project Officer with social work and nursing qualifications to develop and implement the project in line with the reporting requirements of DoHA . A partnership and MOU had already been established with RDGP and senior management of the CRCC.

1. Steering Committee:

Due to anticipated duplication of key stakeholders and similarities of both projects the Steering Committee for RDGP was shared with Intereach's project for the management of the project implementation, and additional 'informed persons' were recruited to working parties or focus groups discussions and individual interviews to assist in critical reflection and evaluation of the research findings. Members of the Steering Committee are included in Appendix 1.

Working parties were convened as required for review and evaluation of key tools and interventions that were developed for the project. These working parties considered the following implementation issues:

- Case management model
- Referral and Intake process
- Assessment forms and consent
- Patient Held Notes / Home Notes
- Communication protocol and pathways
- Role delineation

2. Project Management:

Overall governance of the project was managed by the CEO and monthly reports provided to the Board and Senior Management Team. Initially daily organisational management was provided through the CRCC senior management and a trial was undertaken with the CRCC intake and assessment process for client referral, embedding the project into core CRCC activities.
As the project changed, and additional funding was sourced, (Round Four Palliative Care funding) the project was separated from the CRCC team, and a new program area was developed within Intereach. This change reflected the organisation's commitment to involving themselves with research, and also a commitment to working with people, their families and care giver/s in palliative care which reflected the current gap in service delivery across rural communities.

3. Ethics

An Ethics Panel was established within Intereach to provide ethical approval for the project and also for a range of other research projects being undertaken by the organisation. The Ethics Application and Approval form is included in Appendix 2. A recommendation of the Ethics Panel was for the provision of the names of counselling and psychology services across the region being made available for patients, their families or care giver/s that participated in the evaluation process.

A risk management pathway was also developed for the project, identifying that working with people requiring palliative care, their families and caregiver/s one had to be careful not to place additional burdens on people, or cause additional grief or distress.

4. Literature review

A thematic analysis of an extensive literature search was initially conducted, using MedLine, Care Search, Palliative Care Australia, Cancer Institute, NSW Cancer Council as the main sources. Throughout the project current literature and best practice models were examined as we tried to give meaning to the barriers or challenges that arose in many of the rural communities. Also the literature and reflective practice identified other themes or issues to examine during the course of the project.

The literature supported what is already well documented about patient experiences and service provision issues in palliative care, but a number of issues specific to rural communities were identified. The issues that had implications for the project were:

- each rural community has similar yet unique issues or challenges providing quality palliative care in their community
- currently rural communities are facing enormous economic and psychological difficulties due to the long standing drought, financial insecurity and population shifts
- patients, family members and care giver/s form the unit of care
- many people in rural communities do not access primary palliative care services after discharge from hospital or ceasing curative treatment
- Aboriginal communities in the Riverina Murray region and other rural communities almost never receive formal palliative care services
- Care giver/s, particularly in rural communities, generally don't self identify as carers and therefore do not access traditional carer based services
- educational opportunities or professional supervision in palliative care is scarce or not available in rural communities, and where it does occur has a clinical focus
- there is poor coordination and siloing of services, especially primary and secondary health and community care services, across all rural communities in this region
- there is a lack of qualified primary health and allied health care professionals, and even less qualified in palliative care across all rural communities
- the provision of basic and specialised equipment across rural communities for use by palliative care patients and care giver/s in the home is limited; purchase or rental is only available in major regional centres; waiting times for PADP equipment can be too long for palliative care patients, and their changing needs make them generally ineligible[10].

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[10] NSW Cancer Council (2008) *Inquiry into the Program of Appliances for Disabled People (PADP).*

There were also several models of palliative care identified and promoted in the literature as best practice. These all had common themes and addressed a range of identified gaps depending on the breadth and scope of the models.

Some of the best practice strategies and interventions included:

- clear role delineation across the primary and specialised care spectrums
- specialised palliative trained social worker/professional case manager providing planned psychodynamic[11] and psychosocial interventions and assessment
- liaison and referral across public and private primary and specialist services
- lead agency case management and joint case management
- advanced care planning
- counselling which includes: grief and loss, spirituality and pastoral care, mindfulness and a strengths or solutions approach
- advocacy
- community development
- research and planning
- multidisciplinary care planning, providing seamless coordination of care and incorporating the following:
    - single assessment process
    - shared referral and consent
    - joint case management
    - clear, reliable and effective communication pathways
- supported and educated primary health care team
- home notes or patient held records

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[11] Block. K. (1997) The role of the self in healthy cancer survivorship: A view from the front lines of treating cancer. Advances: The Journal of Mind-Body Health. Vol13, No 1

- patient, family and care giver/s being recognised as a unit of care with equal but unique challenges and needs
- adequately resourced and flexible brokerage of home and community care services
- carer education and support, including access to emergency and flexible respite and
- timely and flexible access to equipment.

Based on this information, the project developed, in conjunction with the RDGP steering committee, a flexible, specialist case management and care planning model that incorporated a range of best practice tools and interventions.

5. After Hours Support : Literature Review

Two social work students (one third year and one fourth year student) commenced their practical placement with the case manager during the project period, and combined both direct and indirect practice as part of their learning agreements.

They commenced a concurrent research project looking at the after hour support provided for patients referred to a palliative care service, their families and care giver/s as well as the quantitative experience of a targeted sample of carers referred to the project. They produced a well resourced and evidence based document called “ *What do people needing palliative care require from an after hour service in rural communities*”. This report is attached in Appendix 3.

Recommendations of this report include:

- not one model of after -hours service suits all consumers across all communities
- consideration has to be given to response rates and effectiveness of the service
- qualitative and quantitative surveys of both patients and care giver/s are needed to ensure quality service provision and maximise user satisfaction
- financial viability of the service has to be ensured.

These recommendations informed the after hours support for both patients and care giver/s referred to the RDGP project and evaluated as part of the research project.

As one carer commented about how the availability of services impacted on her ability to provide care:

> *" As a family, you need more awareness of services. When my husband was first diagnosed with his cancer we were stuck thinking – well where do we go from here? By the time we were referred to the project and found out about the 1800 number (CRCC) and the case management side of the project he (husband) was very sick and my family was very stressed. If we had been put in touch with this service earlier then maybe there would have been less stress in my family – we may have been better prepared."*
>
> *49 year old wife caring for her husband with terminal stomach cancer*

6. Evaluation Methods:

The project officer, in conjunction with the University of Wollongong National Evaluation Team (NET), created and implemented an evaluation plan that occurred at crucial times during the project. This evaluation plan was incorporated into the quality improvement process and PDSA cycles implemented throughout the life of the project. Formal evaluations with key stakeholders, steering committee and targeted consumers was undertaken in conjunction with the RDGP, as the 'model' was trialled on patients accepted into the RDGP project.

The partnership developed for the evaluation process was symbiotic to both the Intereach research project and the RDGP project, as the RDGP project provided a client base for the "in vitro" stage of the research, and the action research methodology provided the RDGP project with quality improvement and ongoing evaluation processes.

Evaluation strategies that were used in the research project included:

- base line surveys to patients, care giver/s, stakeholders, GP's and community nurses using the UOW Palliative Care Evaluation Tool Kit
- implementation of Clinical Practice Improvement processes, including Plan, Do, Study, Act cycles

- the use of in formal semi - structured interviews with a targeted sample of patients, care giver/s and family members across a range of rural and remote communities
- focus group discussions with bereaved carers at critical points (six weeks, three months) after the death of the patient
- the development of an on line questionnaire to service providers (see appendix 4)
- individual interviews with a range of service providers looking at referral and assessment pathways, communication protocols and collaboration.

The data obtained from the evaluations of both the research project and patient referrals to the RDGP project, gave a good reflection of aspects of an effective model of care planning relevant for rural and remote communities .

6.1 Base Line Evaluation results:

The base line evaluation survey provided by the UOW Evaluation Tool Kit, and used to measure awareness, satisfaction, level of support, and priorities for care planning provided a range of responses. The following are interpretations taken from results of different aspects of the base line evaluation process from both projects. This was prior to implementation of the care planning, case management and brokerage support.

Generally the community nurses commented on excellent support provided to them from the regional Palliative Care Clinical Nurse Consultant (CNC).

> *"As a community nurse, mostly working alone, I find the support I receive from the CNC (Jenny) is always present whenever I contact her. She will attend home visits to my clients and support me both professionally and emotionally as the majority of my clients are at least known to me. My immediate colleagues are always at the end of the phone if I need to debrief".*

They did however acknowledge difficulties in providing continuity and adequacy with regard to service provision.

> *"Palliative Care is only available five days/week and during office hours. All extra time is not approved, so if clients require any additional services they have to call 000."*

> *"Good palliative care does not just happen. You have to have permanent, dedicated staff"*

General Practitioners generally commented on poor coordination and a lack of information in rural communities regarding palliative care, which is backed up by literature regarding GP involvement in palliative care.

> *"Palliative Care here is uncoordinated. Continuity of care is an ongoing issue"*
>
> *"Palliative Care is poor in rural communities. Clients can only get sick in working hours!"*
>
> *" GP's need more training in Palliative care. We need more information".*

Stakeholders such as Home and Community Care Services, equipment providers, and aged care services commented on a lack of awareness of services and support available outside their own service structure. They also commented on not being kept 'in the loop' or seen as part of the continuum of care, with regard clients changing care needs. They often saw themselves as providing essential end of life care for many non cancer patients, allowing people to remain at home as long as possible within the constraints of limited resources and staffing.

> *"We are the back bone of community care, but are not recognised as being part of the team". Home Care worker*
>
> *"We don't know who to call or when if our clients are not coping. We tell them to ring 000. If there is not the staff to cover the care needs, or the family can't pay the fee, then they (the patient) have to go to hospital or an aged care facility. This happens too often. People want to stay at home, but we can't provide the level of support they need." Care Services Manager*

In one community with an established fortnightly aged care meeting, coordinated by the local health service, community care staff and case management services such as Community Options and ComPacks were included in these discussions. They commented on improved communication and care coordination and professional support by being involved in these discussions. This is in stark contrast in communities where no such broad community and clinically based continuum of care meetings exist.

> *"We know who is going to need care. Who is in hospital, and when they may go home. We can allocate staff as required if we know. Before we were engaged in the meetings patients were discharged from hospital on Fridays and we were expected to find staff at short notice."*
>
> *"We feel part of the team. We have learnt so much from the whole team – diagnosis, treatment, what conditions mean, what to expect. We feel more supported in our work. If we need an Occupational Therapist we know who to call, or if a client needs a Webster pack, we discuss this at the meetings. The practice nurse is there from the clinic, and she works this out with the GP. This is real seamless care".*

Base line evaluations from service users (patients and care giver/s) were sent out early in the implementation phase of the project, so little knowledge was gained as to their perceptions of the service provision prior to the project implementation. The results did show that carers were initially confused as to what role each professional had and how they related, or who to call for what. The confusion appeared to add to the distress already experienced by many patients and care giver/s, so it was decided not to continue with this level of base line evaluation. Instead it was decided to include questions relating to initial awareness of services at the follow up interviews. The following comments are from carers and reflect this confusion:

> *"Yes I got confused about who was providing which services. Had a lack of understanding of who was doing what. Terminology was confusing amongst professionals".*
>
> *"Most of the time it all worked well. Doctors worked well in the hospital, but after we left we only had our local doctor – we didn't have anyone else. The doctor didn't know who the Palliative Care Team people were and what they did. If he was confused, so were we."*

The information gained from families and patients was used by the steering committee to look at providing information regarding role delineation and coordinating home visits with both the case manager and community nurses. This then allowed the team to clearly identify and assign different tasks to each role, so that patients and families had a better understanding of what each service provided. It also assisted in breaking down the perception that two different services were being provided in many communities.

Results: The PallCare Packages Model

What we found from both the qualitative and backed up by the quantitative aspects of the research was that a sustainable, effective rural model of care planning for people requiring palliative care can be developed. The model implemented – **PallCare Packages**, as part of the research project, and trialled on over 350 people – patients, their families and primary care giver/s, included the following key strategies or interventions and will form part of the recommendations and outcomes of the research project.

These were (the results of each will be discussed in more detail in this section) :

1. Specialist social work case management
2. Common intake, assessment and consent processes that incorporates the unit of care being the patient, the family and care giver/s
3. Flexible brokerage of equipment and services
4. Development of partnerships between key service providers and stakeholders in each community
5. Multidisciplinary care planning
6. Continuity of care and seamless referral processes
7. Psychosocial support, for the patient, carer and family, including grief and loss / bereavement information and support
8. Home Notes
9. Carer support and information, available 24 hours, seven days a week
10. Professional support, education and supervision

The data obtained from the evaluations of both the research project and patient referrals to the RDGP project, gave a good reflection of aspects of an effective model of care planning relevant for rural and remote communities trialled and implemented.

1. **Specialist Social Work Case Management**

Case Management has been described by the Case Management Society of Australia (CMSA) (2006)[12] as a:

'collaborative process of assessment, planning, referral and advocacy for options and services through communication and available resources to provide quality, cost effective outcome. It provides a single point of contact for clients that require a complex range of services or require intensive levels of support on either an ongoing, short term or episodic basis. Case management services focus on maximising the individual's capacity for independent living in the environment of their choice and service to inform service system developments that better meet client needs".

The literature regarding palliative care indicated that working in this field requires some degree of professional specialisation and understanding of the specific and unique needs of people who are dying, their care giver/s and family members. Case Management in palliative care therefore requires the case manager to have a broad understanding of the social contexts of death and dying, system and funding constraints, community and health care systems, needs of families and caregivers, be empathetic and compassionate, and act within organisational boundaries.

Earlier work looking at models of case management, conducted in 1999 by Deborah Yarmo[13], provides substance to support the promotion of specialisation in palliative care case management. She discussed that there are inconsistencies between the theory and practice of generic case management. Her research indicated that this is caused by the diverse qualifications, skills and experience needed for being case managers in different community and hospital inpatient, case management settings. Case management as a profession on its own or as an adjunct profession lacks coherence. She suggests that this makes the role of the generic case manager blurred.

The recent Standards developed by the CMSA[14] may provide more consistency in the case manager role and uniform standards of practice. These standards (see Appendix

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[12] Case Management Society of Australia.(2006) Case Management and Community Care: A discussion paper.

[13] Yarmo. D. (1999) Reconceptualising Case Management in Theory and Practice: A front line perspective. Unpublished Thesis.

[14] CMSA (2008) National Standards for Case Management

5), when integrated with the Palliative Care Australia Standards (see Appendix 6), and Social Work Standards of Practice form the basis of a specialist social work case manager role in palliative care.

1.1 How this was applied to the project

Based on the available literature and theoretical modelling, this project applied the CMSA standards for case management and the PCA standards into a specialist social work role. A social work model rather than generic community or nurse/health model of case management was trailed for the following reasons:

- people requiring palliative care have greater complexity in their presentation, treatments and symptom management
- social work intervenes with the person in their environment, therefore sees the person requiring palliative care, their family and care giver/s as part of the 'unit of care'
- social workers have unique, in-depth knowledge of and expertise in working with ethnic, cultural, and economic diversity; family and support networks; multidimensional symptom management; bereavement; trauma and disaster relief; interdisciplinary practice; interventions across the life cycle; and systems interventions that address the fragmentation, gaps, and insufficiency in health care. These are critical areas for implementing change in palliative and end of life care.
- social workers also have expertise in analyzing, influencing, and implementing policy change and development at local, state, and federal levels that can be used to make important improvements in the care of patients living with life-limiting illness and the dying[15] .
- the scope of social work in palliative and end of life care extends across many practice settings and populations, and requires intervention at the individual, family, group, community, and organizational levels

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[15] NASW Standards of Social Work Practice in Palliative and End of Life Care (2008)

By using a social worker for this role we felt that the gaps identified by the research in psychosocial care and existential issues (Hudson 2003, Gamage 2006, Ellenberg 2004, Madocks 2003, Rumbold 2003) could be more effectively addressed and that the model would meet the comprehensive standards developed by Palliative Care Australia. Looking at the professional standards and ethical guidelines for Social Workers, developed by the Australian Association of Social Workers (AASW), would infer that bereavement support as well as dealing with ethical dilemmas relating to end of life care and questions relating to advanced care planning, spirituality and meaning of life could also be incorporated into the role. Research on Case Management also stresses the importance of establishing clear and respectful professional boundaries and expertise, and developing effective multidisciplinary communication and care planning.

We believed that incorporating a social worker as an intrinsic part of the team will reduce duplication and ensures clear delineation between the clinical and non clinical roles. This also provides a basis for developing a social work role as part of the Allied Health Medicare Enhanced Primary Care Initiative, providing sustainability and equity across rural communities.

1.2 Results

The social work / case manager role was poorly understood by many of the community nurses and specialist palliative care nurses, and in more than one instance this role was openly questioned. This barrier to full implementation of the specialist case manager role was discussed with the project management team and steering committee. It was decided that this problem was due to poor communication of the specific competencies or boundaries of expertise and intended role of the specialist case manager and the reasons for deciding on such a specialized role. The following comments are from community nurses early in the project implementation phase:

> *"They wanted to case manage, but the General Practitioner is the case manager. They have to listen to people who have been doing this for years and know the community".*

"There was miscommunication all along the way. If they'd called (the Division of GP's) us together and said that this is what we are going to do – this is the scope, and this is what we can provide, we would have been more confident. "

Other community service organisations, however, such as Home and Aged Care services are familiar with the case management role, and worked well with the case manager. Their comments can be summarised by these quotes:

"The Case Manager organised a family meeting, and we were invited. It was great to be considered to be part of the team." COPs manager

"We decided on joint management – the Case Manager worked with the family, and we set up and coordinated the services for the carer. It's good when we work well together, and know what each role is. The care plans also helped us coordinate and get things in early for the family." HACC service provider

Patients, care giver/s and families appreciated the role and the specialized support offered by the case manager. As the program expanded the case manager developed clear communication pathways, working on developing trust and rapport with each local clinical and community care team. It was then that the benefits of the role became clearer and there was greater acceptance and collaboration. The following comments reflect this change in acceptance.

"Having a case manger is a positive way to go, but more face to face contact is needed to improve this process". Community nurse

"The program improved collaboration. Everybody worked well together. Sure you had your ups and downs but we worked through them to achieve the best outcomes for the patient. Where services don't refer or show they don't understand the program can make collaboration difficult….we worked through this in most circumstances and in the end we had a better understanding and clear roles." Primary Health Care Nurse

"Having access to the social work side of things prepared the carers for the impending death and their caring role. This included consideration about their finances, advanced care directives, psychosocial support and having someone to talk to. They also had access to Centrelink service and other financial support." Community Nurse.

As a means of improving acceptance and separating the project from the traditional medically focussed Palliative Care Service, the steering committee decided to change the name of the project from the Division of General Practice Palliative Care Project to Rural PallCare Packages .

This concept was seen to be a way of linking it to the concept of the Aged and Community Care Packages already in existence. This enabled the Steering Committee to overcome the difficulties of fully integrating the project into the Area Health Palliative Care Service, and enabled the project to focus on the case management, care coordination, psychosocial support and carer education and support. After this name change, the project appeared to gain wider acceptance across all communities. Anecdotally the community nurses commented that they were familiar with the packaged concept, and that allowed them to feel secure that the project was not nor did not intend to duplicate their roles. This feeling is supported widely in the literature regarding clear role delineation and the development of trust across the multidisciplinary care team. The following are comments from community nurses:

> *“Having access to the social work side of things prepared the carers for the impending deaths and their caring role. This included their finances, advanced care directives etc.”*
>
> *“ This program offers something different – good psychosocial support for the families when they need it…time to talk to families is so important, it allows us to do the nursing better and worry more about the symptom control. Having a social worker was crucial to the success of the psychosocial supports and advanced care planning. They knew when to refer and we worked well as a team. That’s the best approach – working as a team”*
>
> *“For the patient – their total care improved – made it easier and more comfortable for them to be nursed at home”.*

This was an interesting outcome of the project, in that the difficulties encountered in implementing such a model of case management was experienced when ComPacks was first trialled across Sydney’s acute and community service sector in 2003. In this pilot, it is reported in the Compack's Final Report [16], that concerns were also expressed that the new model- ComPacks, was duplicating the role of health service professionals working in communities, such as community nurses and GP's. The ComPacks evaluation report identified aspects of a community case management model that differed from the health service case management model. These aspects were reportedly appreciated by patients, family members and caregiver/s. These aspects, which are also needs identified for providing care for people requiring palliative care are summarised as:

- patients have a higher access rate to mainstream services through assessment, negotiation, management and monitoring of "best fit" that has credibility with other community care service providers
- priority is given to the patient's/client's personal goals, identified strengths and preferences, whereas the health model is based on assessed need or problems
- the focus is on exploring, involving and developing informal networks and infrastructure to achieve long term client/patient, family and care giver/s goals whereas the health models are intended to manage a set of symptoms of health needs and support the person/patient to maximise their quality of life
- the assessment includes the care giver/s and family – is a systems approach, where as the health model work primarily with the patient/client. In Palliative Care it is the patient, family and caregiver/s that makes up the unit of care.
- the ability to provide short term, long term and episodic approaches that allow the "unit of care" to move in and out of the support system with various levels of intervention and without multiple admissions and discharges. In the health care system, when a person no longer has the health need or problem, they are discharged from the service.
- community case managers are better placed to negotiate fees for their clients.

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[16] NSW Health, COPs (2004) ComPacks Project: Evaluation report

The outcomes of the implementation of the Compacks model have many similarities to the outcomes of the PallCare packages model. Opportunities were sought to discuss the outcomes of this evaluation with ComPacks management, and the similarities to the case management model. It was initially thought that this may be the basis for rolling out a pilot project, however it is the opinion of the researcher that Case Management in Palliative Care requires a specialised professional role with different patient eligibility and assessment criteria.

> *Facilitating a good death should be recognised as a core clinical proficiency, as basic as diagnosis and treatment. Death should be managed properly, integrating technical expertise with a humanistic and ethical orientation. We also need research in how to best identify, assess and plan the care of all our patients who are sick enough to die. This is an enormous challenge in politicised, market driven health care models but one that will make an important difference to those most in need".*
>
> *Murray S. & Sheikh A (2008) Making a Difference : Palliative Care Beyond Cancer*

"Palliative Care is active care...where the focus shifts from cure to care...to the patient as an individual...to a member of a family unit."   Queensland Palliative Care

Case Study.

As part of the evaluation, several families agreed to be interviewed regarding their experiences of the PallCare Packages.

Two research questions were asked of the carer and patient. These were

1. *What about the project and case management enabled you to continue to provide care? and*
2. *What were the challenges and barriers to providing care in the place of your choosing?*

One particular couple living in a semi remote community was interviewed. The carers response to the what formed challenges or barriers was the statement: "The day you came!"

This statement proved to be very challenging for the professionals involved in their care, and generated much discussion about what it means from the patients and carers experience to have someone from "Palliative Care" come into your home.

For this couple, they stated that it meant that they were really now going to face death. It had changed their relationship and also their decision to live in a small semi remote community.

The case manager reported that this interview presented questions about the appropriateness and readiness of patients and carers to discuss issues about death and dying – how do you know when the time is right, how do you move people to this point respectfully and with empathy.

These issues were discussed at supervision and in education sessions with other palliative care service providers and it was agreed that it is not easy, especially when many patients and families do not know that their condition is terminal, and so find accepting palliative care and all it has to offer is difficult.

Storm clouds over Gundagai

2. Common intake, assessment and consent processes that incorporates the unit of care being the patient, the family and care giver/s

Patient centered care is the ultimate goal for quality health care delivery across all domains – specialist, primary and community care. Delivering it can be a challenge when organisations and services are constrained by funding body expectations and outcomes, organisational politics and structures as well as siloing of areas of expertise. Many difficulties are encountered by staff working in different organisations, using a variety of assessment, referral and consent forms and pathways. Providing an integrated and holistic service for people requiring palliative care where the unit of care is the patient, the family and caregiver/s means that there are often multiple layers of consent processes that must be addressed before services can effectively be engaged.

One of the goals of the project was the development of a common assessment and consent tool for palliative care that would work across both the clinical and community sectors and provide adequate, accurate information, be reliable and responsive to the complex needs of people requiring palliative care services and include the care giver/s and family concerns.

2.1 How this was applied to the project

Originally the CRCC Intake and assessment form was used in conjunction with the ONI (On Going Needs Identification) Form[17] (See Appendix 7). These forms were trialled for three months on a variety of patients and their carers. They proved to be unsuitable as the focus of these forms was on carer need and the ONI was very burdensome and complex and didn’t reflect the complex and often changing or deteriorating condition of the patient. Although, as the research states, meeting carer need is crucial to providing adequate support to palliative care patients; these forms did not allow enough information regarding the patient, their diagnosis, prognosis, phase or goals of care.

New forms were then developed using key information contained from a variety of sources to include the patient and care giver/s needs as well as goals of care. Electronic versions of all forms were generated so that information could easily be transferred

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[17] University of Wollongong: Centre For Health Service Development. (2002) On Going Needs Identification Form.

across referring agencies. Streamlining of the forms became a priority of the Steering Committee, as this was seen as crucial to providing seamless care and ease of referral across a variety of services and throughout each community. Even though there are similarities in each community between service provision and communication pathways, local practices had to be acknowledged and respected. A working party was established to develop common referral forms, communication update forms, care plans, assessment forms, advanced care directives and patient / carer goals of care. A meeting was held with community nurses from each community and individualised communication pathways were developed.

The Project Officer through the Steering Committee attempted to implement the Palliative Care Outcomes Collaborative (PCOC) clinical assessment tools such as the Symptom Assessment Scale, and Kanofosky Performance Scale in order to assist in developing a common language amongst service providers and support quality initiatives in determining frequency of home visits and other interventions. This initiative was not well accepted or supported by the Area Health Service Palliative Care Program Manager or local CNC. It was decided to delay using these tools until further education and support had been provided by PCOC to the AHS.

2.2 Results:

Even though it took some time for the development of common tools across all communities, the project identified pathways and processes to overcome challenges to providing seamless care and effective communication. It was noted that the forms had to be appropriate for a range of service providers and meet both the patient and care giver/s need. Using both action research and quality improvement methods ensured that barriers to the project's success were reflected upon, solutions were looked for and incremental changes implemented over the life of the project. This process highlighted the challenges facing rural practice and factors that have to be addressed for a rural project to be accepted, sustainable and effective.

The outcome of the project is that there is now a common assessment form, as well as an appropriate referral and care plan update/feedback form has been developed. This form and pathway is currently being used in the Rural Palliative Care Project funded by the Australian General Practice Network across the Riverina.

The PCOC assessment tools and data sets are not being used across the community nursing setting, however in one community, the local GP Practice Nurse is implementing a quality improvement project using the symptom assessment scale and modified Kanofosky scale for early identification and streamlining of palliative care patients in a collaborative partnership with the Case Manager. This process will be evaluated as part of the AGPN Rural Palliative Care project funding and if successful will be rolled out in other GP centres.

3. Flexible brokerage of Equipment and Services

The provision of appropriate and timely equipment is seen as a major support for families and carers to continue to provide care in the home. Without this availability, people no longer have choice as to their preference as to where they want to be cared for and wish to die.

Home and Community Care staff have to be mindful of OH&S requirements when providing personal care, so for many patients, not having access to appropriate equipment, means that they are unable to receive the care they require to remain at home.

The NSW Cancer Council submitted a report to the NSW State Government enquiry into Program of Appliances for Disabled People (PADP) scheme[18]. The report highlighted the fact that the PADP funding is inadequate to meet the current need. This is due to long waiting lists and strict eligibility criteria causing many people requiring equipment who have a cancer diagnosis or are palliative and require equipment to remain at home, not being able to do so under the scheme. PADP funding for specialised equipment requires an OT home assessment, a problem for many patients in rural communities where OT's

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[18] NSW Cancer Council.(2008) Inquiry into the Program of Appliances for Disabled People. Parliament of NSW. General Purpose Standing Committee No 2.

and other allied health professionals are not readily available in the public or affordable in the private system. The Cancer Council research also noted that many rural consumers did not know of the PADP funding or how to access this service.

3.1 How this was applied to the project

> *"..Without the assistance you have provided it would be impossible to care for Mum at home.*
>
> *My parents are pensioners so money to hire such equipment would have been a big issue. We feel caring for Mum at home is the best and nicest for her.*
>
> *She deserves the best and home is where that is..."*

There is anecdotal evidence that health related equipment provision, traditionally provided across the Riverina by the Area Health Service Equipment Loan Pool, is not longer available in many rural communities, is of aging stock and there is great demand for the little they do have. Public purchase and rental of equipment is provided across the region by several companies, and one company was willing to enter into an agreement with the RDGP and the CRCC for very reasonably priced package rates, reflecting the nature of equipment required for people requiring palliative care.
Their staff also showed a willingness to provide support and information to carers and family members in regard to equipment provision and correct use, as well as being very flexible with delivery and pick up, and took the time to understand the specific needs of the project's target group. This organisation had the contract for the Area Health Service for the provision of electric beds and pressure mattresses for community use, and already travelled regularly across the Riverina Murray region.
The funding provided by the RDGP project allowed for equipment to be provided to patients and carers. When possible and available an Occupational Therapist ((OT) was referred to for specialised assessment, however OT's were only available in two communities on a regular basis, and not available in smaller communities. Some basic equipment can be assessed as appropriate for use by a registered nurse [14]. The equipment provider employed a staff member who had Nursing and Rehabilitation qualifications and therefore was able to undertake home assessments for appropriate equipment use and hire.

As the project developed and more sustainable options were looked at for equipment provision, partnerships were developed with community funding groups such as CanAssist, the Leukaemia Foundation, Commonwealth Respite and Carelink Centre, Rotary and Lions clubs, for assistance in covering the ongoing costs associated with specialised equipment.

3.2 Results:

The project allowed for a 'packaged' approach to funding equipment and services to be developed. This enabled the equipment funding provided by the RDGP project to be equitably spread across all communities. Two tiers of equipment and service provision was developed, depending on patient and carer need. This proved to an effective way to anticipate and plan for low and high care needs.

A Carers Pack was developed specifically targeted towards the family and carer need. This was developed as a quality initiative when the case manager identified that certain items and information were consistently proving useful and assisted in discussions relating to ongoing care needs of the patient. This Carers Pack was provided to all carers referred to the project, and items included were individualised to the particular carer need and patient diagnosis. The Carers Pack proved to be innovative and positively commented on by carers in the evaluations.
The following tables show the different equipment packages and Carers Pack. Approximate costing for these packs and the rationale for the Carers Pack is included in Appendix 8.

Low Care Equipment Package:

Brokerage for hire or purchase for lower priced items

- Carers Pack
- Over toilet support
- Four wheelie walker with seat
- Shower chair with supports
- Lambswool
- Bed stick

Carers Pack Includes:

- Plastic crate
- Carers book – Red Cross
- Hand cream
- Lip balm
- Stress ball
- Relaxation CD
- Alcohol wash
- Bed bath samples
- Samples – as appropriate, but includes body wash, incontinent products
- Resources & brochures – as appropriate

High Care Equipment Package:

Brokerage for hire or purchase for lower priced items: A low care package, carers pack PLUS:

- Electric bed
- Wooltech overlay or if end stage with pressure sores - pressure air mattress
- Bedside commode
- Incontinent protection

> *"We wouldn't have been able to keep Mum at home without the service for as long – special beds, lifter, everything there when we needed it. When the time came for her to go into a nursing home, respite care was anticipated... we had what we needed ready......". Daughter – carer of mother with Multiple Sclerosis*
>
> *"Having the equipment package as part of this has been terrific. It has made the role of the carer easier. It also opened doors as to what services the nurses and program could help with." Community nurse: Tumut*
>
> *"The most important element of the project was the equipment – because it facilitated the person getting back into their own home and being cared for in their homes." Rural GP*

4. Development of partnerships between key service providers and stakeholders and in each community

The development of partnerships, with the intention of increasing collaboration, with significant stakeholders, was seen as essential to develop an increase in community awareness and participation in Palliative Care. For the project to develop interventions that were effective and patient centered, partnerships were essential so that there could be a shared commitment and ownership of the project across the region. This was considered essential for sustainability and integrating the learning's of the research into change management practices.

NSW Health (2006) suggests we need to collaborate and form effective partnerships when:

- clients or communities have complex needs that cannot be met by a single policy, program or service
- other agencies (eg. State, Commonwealth, Local Government, non-government or private sector agencies) affect your services or clients
- your policies, programs or services have a flow on effect to others.

The literature also identified that there can be difficulties with integration and partnership development due to "professional territorialism[19]", funding guidelines,

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[19] Vic. Government. (2004) Promoting partnerships in Palliative Care : Final report

differences in defining the palliative care population[20,20] and differences in models of care. These can all impact on the ability of effective partnerships to be formed.

In the Elements of Governance Discussion Paper[21] developed as a result of the Griffith Palliative Care Service (GAPS) the authors suggest that in order to achieve effective collaboration and partnerships, good governance practices and principles are crucial its success. They state that:

> *"Good governance means developing the capacity and capability of the governing body to be effective. The level of involvement of stakeholders' participation at a governance level has a direct impact on outcomes and sustainability. Good governance will also ensure that the project's aims and goals remain clear.* [15]"

In this paper, the author quotes Leigh et al (2004)[22] also states that 'with quality clinical care, the change agenda needs to involve people and systems beyond local clinical teams'. This change needs to permeate across organisational and professional systems that contribute directly or indirectly to clinical practice. Leigh argues that whilst clinicians can effectively work on change within their immediate areas, they also need an avenue to address organisational issues beyond their control but affecting their practice [17].

4.1 How this was applied to the project

Representatives of key stakeholders and partner organisations were members of the steering committee, and MOU's had been developed with each organisation describing their involvement or commitment to the RDGP project. Intereach also had MOU's with community service organisations. It was inferred that partnerships would be developed, and thus buy in to the research and RDGP project would occur across these organisations.

Individual partnerships were developed with other key stakeholders in local communities, including the equipment provider and local community care providers.

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[20] Oliver. M et al The Impact of partnership on capacity building in palliative care among rural communities : A south Australian experience. Discipline of Nursing and Rural Health. University of South Asutralia.

[21] Rural Palliative Care Resource Kit. (2007) Governance Strategies: Elements of Governance Discussion Paper

[22] Leigh et al (2004) The clinical Support systems program ; supporting system-wide improvement.

An important partnership developed with the Riverina Cancer Care Co-ordinator (RCCC) in Wagga Wagga who was able to identify early from patient data and discussions with the Medical, Surgical and Radiation Oncologists, those patients that would qualify for the project. A quality project was initiated with the RCCC looking at early patient identification, joint care planning, ease of consent and referral, patient and care giver/s follow up and peer support.

4.2 Results

At the beginning of the implementation phase this process of building trust and rapport proved a considerable challenge for the Case Manager when attempting to implement multidisciplinary care plans, joint case management, or involvement in the care team with the patient and their family or care giver/s. This situation arose from the lack of consistent buy in from managers of the primary health and community service providers across the region. This was attributed to the following reasons:

- the Area Health Service not fully informing the local health and community nursing services about their partnership or MOU with the RDGP project, and so each community nurse and medical centre had to be have individualised education, information and communication strategies developed
- community service managers such as Home Care had not informed their local managers as to the existence of the project or referral pathway
- a new model of Palliative Care being trialled and lack of familiarity with the model or the principles of Palliative Care in general
- poor communication by the RDGP Project Manager and Intereach Case Manager as to the rationale for the model across all communities. As the research used an action research methodology, and evaluations and further research generated changes to the strategies being implemented, this model of case management evolved over the life of the project.
- lack of attention by the steering committee to issues relating to governance.

The following comments were from evaluations of the RDGP Steering Committee members regarding governance of the project:

> *"I don't think that the……(Area Health Service) had buy in to the program. They were obstructionist on many occasions, and suspicious of an initiatives that they…(the NGO) had with the program."*
>
> *"The goals of the project were not given enough consideration such as the Multidisciplinary Teams, Care Plans or GP engagement. We were more involved in issues relating to the Area Health Service buy in to the project"*

What the project did tell us is that developing effective communication strategies is essential for clear understanding and collaboration from key stakeholders, and time has to be invested in this process.

The outcome of this is supported by the literature where the mix of public, private and community based services are seen to be complex , poorly coordinated and understood, siloed with often conflicting assessment and consent protocols. There is also confusion over role delineation, and little agreement on a common language or referral pathway for palliative care (Currow 2003, WA Health Dept 1997, RDGP, Hudson 2003, PCA 2008).

5. Multidisciplinary Care Planning

Delivering multidisciplinary care for people requiring palliative care requires a shift in the focus of health systems from separate entities to a more integrated model of care. It requires separate entities such as acute care services, general practices, community health centres, aged and community care services and private enterprises, to shift the care across organisations for a region or a group of people[23]. Holtom (2001) in the APHCRI report offers the comment that integration of services is different to collaboration or partnerships, in those individual systems must change to allow for the integration of a new flexible, dynamic solution. For palliative care services to adapt to

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[23] Aust Primary Health Care Research Institute. (APHCRI) (2006) Integration, Coordination and Integration in Australia: Growth via optimal governance arrangements.

changing palliative care needs of rural communities, services need to be integrated into a 'system' of care delivery[24] across regions.

Palliative Care Australia in their "Glossary of Terms" published in 2008, describe multidisciplinary teams as a " mix of health care disciplines, who share common goals, collaborate and work together in planning and delivery of care." The process of developing a true multidisciplinary team in rural communities requires a shift to integrated care systems, bringing specialist and primary health care services together, across often large geographical areas, with limited communication structures, depleted professional workforce, and growing aged care community. This process requires multi-skilling, trusting relationships, good governance, adequate resourcing, and a willingness to place the patient and their family and care giver/s as the unit of care at the centre of the care continuum.

In the Victorian Government Breast Services Enhancement Program[25], they indicate that the "effectiveness of multidisciplinary pathways and protocols in facilitating inter-professional communication depends on the implementation strategy and their integration with other coordinating mechanisms."

5.1 How this was applied to the project

The project identified through the literature and input from the steering committee that a multidisciplinary approach to care planning and case management would achieve the best possible outcomes for patients, their families and carer giver/s across the rural communities. This however was difficult to achieve due in part to the poor communication processes across most of the rural communities and poor buy in from project partners, resulting in poor collaboration and ineffective partnerships. This created the challenges the case manager encountered in the implementation phase of the project.

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[24] WA Health Department (1997) Palliative Care: The Plan for Western Australia

[25] Victorian Government (2005) Learning from the past – Informing the future: Continuity and Coordination of care – Improving the cancer journey. Breast Services Enhancement Program:

As the project expanded, and relationships and trust was developed in many of the communities, multidisciplinary care that included the following was achieved:

- common goals of care
- continuity in care provision
- effective communication strategies
- trusting relationships
- clear role delineation
- sharing of common assessments and referrals.

5.2 Results

A lesson learnt from this project, backed up by the literature on rural and remote service provision, is that good governance and a willingness to break down silos and incorporate change across systems is the key to effective and outcome focussed integration and multidisciplinary care.

In many communities there was willingness by all service providers across the specialist and primary health care sectors to work in an integrated and multidisciplinary manner, however without good governance and integration from key decision makers and stake holders, then this willingness is not sustainable. The process ends with the personnel, and is dependent on current available resources. The success factors and barriers put forward by the APHCR for good governance to ensure patient centred multidisciplinary care occurs are included in Appendix 9.

The information provided by the APHCR report is backed up from interviews in the evaluation of the project implementation, and evidenced in the literature as to what needs to be done and when for good governance to allow integration and the provision of client / patient centred multidisciplinary care.

6. Continuity of Care and Seamless Referral Process

Continuity of care is believed to be a key factor by patients and their carers in being able to have their needs met across the complexity of the care system. It has been proven to improve health outcomes for patients, their families and carers beyond that of just clinical outcomes.

Achieving continuity of care and care coordination is a shared responsibility across the health care team, and is a system based approach that relies on linkages and open communication across the health and community care system, between the public and private sectors and specialist and primary health care. Care Coordination for the patient their family and care giver/s often means, however, that there is one key contact. This person has a relationship of understanding and the development of trust and mutual respect that goes beyond and enhances continuity beyond just a series of processes [26].

The Clinical Oncological Society of Australia in 2007 conducted a report[27] on care coordination, which is the basis of achieving continuity of care across the various health and community care sectors. Their report states that "*in the absence of appropriate coordination of the different elements of care, patients and their families report becoming lost in the system, often experiencing unnecessary morbidity and distress. Lack of coordination between services can result in fragmented care, sub-optimal management and high health care costs. Such fragmentation of care is exacerbated by the absence of clear referral pathways and suboptimal communication between health care providers and between providers and patients.*"

Professor Patsy Yates in this workshop also commented that achieving continuity of care is a multilevel issue and that a range of other strategies may also be relevant to its implementation, including development of role descriptions and education of health professionals [26].

6.1 How this was applied to the project

Achieving continuity of care and care coordination in rural communities faces enormous challenges and barriers in part due to the very nature of Australia's diverse geography and isolation.

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[26] Victorian Government (2005): Continuity and Coordination of Care – Improving the cancer journey

[27] Clinical Oncological Society of Australia (2007) Care Coordination Workshop report. Report given at the 34th Annual Scientific Meeting of the Clinical Oncological Society of Australia.

To achieve continuity of care the following strategies were initiated:

- the case manager was appointed to be the point of contact for referrals to the project with the intention to liaise with families, local health and community care providers
- individual and local communication pathways were developed in each community
- discussions were held with individual patients, their families and carers and information provided as to the members of their local team, and methods of communication
- a range of communication methods were used across different providers as not one method was suitable for everyone. Email, Fax, phone – both land line and mobile and teleconferencing were used, depending on the technology and telecommunication availability. Mobile phone reception is still problematic in many areas of rural and remote Australia, and email is not available to many rural health care workers.
- home notes were trailed in some communities
- the case manager attended pre existing continuum of care meetings in several communities

6.2 Results

This project faced additional challenges in achieving optimal care coordination due to the governance and integration issues identified previously. There were successes as well as lessons to be learnt over the life of the project. Local communication pathways were modified where barriers existed, specific role descriptions were identified and considerable effort was expended on building local relationships and systems. Continuity and coordination was greatly improved by the end of the project. The challenges identified that impacted on continuity of care were:

- territorialism and traditional turf issues
- lack of understanding of case management or joint case management
- poor understanding of the project at the local level and lack of clarity as to what the expected outcomes were

- no one communication pathway used across all local communities
- not all service providers having access to electronic (email) or mobile telecommunications
- part time or agency local community nursing staff
- large geographical area

It was explained to community nurses particularly, that communication is a two way process and many of the communication issues faced by the Case Manager and reported by the community nurses were due to different hours of work. If there was no buy in from managers to the project, then nursing staff were not released to attend multidisciplinary meetings or education sessions, adding to the lack of awareness. Many of the nurses did not have access to mobile phones or email, making communication difficult and there were often long periods of time between contact to and from the case manager.

The following are comments from rural community nurses regarding care coordination early in the project:

> *"There are a lot of programs around...staff need to be refreshed as to what program it is, how it works and how to contact people".*
>
> *"It didn't work at the start. Miscommunication! If we had known about it (the project) from the beginning we might have worked better together".*
>
> *"Scheduled and prearranged teleconferences would have been good if resources allowed."*

At the end of the project most of the stakeholders however felt that the case manager had improved care coordination, had improved psychosocial care, had provided support to the health care team, and that the project had made a difference to people requiring palliative care in their communities.

> *"Having a case manager is a positive way to go. Leaves us nurses to do the clinical things".*
>
> *"The family did receive a visit from the case manager. They became aware that she was available as a resource and support person. They were appreciative of having the service in place....loved the little things like the carers box, their recognition of the carer as an independent person".*
>
> *"For the patient ...their whole care improved."*

7. Psychosocial support for the patient, carer and family including grief and loss / bereavement information and support

Psychosocial care is identified through all the literature as an important component of Palliative Care. The Clinical Oncological report commented that it is often when non clinical issues are resolved, that clinical issues have better outcomes for patients and their families. The Standards developed by Palliative Care Australia (2004) place psychosocial support for the 'unit of care' being the patient, the family and carer/s as important as managing physical symptoms.

The principles of providing Palliative Care are concerned with providing *quality of life* at *the end of life*. That includes providing excellent clinical and psychosocial care. Providing excellent or evidence based psychosocial care incorporates such things as:

- empathy and compassion
- respect for the person's personal and social circumstances
- optimising the person's sense of control and personal resources
- seeing the person, their family and carer/s as the unit of care and not separate entities
- the provision of holistic, person centered care
- open, honest communication with regard spirituality, sexuality and intimacy, personal choice regarding preferences for dying
- acknowledgement of grief and different manifestations of grief responses such as: anticipatory grief as seen with chronic illness, complicated grief where there have been multiple or unresolved losses, unrecognised grief as felt by care giver/s or other people caring for the dying person
- use of assessment tools for identifying issues such as depression, quality of life, carer strain, suicide ideation.

Psychosocial support and care is multifaceted and multidimensional and has to be the responsibility of the whole team. Having dedicated professionals such as social workers supporting the clinical team enables the psychosocial issues to be incorporated and supported across the care continuum.

7.1 How this was applied to the project

Finding ways to provide optimal psychosocial care based on evidence based and best practice initiatives for patients their families and carers was an important part of the research project and a variety of interventions and sustainable models were trialled via the RDGP project.

A variety of documents were used to guide the steering committee's working party on psychosocial interventions. Key documents included:

- Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advanced stages of a life limiting illness, and their care-givers – an MJA special supplement
- Psychosocial care of people with cancer
- Caring for the Spirit: lessons from working with the dying - Bruce Rumbold
- Spiritual Care for Self and Others – Anne Bloemhard
- Caring Communities – Alan Kelleher
- The Hardest thing we have ever done – Palliative care Australia
- There's no place like home – NSW Cancer Council

7.2 Results

From the beginning of the project, carers commented positively on the psychosocial support provided and having someone available to "talk things through". The discussions with patients, families and carers centered on personal goals and hopes for their future, and how their care reflected this. Other issues were explored such as feelings about dying, knowledge of the dying process, thoughts of an afterlife, concerns, fears, and stages of grief. Several of the families referred to the project had young children, either their own, or grandchildren, and so age appropriate resources were provided, and a chart explaining children's stages of grief was adapted from the Children's Hospital at Westmead and used with these families. This and other grief resources are included in Appendix 10. During the interviews with carers as part of the evaluation process, many carers indicated that they greatly appreciated the support provided and wished that it had been more readily available whilst the patient had been alive and for longer periods after. The following are comments from carers:

> *"The only thing was that we didn't see enough of xxxx (CM) because she was too busy. I mean to have a coffee and a chat. She was an absolute saint. She would come in here and have a chat and it was like – oh god, someone understands. You walk around and think you are mad – but it is amazing to have someone who understands and can talk to you..."*
>
> *"...the program worked well...when the case manager came on board the weight lifted as support was provided. She knew what was needed and anticipated issues and problems. She provided counselling and was there to talk things through. She was very understanding, but understaffed and needed help."*
>
> *"The only thing I look back on and think that I should have contacted the case manager earlier. Then Dad got to the stage when he really needed her.....yes, the case manager came out and saw Dad and we had only been told the news a couple of days before that...She discussed the outcome with Dad, myself and my sister and spoke to Dad at length about what to expect and how he felt. She asked what his fears were..... It was wonderful what she did for us and how good she was to us. You have no idea what it meant for us to have that support..."*

Initially the community nurses and CNC staff were concerned that the Case Manager duplicated the psychosocial role provided by nursing staff. One of the measures to alleviate concerns was to ensure that the community nurses were available to provide combined home visits. This proved to be very effective in that the community nurses reported feeling more confident in the case management role, and they could appreciate the complementary nature of the role. This shared care arrangement, or joint case management, became the ongoing model in many local communities, particularly in communities where the community nurses had a passion for providing holistic palliative care.

Comments from members of the local community multidisciplinary team include:

> *"This program offers something different – good psychosocial support for the families when they need it. Time to talk to the families is so important, it allows us to do the nursing better and worry more about symptom control. Having a Social Worker was crucial to the success of the psychosocial supports and advanced care planning...."*

The steering committee acknowledged that adequate access to specialist psychosocial support was difficult due to the large geographical region, the large number of referrals to the project and limited access to additional or locum qualified allied professionals.

An outcome of the RDGP project was to upskill local health care providers to provide this level of support for the patients, families and care giver/s. This is an ongoing commitment with the new AGPN Rural Palliative Care funding round.

8. Home Notes

Home notes or patient held records are recognised in the literature as having benefits for patients, their families and carers, health professionals and community service providers. They potentially give patients more control of their information, greater ability to be involved in their treatment and care and increase confidence with information provided and reduce uncertainty[28]. Their use, however, is influenced by the commitment of their health care providers to completing the record and assisting them with necessary information.

The amount of literature describing different types of patient held records, home notes or diaries indicated that not one type of record suits all people or service providers, however all indicated that there were benefits to be achieved regardless of type.

8.1 How this applied to the project

The steering committee instigated a working party to look at the range of patient held records (PHR) or home diaries available and decide on a common form of home notes that could be shared across the multidisciplinary team. They had to include both clinical and psychosocial records as well as generic patient information. Two models were specifically looked at – the GAPs Patient Held Record and the Adelaide Hills Rural Palliative Care Project Patient Home Diary.

The working party developed a trial model with the view to continually review and modify the record over the life of the project. It was anticipated that this would be a sustainable resource used by the rural community nurses depending on the results of the patient evaluations. A copy of the Home Notes is included in Appendix 11.

8.2 Results

There were difficulties implementing the home notes across the region. As the research states the success of such records is dependent on the commitment by the health care

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[28] Victorian Government (2005) : Continuity and Coordination of Care

providers using and completing them with the patient and the family. The failure of the Area Health Service to have commitment to the project meant that this initiative was dependent on individual multidisciplinary teams in only some of the communities where referrals were received, using them effectively and routinely. This difficulty again reinforces the importance of a good governance model for new projects and commitment and buy in by all stakeholders to enable initiatives to be effective and improve patient outcomes. Despite this barrier, the home notes were used as often as possible, and many patients used them for their own information and communication with their GP and the case manager. Comments from the community nurses regarding home notes include:

> *"Home notes improved communication and were a good resource for the GP's – They came back to the centre (when the patient died) and were retained in the files at the centre."*
>
> *"Sometimes with the home notes – you don't know what to write – you have to be sensitive to the patient and carer needs"*
>
> *"Ongoing education would have helped, especially with home notes.."*

Comments from families and carers include:

> *"The pain scales are good. They help us manage the pain and know what to tell the GP and nurses. We didn't know about such things. In the communication section, we can write about how his days are going...saves trying to remember all the stuff." Husband*
>
> *When Mum died we read the home notes – comments and medications and such. It made such a difference to managing all the care. We know we did everything we could – you forget little things as you are so busy doing it all. The home notes help us to remember." Son*
>
> *"We all had our jobs... different shifts. Mum did the day and I did the evening. Having the diary helped me to let Mum know things that happened, and she could carry on without me telling her, or her asking it all." Daughter*

9. Carer Support and Information available twenty four hours a day, seven days a week

Research undertaken by Peter Hudson[29] has looked extensively into the needs of caregivers and family members in caring for someone requiring palliative care. Palliative Care Australia and the NSW Cancer Council have also undertaken extensive work looking at the needs of caregivers and the challenges they face as well as the benefits they experience when providing care for a person requiring end of life care. The needs of carers have also been identified by carers' organisations and are well documented. An important international document to guide carer inclusion and strategies is the "Carer Compass" developed in the UK by the King's Fund, which is a framework developed to support carers across the 8 domains that the research has identified that carers need support. (see Appendix 13).

The ComPacks evaluation report also identified the challenge of providing adequate support for carers across their carer journey. Their report adds the additional comment that ' *the expectations of carers and agencies expectations of carers is changing rapidly to align with different generational expectations of supporting family needs*". This will be the challenge for a comprehensive, holistic, system based model of care and will need to be further researched to ensure that future carers are not marginalised with traditional notions of care and care giver roles.

This body of knowledge was used to inform the research model and RDGP project centering around the following themes regarding carers. The significant issue identified is that carers experience difficulties across a range of areas, and often 'make do' with whatever information and support is available[30].

Some difficulties that have been identified by this research and what carers have identified in the evaluations of the RDGP project are:

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[29] Hudson (2003) Home based support for palliative care families: challenges and recommendations.

[30] Palliative Care Australia (2004) The hardest thing we have ever done. The social impact of caring for Terminally Ill People in Australia.

- carers need access to financial support that is appropriate to their employment and life situation
- carers face difficulty in maintaining employment, and having access to flexibility in work place arrangements to meet the changing needs of the person they care for
- carers need adequate information regarding the progression of the disease and issues that may impact on their ability to provide adequate care for a person who is dying
- carers need education about the management of symptoms and pain relief
- carers need access to respite that is appropriate to the age and circumstances of the person they provide care for
- carers need access to psychosocial support, empathy and compassion
- carers need access to support services that are responsive and affordable
- carers want to be fully involved in decisions regarding care and treatment of the person they care for
- carers include people of all ages and their age, experience and confidence in caring for a person who is dying needs to be taken into account
- carers want to be recognised and respected as individuals in their own right with health needs and issues separate to but also with their person they care for

Key recommendations suggested by Hudson [28] for improving family centred palliative care are included in the Appendix 13.

9.1 How this was applied to the project

Carers were provided with a range of support materials and information based on what the literature and carers were telling us that mattered. A Carers Pack (see Appendix 12) was developed with a range of resource materials, individualised information and samples and provided to approximately 80% of all carers referred to the project. The RDGP developed a booklet : Caring At Home, adapted from the South Australian Palliative Care, Carer Support material which was also supplied to all carers as part of the carers pack.

Integral to carers support was the partnership with the Commonwealth Respite and Carelink Service (CRCC) located in Wagga Wagga, and auspiced by Intereach. This service is a Commonwealth funded, carer focussed service providing 24 hour short term or emergency support and assistance. Referrals were made to this service if carers were identified as having a need for short term assistance with domestic duties or with their provision of personal care for their loved one. The carers were then provided with the twenty four hour per day, seven day per week emergency service number. This service was explained to the families and carers, resources and flyers were provided about the CRCC including and a fridge magnet as a reminder of the 1800 number.

In many instances there was a lag time between referral to the local community service or Home and Community Care (HACC) service for domestic assistance or personal care. In this instance, the CRCC was able to provide short term brokerage funding to commence the service so that care was provided at the time of need. They were able to contract services directly, or in some instances, pay for the hire of essential equipment. This filled the gap for carers until the local services were able to do their assessment and provide the necessary services. CRCC in some instances were able to 'top up' regular HACC services so that an appropriate amount of care was provided to the patient in order to provide respite for the carer. The range of Riverina Murray CRCC services is listed in Appendix 13.

A Carer Assessment formed part of the initial home assessment. Issues relating to anticipatory or complicated grief, carer strain or burden and carer burnout were assessed and identified if present. This assessment formed part of the common assessment and referral forms used across the multidisciplinary team.

9.2 Results

The partnership with the CRCC proved to be very successful. They provided the RDGP project with copies of the Carers Guide to accompany the Carers Pack, and their Service Coordinators participated in ongoing training and education sessions relating to palliative care. Carers referred to the CRCC were able to receive immediate, brokered personal care and domestic services for short term assistance until the local community service provider was able to conduct their assessment and provide an ongoing service. In instances where the patient did not have long to live, or the family and care giver/s needed short term assistance whilst the patient was receiving treatment, the CRCC brokered services for this short period of time. The carers were able to contact the 1800 number at any time to discuss services, or other carer support available such as Carer Counselling and Young Carers Support. In some instances home care services were required on weekends to enable carers to access respite.

At all times this support made the difference for carers in being able to provide the amount of care that was required to keep the person they were caring for at home as long as possible, and in many cases, it enabled the person to die at home.

Comments from carers included:.

> *"We were able to ring the 1800 number or the case manager after hours if we needed to."*
>
> *"Community nurses didn't say anything about it (the 1800 number). I don't think they knew about it then. When the case manager arrived, she set us up with this support. We could ring if we needed to. "*
>
> *The case manager gave us the carers kit and the phone number(1800). We went through a plan of what to do in the later stages."*
>
> *"Yes...I used the services at the CRCC a lot. I also rang the case manager. This was particularly useful on the night my husband died."*

The systems approach used by the social work model of case management ensured that care giver/s and family members were considered as important as the patient in providing appropriate levels of support and care. The case manager was also able to advocate for the needs of family members and caregiver/s in order to provide the level of care they wanted to and where they wanted to do it.

10 Professional support, education and supervision

Throughout the project, many of the health care professionals commented on the lack of professional supervision and access to ongoing education in issues specific to palliative care. It was also recognised that many community based organisations are providing a palliative approach for their clients and carers that are frail aged, living with chronic illness or disabilities and wish to remain at home as long as possible. Residential Aged Care facilities staff commented to the case manager about the lack of education and support for initiating a palliative approach or palliative pathways in their facilities.

10.1 How this was applied to the project

Several education sessions were offered to community nurses and practice nurses across the region through the RDGP education program, but the lack of support from the Area Health Service for these sessions meant that many staff came out of hours and at their own cost. Additional sessions have been requested. Carer education workshops were conducted in two semi remote communities and included many current and bereaved carers, volunteers from CanAssist and Palliative care volunteers and Home Care service providers. These sessions were well received and evaluations indicated that these sessions provide a valuable opportunity to share experiences, debrief, learn new skills, and generally build a sense of cohesiveness within the communities and community capacity in regard to caring for people who are dying.

The Palliative Care Australia Certificate 111 and 1V were purchased and two information and education sessions were provided for community service providers in the region.

The Case Manager and Social Work students attended state in-services and critical reflection training provided by the NSW Palliative Care Social Work Interest Group. These however, were only provided in Sydney, which for rural practitioners is difficult to manage with busy work loads. It is intended that this group will also run some rural meetings and training in 2009.

Palliative Care education for nurses was provided in Albury and attended by the case manager and a service coordinator from the CRCC. Other online Palliative Care education was sourced, as well as a comprehensive resource library developed for use by RDGP staff, the case manager, CRCC staff and social work students across the region.

10.2 Results

The evaluations of the nurse education and from the community service providers indicated that ongoing education is considered essential to their professional development and provision of integrated palliative care. A range of issues were identified as being a priority for education, which included psychosocial support, advanced care plans, delivering bad news, as well as symptom management and pain control. Further education sessions will be delivered as part of the RDGP Rural Palliative Care funding round.

The Oncology Social Worker for Wagga, the Riverina Cancer Care Corodinator and the Case Manager met monthly for formal professional reflection and support. This was an immensely rewarding opportunity to de brief and discuss issues relating to working with people challenged by death and dying as well as theoretical perspectives and professional interventions.

The community and carer education was also very successful, but time and funding prevented rolling this out to other rural and remote communities. Alternative funding will be sourced by the RDGP in 2009 to continue to develop carer support strategies and education opportunities.

On the road to Talimba, near West Wyalong. NSW

On the road to Tumut, Riverina, NSW

Discussion and Conclusions

The project's achievements and strengths:

Using an action and phenomenological research methodology and ongoing evaluation processes, including critical reflection, provided a solid platform for a new model of care planning – Pall Care Packages, to be effectively implemented to over 350 people and across 32 rural and remote communities in the Riverina.

Even though there were challenges at various points of the model's development, using a process of critical reflection and ongoing evaluation enabled many of these challenges to be resolved. The most significant of these challenges, which eventually became a road block was the failure of the Area Health Service to fully participate in the implementation of the care planning model. This failure to collaborate had a ripple effect throughout all of the rural communities, which made many of the interventions such as MDT and continuity of care difficult to achieve. Where it did work, it was due to the effort that was put into developing trusting relationships, clear role delineation and the identification and support of champions at the local level.

Before the commencement of the project, there appeared to be minimal information available to patients requiring palliative care, their family members and carers, and the support provided to them was ad hoc or and dependent on the knowledge of or referral to community nurses. Prior to the project, if a patient required palliative care it was only provided by the community nurses, backed up by a Palliative Care CNC with many nurses in rural communities working part time with no back fill for holidays or sick leave.

There is no specialised psychosocial support for the patient, other than that provided by community nurses, who many have indicated, lacked training in end of life care issues and advanced care planning, nor was there specific carer support provided. Minimal equipment was provided in some instances by the community nurses, and people who had accessed community aged care packages already had most functional equipment supplied. Many rural communities have a very limited equipment pool, and equipment is generally not available through PADP for palliative care patients.

Both community nurses and GP's reported in the evaluations that there was no formal after hours service, and many patients stated that they had difficulty accessing GP appointments when they required them. Many patients stated that they used the emergency departments of local hospitals if they had problems, or just waited until they could be seen.

Pall Care Packages has elements that all stakeholders, at all levels, agreed made a difference for patients, their families and care giver/s. The key success factors were:

- patients, their families and carers were **referred earlier** to palliative care services due to the relationships developed with the Cancer Care Coordinator, Oncology Social Worker and HACC regional manager
- **communication was improved** between the cancer care coordinators and local service providers
- **practice Nurses became involved** in the early notification of palliative care patients who were triaged when they rang the GP clinics. Many patients were able to be seen immediately by the practice nurse, or an appointment was facilitated with the GP if necessary
- **care Plans were developed** by the Case Manager and communicated with all members of the care team. GP's were able to claim the Medicare EPC (Enhanced Primary Care) initiatives for contribution to a care plan, GP Management Plans and Team Care Arrangements.
- **carers were recognised** for their essential role in supporting the person requiring palliative care, and initiatives developed as part of the model, such as the Carer Pack; access to CCRC after hour support; and grief and loss support, were greatly appreciated
- several carers (4%) were **identified early as being at risk o**f complicated grief and referred to the GP Mental Health program and subsequently referred to a psychologist.
- **GP's** reported that they felt the **project was beneficial** as patients, their families and carers reported positive outcomes

- there was **increased awareness of the Commonwealth Respite and Carelink Centre** across the rural communities
- a **specialised social work case management model** was trialled, and the evaluations indicated that this is a very effective, essential role in providing holistic palliative care
- **liaison has occurred with local rural universities** for the identification of opportunities for ongoing Social Work and Nursing student placements in Palliative Care
- **the packages approach assisted in acceptance of the model** with the clinical providers and took away the misconception of duplication of roles

The areas that presented challenges to the implementation of the model and have been discussed elsewhere in this report, were issues related to governance and communication. The GAPs model that was extensively evaluated and became the basis for the Rural Palliative Care Projects had already identified that difficulties would arise if there was not strong governance and early buy in by all stake holders. Time has to be dedicated to this process for projects to be a success.

Unexpected outcomes

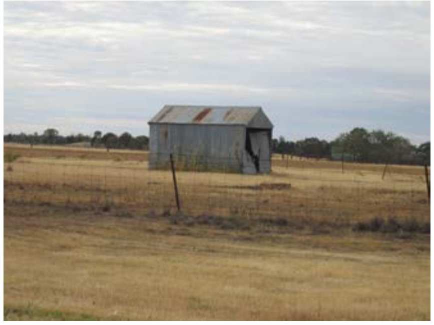
There were many opportunities that arose from the project that could be considered with additional funding for further research opportunities. These were considered to be unexpected outcomes from the research project. Some of these were:

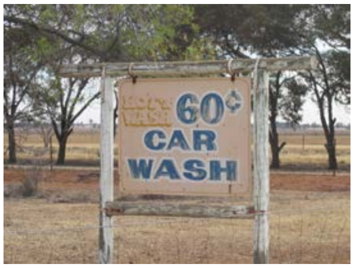
1. **Partnership with Home Hospice** to roll out their program of Volunteer Home Mentors, and to offer training programs for volunteer mentors in rural communities. This will enhance the support available to carers of people requiring palliative care and have expressed a wish to remain at home as long as possible, or to die at home. This will roll out in early 2009.

2. **Development of a quality project with the Cootamundra HealthOne** Medical Practice in developing initiatives to support patients and their carers accessing psychosocial support and timely access to their GP's through involvement of the senior Practice Nurse (PN). This project is supported by the

Case Manager, the RDGP palliative care project, the GP principals, and the AGPN. It is envisioned the practice nurse will receive referrals from a variety of sources, and discuss with the relevant GP the development of a GP Management Plan and Team Care Arrangement, which will in turn provide for allied health referrals. In this way the PN can work with the GP, using the Medicare EPC initiatives, for people who require palliative care, their carers and families. If this project is successful, then it will be rolled out to other GP clinics and practice nurses with allied health professional input for specialised psychosocial interventions.

3. **Discussions with local universities** – social work and health sciences, regarding specific training and learning outcomes in palliative care as a separate area of study, in order to encourage more SW and other allied health care workers to gain competency in aspects of Palliative Care – whether it be specialised Palliative Care or in understanding and providing the palliative approach in a range of settings.
4. **The collaboration with the NSW Cancer Council** policy branch in providing contributions to the PADP enquiry from outcomes of the research especially in regard to equipment availability and provision for palliative care patients, and their carers.
5. **Working with the Case Management Society of Australia** in examining best practice in case management for palliative care and identifying aspects of the CMSA standards that are relevant, as well as opportunities for ongoing education for case managers in the palliative approach and primary palliative care.





Rural scenes on Mangoplah Road – Urana, Riverina. NSW

Recommendations

Based on the implementation and evaluation of this research project and the development of PallCare Packages as a new model of providing evidence based Palliative Care across rural communities, the following recommendations are made to government. As this model has system wide impacts, the recommendations are divided into the three system impact areas – Organisational, Provider and Client.

ORGANISATINATIONAL LEVEL RECOMMENDATIONS

1. **Implementation of PallCare Packages across all rural regions, however it is suggested that initially three broad geographical regions would be extensively trialled.** Initially these areas could be :the Riverina Murray, North East Victoria and South West NSW. This would provide an opportunity to trial the model across three distinct rural and semi remote regions and across state boundaries.

Once trialled and further refined, negotiations could commence with the states and territories to fund the incorporation of PallCare Packages model within their relevant palliative care policy frameworks. Adequate funding would need to be allocated to ensure that all elements that have been identified as being successful to implementing a coordinated, evidence based, specialised psychosocial program – such as flexible brokerage of equipment and services, home notes, multidisciplinary care planning and continuity of care be fully implemented. This funding would be similar to ComPacks, however with differences due to the specialisation of the Case Management role and complexity of the client need.

2. **That a Peak Body be funded as an external organisation to provide governance and management of PallCare Packages and monitor the implementation of the model across rural regions of Australia**. This model is similar to the establishment of ComPacks.

2.1 This organisation would be responsible for reporting, data collection, and evaluation processes, as well as research and project development in the areas of rural Palliative Care.

2.2 The Peak Body would be responsible for the development of a comprehensive evaluation plan in collaboration with the University of Wollongong, Centre for Health Service Development.

3. **That Rural Palliative Care Collaborative Networks be established with the Peak Body as lead agency, to facilitate cross sectoral communication, professional development and planning.** This would ensure that regional and rural Palliative Care programs were integrated across all clinical levels of care (specialist and primary health care) and the community service sector.

These Networks would foster links with rural Universities to:

- develop research projects related to rural Palliative Care
- encourage and facilitate student placements for Health Science students in Palliative Care Services – both clinical and non clinical placements
- develop elective subject courses for Social Work students in Palliative Care and End of Life Care Planning
- collaborate with the Charles Sturt University, Centre for Inland Studies, in developing and funding an Rural Palliative Care Advisory Group with key stakeholders such as Cancer Council, MS Society, Oncology specialists, Rural Divisions of GP's, Rural Palliative Care CNS, AHS Palliative Care Development Manager, DADHC Regional Managers, PADP Managers, and other interested organisations in identifying organisational and service delivery barriers across rural communities.

4. That this Peak Body collaborate with the Palliative Care Outcomes Collaborative (PCOC) in the dissemination and collection of palliative care data and the development of and education in the use of community based data tools.

5. That the Palliative Care Social Work Interest Groups and Palliative Care Australia develop Social Work standards for Palliative Care similar to the National Association of Social Workers in America. This would allow for the development of a specialised social work role, underpinned by specialised standards of practice in providing psychosocial care in Palliative Care and End of Life Care.

6. That the Medicare Allied Health initiatives be broadened to include a category for rebatable items for specialist Social Workers and Psychologists providing Palliative psychosocial care and end of life care.

PROVIDER LEVEL RECOMMENDATIONS

7. That the PallCare Packages, through effective governance by the Peak Body, develop effective collaboration with service providers in each local community, and identify gaps in service delivery to patients, their families and caregivers requiring palliative care.

8. That a phenomenological rural research project be funded to elicit the lived experience of patients, their family members and caregiver's experience of the transition from curative care to palliative care. This will provide valuable insights into the specific psychosocial supports and interventions that are considered useful, identify language barriers and communication strategies to enhance and improve these people's experience and understanding of Palliative Care and End of Life Care, ace to be cared and understand the key issues that support a person with a terminal illness to live until they die.

9. That all patients with a terminal illness be identified early in their disease trajectory and that a palliative approach to care planning and supports be available that considers the psychosocial aspects of living with a terminal illness.

10. That consistency be developed in defining a person requiring or referred to Palliative Care across all chronic disease trajectories, and that both the clinical health care team and community service providers share a common language. This will greatly reduce confusion for patients, their families and caregivers, and provide consistency and equity of access to high quality palliative care across all rural and remote regions.

Driving to Cootamundra North of Wagga Wagga, NSW

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Abbreviations:

AASW:	Australian Association of Social Workers
AHS:	Area Health Service
APHCRI:	Australian Primary Health Care Research Institute
CCRC:	Commonwealth Carer Respite and Carelink Centre
CMSA:	Case Management Society of Australia
CM:	Case Manager
CNC:	Clinical Nurse Consultant
CNS:	Clinical Nurse Specialist
DADHC:	Department of Ageing Disability and Home Care
DoHA:	Department of Health and Ageing
DADHC:	Department of Disability, Ageing and Home Care
GAPS:	Griffith Area Palliative Care Service
GP:	General Practitioner
HACC :	Home and Community Care
LGA:	Local Government Area
MOU:	Memorandum of Understanding
NET:	National Evaluation Team
OH&S:	Occupational Health and Safety
OT:	Occupational Therapist
PADP:	Program of Appliances for Disabled Poeple
PCA:	Palliative Care Australia
PCOC:	Palliative Care Outcomes Collaborative
PN:	Practice Nurse
RCCC:	Riverina Cancer Care Coordinator
RDGP :	Riverina Division of General Practice and Primary Health Care
RPHC:	Rural Primary Health Care
RSDG:	Regional Social Development Group
WA:	Western Australia

Commonwealth Department of Health and Ageing

Local Palliative Care Grants Round 5

The Amaranth Project : Your Mind Does Matter

Julianne Whyte
CEO
Amaranth Foundation

www.amaranth.org.au
julianne.whyte@amaranth.org.au

Phone: 0409 388533

EXECUTIVE SUMMARY

The Your Mind Does Matter project aimed to develop a “Social Work Palliative Care Case Management” approach for the delivery of a “PallCare Packaged” model of care, and to pilot the integration of mental illness into ‘palliative care’ care planning and case management interventions for people with life limiting or terminal illnesses across selected rural communities.

There were several successful strategies adopted that were based on the action research models developed over previous Palliative Care Grant Rounds (3,4 and 5). These included:

- The development of a **social work palliative care case management model, using Mental Health Social Workers,** that addressed the complex needs of people with terminal illness and those with a mental illness, either pre existing or developed as a result of the diagnosis and prognosis;
- **The utilisation of the Chronic Disease and Mental Health Medicare items** for bulk billing and involvement of other primary health care professionals in Team Care Arrangements and Multidisciplinary Case Conferencing;
- **The development of a Rural Primary Health Palliative Care Resource and Information Guide** based on best practice models;
- **action based research using both qualitative and quantitative methodologies,** and a comprehensive literature search of the needs of people with terminal illness and those **experiencing mental illness and psychological distress;**
- the delivery of **appropriate education and training for primary health care clinicians** and service providers in mental health issues for people with terminal illness, their families and care givers utilising an asset **based community development approach** to plan, develop and coordinate community engagement and education events and training**.**
- The development of a collaborative partnership with **NSW Ambulance in the use of their P1 Adult Palliative Authorised Care Plan.** This included a comprehensive education and information campaign across several rural communities.
- **Roll out of the Advanced Care Planning and Family Planning Guide based on the Respecting Patient Choices® Program.** These resources were developed using a Dementia Community Grant, and with endorsement from the RPC team.
- **Team based or shared care approach to patient and family support,** where the MHSW accompanied the community nurse on home visits, and provided psychological assessment and the provision of psychological interventions where appropriate to the patient and or the care giver.
- **Use of Home Diary,** based on the Flinders Chronic Disease Self management model.

A significant outcome of this project was a greater understanding of the extended and specialist role of Mental Health Social Work in Palliative and End of Life care across the primary health care sector, and the endorsement by the Australian Association of Social Workers, and the newly formed Australian College of Social Work for the development of competency standards for Social Workers in this important field of practice.

The project, Your Mind Does Matter, delivered psychological assessment and interventions to over 100 patients, with a further 250 family members and care givers supported through out the eighteen months.

Evaluations with bereaved carers and family members has identified that programs like this should be continued, and they have commented that their **distress had been greatly reduced, and their coping in the bereavement period enhanced** due to having access to the professional support that the social workers provided. Patients reported that they benefited from :

- Having someone to coordinate their care

- Having someone to anticipate their equipment and support needs
- Having someone to advocate for them in navigating the health and community care system
- Having someone available to talk that is not afraid to talk about the “hard “stuff – like is there a God, why should people suffer, how can I have hope?
- Having someone that will answer their questions honestly
- Having someone that considers the family and care givers as equals in the care team
- Having someone that is respected by their other health care professionals.

FINDINGS

Examination of the positive outcomes as well as the barriers to implementation and sustainability of the project have identified many issues with the provision of quality, evidence based psychological care for people requiring palliative and end of life care. A summary of the key findings are:

- **Enormous gaps exist in the provision of appropriate, timely and evidence based psychosocial interventions** for people with life limiting illness, their families and caregivers across all rural communities
- People with MH issues or those with psychological distress **felt that these issues were not adequately addressed** by existing services
- Primary health care professionals stated that they **felt unskilled when working with people with terminal illnesses, or with grief, loss and bereavement**, and that symptom management was paramount or took precedence in palliative care
- **Lack of understanding of the psychological and psychiatric needs of people** with terminal illnesses, their families and care givers.
- **Lack of knowledge and awareness of appropriate screening and assessments tools** to identify psychological distress for people with terminal illnesses, their families and care givers
- **Lack of care planning and referral pathways for people requesting hastened death** or requesting euthanasia.
- **Referrals for psychological support occurred late in the disease trajectory** and were then acute or crisis driven
- **Advance care planning conversations and recording of statement of wishes was poorly done** across all communities. NFR orders were only discussed at end of life and only relevant for each admission.
- **Values and issues related to dignity, finding hope and meaning** were seldom well addressed.
- **Paucity of literature regarding primary health care psychosocial or psychological interventions for people with mental health issues and co existing terminal diseases or conditions.**

RECOMMENDATIONS:

Recommendations to policy makers and fund holders for primary health or palliative and end of life care as a result of the Your Mind Does Matter project include:

- recognition and support for the AASW in the development of specialist Mental Health Social Workers in Palliative and End of Life care to ensure that psychological care is provided in a manner that responds to the unique needs of people living with dying, their families and care givers
- that support is provided to enable the lobbying of increased access to Medicare items under the Better Access to Mental Health for specialist Mental Health Social Workers where a referral from a patient’s general practitioner is delayed or difficult to obtain

- that the Respecting Patient Choices® program be considered as an appropriate universal resource to address the clinical and psychological needs of people who wish to record their wishes
- that the NSW Ambulance P1 Protocol – Authorised Palliative Care Plan be supported and implemented in collaboration with key health care professionals, including those in primary health care, and not just limited to specialist Palliative Care teams. That this initiative be evaluated for implementation nationally
- that where successful and rigorously evaluated projects that address the needs of people requiring palliative and end of life care, and their family and care givers, are provided with ongoing funding to enable sustainability and the commitment to change. This includes both an emphasis on the clinical and psychological outcomes as equal determinates of care provision
- That the WHO definition of palliative and end of life care as well as the Australian Standards for quality Palliative Care be fully understood, implemented and evaluated across all programs and settings, including primary health care settings.

CONCLUSION:

Amaranth Foundation have made a commitment to providing quality, evidence based psychological care to people living with the effects of an advanced chronic or terminal illness, their families and caregivers. Their Mental Health Social Workers have a commitment not just to the individual concerned, but to the family, caregivers and community in which they live, and also to organisational and structural change.

The model developed over the past six years and with consecutive Local Palliative Care grants, has been rigorously evaluated and tested across many regional, rural and remote communities, and can be translated into the metropolitan setting. Individual and families have reported that the shared care model and personalised MDT, as well as the access to bereavement support and care changed their experience of living with dying.

The collaboration with the NSW Ambulance further enhanced the Foundation's responsiveness to individuals' and families' concerns in regard to Advanced Care Planning, and is a program that will continue to grow as clinicians become more educated in the role of these highly trained paramedics in palliative and end of life care.

Whilst the Foundation is appreciative and grateful to the Department of Health and Ageing for the awarding of successive grants, it is considered vitally important that successful projects that deliver value for money, receive ongoing funding to ensure that the gains and organisational change made are continued and committed to, especially with such vulnerable groups of people.

How people live matters – and people die as they have lived. Providing the right care at the right time can and does make a difference to the lived experience of people living with dying and those that love them in their bereavement. Continuing projects such as Your Mind Does Matter is essential if we want to respond to the unment needs of this population group.

Julianne Whyte
CEO
Amaranth Foundation

FINAL REPORT - AUGUST 2011

Name of Project	**The Amaranth Project : Your Mind Does Matter**
Name of Participant	**Amaranth Foundation**
Target population and/or geographic area the Project covered	People with life limiting or terminal illnesses, their families and care givers across the following rural communities: - **Riverina NSW**: Cootamundra, Coolamon, Junee, Temora, Tumut, Adelong, Batlow, Tumbarumba - **Murrumbidgee NSW**: Leeton, Narrandera, Griffith - **Murray NSW/VIC**: Corowa, Mulwala and surrounding remote villages of Rutherglen, Chiltern and Indigo Valley

Part 1 – Project definition

Purpose of Project	*Please describe the project purpose* *How was the objective achieved? (maximum 250 words)* **Purpose**: to develop a "**Social Work Palliative Care Case Management" approach** for the delivery of a "**PallCare Packaged" model of care,** and to pilot the **integration of mental illness into 'palliative care'** care planning and case management interventions for people with life limiting or terminal illnesses across selected rural communities. **Strategies utilised to achieve this objective**: 1. Developing a **social work palliative care case management model** that works with rural communities addressing the complex needs of people with terminal illness and those with a mental illness, either pre existing or developed as a result of the diagnosis and prognosis; 2. Developing eight **rural outreach social work led primary health care clinics** for people with a terminal illness, their families and caregivers; 3. **Encouraging utilisation of appropriate Chronic Disease and Mental Health Medicare items** for bulk billing and involvement of other primary health care professionals in Team Care Arrangements and Multidisciplinary Case Conferencing; 4. **Developing a Rural Primary Health Palliative Care Resource and Information Guide** based on best practice models; 5. **Researching** the needs of people with terminal illness and those **experiencing mental illness and psychological distress;** 6. D**elivering appropriate education and training for primary health care clinicians** and service providers in mental health issues for people with terminal illness, their families and care givers; and 7. Utilising an asset **based community development approach** to plan, develop and coordinate community engagement and education events and training**.**

Estimated number of people impacted by the project (if known)	*How many people (e.g. patients, carers, staff, other health professionals) were directly impacted by the project? How many people do you estimate will benefit indirectly from the project?* Patients and carers – we currently have **approximately** 350 patients and carers **registered with Amaranth Social Workers. S**creening and assessment for mental illness and psychological distress (HADs, DASS21,Distress Thermometer) was trialled for over 100 patients and primary carers, and an additional 250 family members and care givers were assisted over the 12 month period. **We would have had a direct impact on more than this number of patients and carers throughout the life of the project through educating stakeholders and consumers about Amaranth, EOL, PC, dignity, hope and meaning, at community roadshows, presentations at community meetings, mail outs to community groups, attendance at health expos. Over the past n two months, the impact has greatly increased and direct referrals and requests for information increased, due to the joint initiative with NSW Ambulance in the roll out of the Protocol P1 Palliative Care Management Plan, and the immediate impact of the Leeton Health Expo. The road show which included visits to aged care facilities and individual GP clinics has across Leeton, Narrandera and Griffith communities, and now extending to Alpine and Murray Shires, has increased awareness and uptake of the Amaranth psychosocial support and NSW Ambulance Protocol.** **Staff and other Health Professionals – a direct impact would have been seen in** upwards of 1, 000 health professionals and staff **over the past 12 months through shared client care and referrals as a result of presentations at events such as the regional HACC conference, face to face meetings, dissemination of information regarding our services through Division of General Practice Newsletters, education and information sharing sessions, interagency mailing lists and newspaper articles. The media was well engaged for the Road Shows, with each community and ABC Radio supporting the initiative. These opportunities (radio and print media) created increased awareness and increase in families and health professionals requesting information and referrals. One gerontologist from Wagga made contact commenting that this initiative was "what was required in End of Life Care". He expressed concern as to the current process in place in health facilities, and available to them in general practice, and strongly supported the initiative and requested ongoing information and resources for his practice.** **The catchment area that the project covers has a population of approximately 295, 000 people. Through Amaranth's attendance at 'Health Expos' in a number of towns, articles in the local newspapers, segments on local and ABC radio stations and appearances on the local news, the Amaranth website, as well as the distribution of Amaranth brochures, newsletters, and through word of mouth, we expect the** indirect impact could be close to 300,000 people. **A number of these people may soon move into the direct impact category through hearing about our services and contacting us as they believe we offer services they require.**

Service infrastructure	*List the resources funded by the project grant i.e. what was needed to make the project happen? (dot points)* - Rental of office space and general office equipment, including filing cabinets, bookcases, counselling furniture, chairs - IT including laptops, mobile phones, printer, fax - Lease of Car and travel allowances - Printing of Amaranth brochures - Business cards, name badges - Small equipment purchases to support patients and carers such as mobility and continence aids - Provision of brokered / rented equipment to support patients to be cared for as long as possible at home and to support home death if preferred and possible, such as electric beds, electric mattresses. - Development of resources – Advanced Care Planning resource, End of Life Care Planning resource (“Looking Forward, Looking Back”), Home Diaries, Carers Kits, Memory Boxes, counselling resources to support Mindfullness and Dignity Therapy,

Part 2 – Project objectives and outcomes

Notes:

- The sections ***Project objectives*** and ***Key activities*** should contain information based on your grant submission.
- The following sections should contain information that explains **W*hat actually happened***, as well as ***Revised objectives*** and the ***Rationale for any changes*** if applicable.
- ***Outcomes*** and ***Performance indicators*** should describe the actual outcomes (qualitative and quantitative) that the project achieved and how these were measured.

Where applicable, attach any tools, resources and other material produced for this Project, in support of this Report.

Project objectives:
1. Recruit and develop the roles and skills of the Social Work Palliative Care Case Manager (SWPCCM) in psychosocial assessment and care planning. 2. Develop a project steering committee which functions as a team and ensures project activities are implemented on time and within budget. 3. Implement the current "Pallcare Packages" model in identified towns within the Riverina, providing SWPCCM, brokerage of equipment and access to a range of patient and carer supports, including case management and care planning. 4. Pilot the "PallCare Packages" model in the Murrumbidgee and Murray catchment areas, providing SWPCCM, brokerage of equipment and access to a range of patient and carer supports, including case management and care planning. 5. Provide appropriate education, training and support to all identified Primary Health Care Professionals (PHCP) and key stakeholders in the palliative approach, care planning and end of life (EOL) options. 6. Undertake a needs assessment and implement an asset based community development approach to identify the needs of Palliative Care (PC) patients with a Mental Illness (MI). 7. Support local general practice (GP) and other primary care providers to develop frameworks that facilitate localised and integrated rural case management and care planning for PC patients with a MI. 8. Develop and trial the usefulness of a "Rural Primary Health PC and MI Resource and Information Guide" in the identified Riverina, Murrumbidgee and Murray rural communities. 9. Plan, develop and coordinate community engagement and education events that support the community to care for and understand issues in PC and MI.
Revised objectives (if applicable):
2. Report bi monthly to Amaranth Board of Directors which functions as a working and collective skills based team and ensures project activities are implemented on time and within budget. 3. PallCare Packages Model was changed to a Specialist Social Work Primary Health Care (SSWPHC) Model of Care 5. Provide appropriate education, training and support in the palliative approach, prognostication, care planning and EOL options to PHCP and key stakeholders requesting this education across the Riverina 6. Undertake a needs assessment and implement an asset based community development approach to identify and overcome the gaps that exist around community based EOL care and the screening and assessment of psychological and mental health issues due to living with a terminal illness for patients, their families and care givers. 7. Support local general practice and other primary care providers to develop frameworks that facilitate localised and integrated rural case management and care planning for PC patients with a MI using the appropriate Medicare items. 8. Develop and market a "Rural Primary Health PC and MI Resource and Information Guide" based on best practice models. Have this resource available in hard copy and electronically for the use by other HCP, PHCP and consumers.

What actually happened:

Objective 1:
We recruited a full time SWPCCM and developed the role and skills in psychosocial screening, assessment, care planning and evidence based therapeutic interventions. The role of the SWPCCM included implementing the SSWPHC[1] model of care and developing the monthly clinics held at Cootamundra, Coolamon, Tumut, Leeton, Griffith, Corowa, Henty and the soon to be developed clinic in Beechworth, Victoria. A Community Development Worker (CDW) was also employed who assisted the SSWPCCM[2] to establish the monthly clinics. Orientation and in-house training were provided to all new employees, as well as Professional Development (narrative and dignity therapy) to enhance the SWPCCM skill set in delivering psychosocial assessment and care planning.

Objective 2:
Initially, a project steering committee (SC) with 14 members was established and members formally invited. The first meeting was held on 29 June 2010 with only 3 non-Amaranth members in attendance. Three further monthly meetings were held that were also poorly attended. Considering the poor attendance at these meetings, the ToR were unable to be fully discussed and endorsed and there were concerns regarding time spent at poorly attended meetings including investment in travel time and room hire. There was also a SC established for the Riverina Division of GP (RDGP) Rural Palliative Care project that was seen as a duplication of projects, clinicians and stakeholders. There was initial discussions regarding merging the two SC's, however due to the differences in outcomes of the two projects, this was not pursued further. There was mutual inclusion on both SC's between the RDGP and Amaranth.

Engagement with mental health clinicians for involvement in the SC was difficult due to their perception that Palliative and EOL Care was not their domain.

The Australian Government's announcement to stop social workers accessing Mental Health Medicare funding under the Better Access program in the May 2010 budget, caused considerable concern for all stakeholders and the current SC, causing governance of the SC difficult.

The Amaranth Board therefore took on the role as project steering committee since they were already overseeing the deliverables and budget. An Amaranth Working Group, that included 4th year social work students from Charles Sturt University, and an Assoc/Prof from the social work department of CSU was established to meet monthly to discuss resources, interventions and ongoing implementation issues for the project. Focus groups with consumers (patients and carers) as well as with Rural Support Workers from the Department of Primary Industries in the region, were also established to reflect and comment of project deliverables related to direct service delivery. This turned out to be a better use of staff and stakeholder resources and time. The CEO and Amaranth Working group met with and reported bi monthly to the Board. The Amaranth Board consists of a Business Project manager with involvement in radiopharmaceuticals and cancer treatments, an Accountant with a strong rural practice, a Rural Drought Support Worker/Counsellor from the Department of Primary Industries, a retired Paramedic and now Business Manager with extensive rural management experience, a retired rural Local Government Councillor and farmer. It is believed that the Board has the experience and knowledge to provide appropriate support and assistance to this project. The better than expected outcomes can be attributed to the commitment of the Amaranth Board and Working Party, as well as their ability to have a fresh and questioning approach to EOL and PC. They all had a good working knowledge of Mental Health issues, and were able to question established and traditional models of EOL care, from a lay (non medical) perspective. This fresh approach to the project deliverables as opposed to the initial medically and palliative orientated steering committee, actively encouraged engagement with the community and rural mental health sectors.

Amaranth Foundation has been requested by the Working Group established in Leeton, to continue in the community development role, with the establishment of a Community of Interest Group. The Leeton have expressed a desire to remain engaged in discussing and working through issues relating to caring for people at the end of their lives in rural communities. The minutes and outcomes of these meetings will be discussed with the Amaranth Board.

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[1] SSWPHC: Specialist Social Work Primary Health Care

[2] SSWPCCM: Specialist Social Work Palliative Care Case Manager

Objective 3 and 4:
We have implemented the SSWPHC model through monthly outreach clinics across the Riverina, Murray and Murrumbidgee catchment areas. The model is providing SSWPCCM, brokerage of equipment and access to a range of patient and carer supports, including psychosocial and community based case management (if required), care planning, advocacy, screening, assessment and the delivery of therapeutic interventions for a range of mental health issues including anxiety, distress, despair, complicated grief and request for hastened death.

In order to develop the monthly clinics, the CDW utilised an asset based community development approach to research, identify and map existing PHCP and other appropriate PC service organisations in the rural communities identified, including existing palliative care services, primary health care services, including GPs and link nurses, community care services, mental health professionals including Rural Drought Workers, Centrelink Rural Support Officers, Divisions of General Practice and any other service providers or community groups relevant to EOL, PC and MI.

As part of the community development activities, the project team ran community ‘roadshows’ in six rural towns to educate and raise awareness of who Amaranth is, why there was a need for such as organisation and what services we could provide. Where good engagement with the communities and the monthly clinics were well established, the road shows were well attended (Cootamundra and Leeton,), however, where Amaranth did not have an established presence there was less engagement and attendance. As a result of the evaluations of the effectiveness of these events, conversations were held with the Department and approval sought and gained from the Project Officer, to change this objective to engage with existing community groups and use their existing meetings schedules for presentations. As a result, we didn’t hold ‘stakeholder engagement roadshows’, but mailed out introduction letters, referral templates and organisational brochures to all of those identified in the mapping exercise, followed by a phone call to organise face to face meetings to further discuss Amaranth’s services and how we could work together and complement the services already in place. The project team provided over 40 group sessions to organisations such as Probus, Country Women’s Association, Catholic Women’s Association, Red Cross, Rotary Groups, Apex, Can Assist Groups, Country Hope, Mental Health Professional Network groups in Wagga and Albury/Wodonga, disability carers groups, mental health carers groups, specialist Mental Health Teams in Temora and Wagga, Centacare, Mission Australia, the Riverina and Murrumbidgee Divisions of General practice (now the Murrumbidgee Medicare Local) Mental health teams and headspace teams.

At these meetings we discussed MDT procedures for the provision of ongoing psychosocial support services and looked at procedures and pathways to encourage the development and implementation of a “Priority PC pathway and referral process” in each community, including assessing each practice’s or agency’s capacity to implement the model. Communication pathways were discussed to ensure seamless and continuity of care within each identified community with identified PHCP and community care services. Once accepted by local service providers, referrals to Amaranth commenced which saw the establishment of the monthly clinics.

We have implemented evidence based screening and assessment tools for psychological distress and MI that have been validated in this population group as well as PC specific assessment tools. These include the Modified Kanofsky Scale,the Stages of Illness Data Sets, the DASS 21, the HADs and the Distress Thermometer. Carer strain is incorporated in the Modified Kanofsky and we have added the suicide ideation question from the Edinburgh Depression Scare to the HAD to cover desire for hastened death or euthanasia and suicide ideation. We have also developed education and quality projects for community and aged care staff, using the Clinical Excellence Framework tools (PDSA cycles) for the incorporation of the “no surprise question” as part of prognostication and the implementation of an early triage of aged care clients for Advance Care Planning (ACP) and supportive care, as well as screening for psychological distress and problems with bereavement. We have been working with community and residential aged care providers in the implementation of these tools to assist with the agency’s sustainability of these measures and accreditation processes.

Amaranth Foundation is now respected in the region in their provision of specialist grief and loss counselling and ability to present seminars on topics such as: Work related grief, Self Care in the Caring Professions, dealing with vicarious trauma, new theories in grief, loss and bereavement.

In August the CEO was invited to present the Amaranth project to the Specialist Mental Health in Palliative Care projects in South Australia. This joint initiative of both the SA projects teams, and Amaranth CEO enabled the presentation of the social work skills and competencies to over 25 social workers currently working in both inpatient and community palliative care services in SA. There was then an invitation only public presentation of the 3 models of care and discussion as to the best way forward for the integration of mental health screening, assessment and appropriate therapeutic responses into palliative care across the specialist and generalist sectors. This will be an ongoing dialogue between these three teams.

Objective 5:
The Amaranth Project Team have worked with the Austin Hospital and their Respecting Patient Choices (RPC) Program to ensure that all Amaranth Foundation staff have completed training and are Facilitators of RPC ACP. We have modified the RPC resources, with the Austin's endorsement and support, to meet our client's needs and the NSW legal context (Enduring Guardian). As part of a Commonwealth Community Dementia Grant (Round Three) we have produced an ACP document and resource, which is used in our education programs and face to face with clients and their families, across all of our rural communities. We have been educating PHCP in the use of these materials and the importance of ACP, as well as the availability of the online RPC training to become a facilitator. Our aim is to have 100% of our patients with a complete and current ACP, and communicated with their MDT and GP.

We have been providing ongoing support and education to practices and PHCP to enable them to implement and use appropriate MBS billing items for effective patient management, including the Chronic Illness and Team Care Arrangement and the Mental Health Management Plan. Medicare Items 2710, 2702, 721, 732 and 723

As mentioned above, we have developed education and quality projects for community and aged care staff in prognostication in order to triage clients for ACP and supportive care, as well as screening for psychological distress and problems with bereavement.

[Further training and support for GPs and PHCP would see the NSW Ambulance Palliative Care Management Plan – Pre Authorised Care Plan P1 initiative really bedded down across each of the 8 rural communities where we have outreach clinics.]

In July 2011, Phill Good and the Amaranth CDW and CEO engaged with a three day Road Show across the communities of Leeton, Narrandera and Griffith, explaining the Protocol P1 Palliative Care Plan and Amaranth psychosocial services. Education was provided to all GP clinics in the regions, which in most occasions included the primary practice nurse, practice manager/s, chronic disease nurses, as well as GP's. Education was also provided to Care managers at four of the largest Residential Aged Care facilities (RACF) in Narrandera and Griffith. The feedback to this road show has been extremely positive, with two GP's and three RACF referring clients in the first week. Additional education and follow up will be provided over the ensuing weeks and months. Amaranth has had requests from communities across the Riverina for similar educational events, and has commenced discussions with NSW Ambulance Station Managers in many of the rural communities regarding support for the initiative. We have established communication and referral pathways with the Education Officer of the NSW Ambulance, Riverina, so that when a new referral is received or an appropriate patient is identified, he is informed so that the local Ambulance officers can be updated, if required. Initial evaluations of this implementation have been very favourable from both GP's and patients. Ambulance officers in Griffith and Corowa have expressed great support and encouragement as they state that this formalises what they have tried to do locally. Patients and carers have reported that they feel "*safer at home*" and that they "*know their wishes will be respected*" and again "*this is good for families, as everyone will know who will do what, and what to expect if we need the Ambulance*". One GP in Corowa stated that with "*difficulties in continuity of care with after hours clinical support for people who are palliative, this provides for better planning and care delivery*". An invitation has recently been extended to Amaranth to present this initiative, the psychosocial/mental health support to the Corowa Health One medical and nursing staff.

Objective 6:
One of the community roadshows (Leeton) was very successful and as a result we have been liaising with key stakeholders this community and have established an ongoing "Community Of Interest" group. This group has been meeting monthly to discuss issues relating to caring for people with advanced diseases, and the supports available for people to remain at home for as long as possible, and to die at home if that is their choice. Many issues were raised with regard to people dying at home, due to the lack of afterhours clinical support available, and the strain on

emergency services to provide this support, especially in the absence of any instructions as to EOL care. This led us to look at ways to improve this situation. Discussions with key researchers and clinicians led our research to the Westmead Paediatric Palliative Care project and the work being undertaken on replacing Not for Resuscitation (NFR) with Allow a Natural Death (AND).

After consultation with Westmead Quality Manager, we have been working closely with the Medical Director of the NSW Ambulance Service for the AND project – Dr John Mackenzie. We have since had a number of meetings with John and Phil Goode (Patient Safety Manager and Clinical Services, NSW Ambulance) who have been very supportive of our work with rural patients in ACP, and the ACP documents we have produced and are using. They have agreed to implement a similar protocol (Palliative Care Management Plan – Pre Authorised Care Plan P 1) with Amaranth patients across the Riverina. They have commenced training Ambulance officers in Leeton, Narrandera and Griffith (as this was the community that indicated that they were open and willing to implement the protocol and where we have established a busy clinic) and we are in the process of finalising the pathways for implementation. We are hoping to launch this on 30th June, at a Health Professional and GP Dinner prior to a Health Expo planned for that week. We have invited John Mc Kenzie to be the guest speaker at this dinner. The Health Expo is also an outcome of the YMDM project as the '*lack of awareness of the Leeton community as to what services are available to them*' was another gap identified by the Leeton community which is being addressed by holding a 'Health Expo' to showcase to the community what services are available to them.

At the 'Health Expo' we plan to have questionnaires for community members to complete, asking them to identify the needs of PC patients with a MI and their families – the results of these questionnaires will inform further community development and service provision.

The Health Expo was an outstanding success for the communities of Leeton and Narrandera, with 30 service providers in the region servicing those communities represented, and over 170 people coming during the day. Talks were delivered during the day, with topics including "Recognising Dementia:, :The Importance of Advanced Care Planning", "Medication Management in the Community", and "Road Safety issues". The evaluations from this day have indicated that the community want this to be a bi annual event, with relevant themes and topics for the community. The most popular topics were Dementia and Advanced Care Planning. This initiative will be followed up by the Community of Interest established in the Leeton community.

Objective 7:

- Research and adapt, or develop local PC policies and frameworks that include appropriate MI standards in PC case management and care planning and based on the outcomes of the needs analysis

As the RDGP project was focussed on the education of PHCP in the Palliative approach across the Murrumbidgee and Murray regions, and as members of this SC Amaranth contributed to several education events, providing information relating to social work interventions, case management and referral pathways to Amaranth PHC clinics.
Positive working partnerships have been made with existing MH services, equipment provider/s; the community service sector and MH carer and respite services; and existing PHCP to identify improved integration pathways and referral tools based on the frameworks identified.

Throughout the project it has become apparent that mental health issues are not routinely screened or assessed in people with advanced or terminal chronic illnesses. Amaranth social workers have participated in many MDT and case discussions regarding clients across the rural communities, there is an apparent lack of knowledge of appropriate screening tools for psychological distress or mental health issues, including drug and alcohol issues. Few nurses or generic mental health clinicians understand the unique circumstances of people with life limiting or terminal illnesses and appropriate mental health responses. This fact was reinforced by the SA project teams. It has been reported by many clinicians that anxiety, sadness and distress are normal in the palliative care population, and one rural palliative care Clinical Nurse Consultant commented that screening and assessing for mental health was "*looking for problems where there were potentially none*". She also stated that " *most people only need support, not counselling*".

The following case study helps explain these observations:

> *We received a referral from the Psychologist in a rural community, for a woman in her early 70's who had stated to the psychologist that she had planned to take her life when her husband died. He had been diagnosed with terminal lung cancer and was only expected to live several weeks. The couple lived on a rural property, 40 kms out of town, the wife did not drive and had never driven, they had few neighbours, and their adult sons lived in Sydney. The mental health services in this community included a Specialist Mental health team, a hospital based psychologist, a counsellor employed by the local health service and a transitional care manager, as well as 5 GP's and 2 community nurses. The woman had been referred by the psychologist initially to the consultant psychiatrist, who assessed her as a low risk of suicide, and not requiring of specialist MH support or admission to an acute facility. She was commenced on an antidepressant. The MH team had discussed her ongoing care needs at a MH meeting and decided that she would be discharged from their service. Amaranth was contacted by the psychologist for ongoing community based support and at the time of referral expressed frustration and lack of knowledge of appropriate MH interventions. The Amaranth SW assessed the woman and identified significant distress and lack of hope and meaning in her life. A supportive plan was initiated that included the local MDT, and her GP, and counselling was commenced that included strengths and narrative approach, dignity therapy, mindfullness and ACT. The woman was encouraged to discuss her feelings with her adult children, who were able to provide her with ongoing psychological and practical support. She now has an Ambulance Protocol, an emergency plan and advanced care plan in place and is regularly visited by community volunteers. Her family are working out long terms plans and communicating more openly. The Amaranth SW visits monthly and makes phone contact in between when required.*

- ➢ Identify and adapt aspects of "PallCare Packages" model of care planning that is appropriate to people with MH problems and trial these together with the pathway and integration tools within the communities where "PallCare Packages" are being implemented

In our consultation with PHCP and service providers, it was identified that there was difficulty in identifying people who may benefit from early intervention in regard to ACP and EOL conversations. It was also evident that the screening and assessment of mental health issues in people with terminal illnesses was under recognised and undertreated. For people with pre existing mental health problems, and who were now living with a terminal illness, compliance and support for their ongoing MH treatment or to deal with exacerbation of their MH symptoms was problematic. The current referral pathway in this region to an adult MH team is through a 1800 call intake system. The MH focus groups we consulted reported that this was problematic due to difficulty with accessing the MH system and with appropriateness in the service response.
So as not to duplicate the existing MH triage and referral system, we trialled the use of the "No Surprise Question" from the UK Gold Standards Framework in Primary Care document as a form of EOL triage for PHCP and MH service providers. We have provided resources and education in the use of this aspect of the Gold Standards Framework, in order to change the culture of existing case management and care planning of PC patients with a MI. The question used was :

> *"Would you be surprised if this person were to die in the next year?'*
> *If you wouldn't be surprised, what should you do to ensure that everything is ready, just in case they deteriorate quickly?"*

"If the PHCP indicated that they would not be surprised, we encouraged them that referral to an Amaranth would be appropriate to ensure ACP and EOL discussions were commenced as early as possible and referrals to appropriate services providing MH and clinical support were available in a timely and at a stage appropriate time.

- Promote the frameworks and protocols to the wider community and stakeholders at the local level

Through out the project several presentations were developed relating to the ACP, EOL, prognostication pathways using the No Surprise Question, referral processes and evidence based EOL and PC and many requests were received from a range of organisations to present this information. Presentations were made at the Regional HACC conference in Wagga, the Aged Care services Expo in Wodonga, Tumut and Temora, the Continuum of Care meetings in Culcairn, Coolamon, Cootamundra, Junee, Holbrook, Howlong and Lockhart, the Chronic Disease Workshop/Symposium in Albury. We have been invited to present at two Aboriginal Aged and Disability Forums in Deniliquin and Wagga as well as an additional Symposium in Chronic Illness in Wangaratta.
The CoI formed in Leeton has ensured that the pathways and processes as well as all the ACP and EOL resources have been adopted by the whole community.

- Liaise with Divisions of General Practice to facilitate social work PC structures within the “Access to Applied Psychology Services” (ATAPS) framework

Initial discussions have been held with the Riverina, the Murrumbidgee and the Border Division of GP, mental health managers in regard developing referral pathways between Headspace, ATAPs and Amaranth PHC clinics for the provision of evidence based grief and loss counselling, ACP, bereavement support and post suicide counselling. We have participated in several MH case conferences for older people who have expressed a desire for hastened death and suicide ideation and provided clinical support to the adult MH teams in this context. This has occurred in Temora and Junee. Initial discussion have been held with Centacare MH services in regard to suicide and bereavement and PTSD counselling/therapeutic interventions. Referrals have been made to the Centacare Personal Helpers and Mentors program form several clients in Henty and we have instigated a very positive professional relationship between the two services. The interest and positive engagement with MH services has come about after twelve months of Community development activities with local communities and repeated presentations across these communities and to PHCP’s. We are also proving to MH and PHC services that we are capable of providing quality and evidence based interventions and achieving positive outcomes for clients, their families and care givers. Recently Amaranth was involved in a regional MH planning day convened by the Mental Health Coordinating Council, and encouraging discussions were held with the Director of Mental health Services for the new Murrumbidgee Medicare Local. This discussion has led to further opportunities for Amaranth to be involved in the Suicide Task Force, and training for mental health clinicians in the ATAPs program as well as in the provision of supervision for SW clinicians in HeadSpace and also for Riverina Centacare.

Objective 8:

- Develop and trial the usefulness of a “Rural Primary Health PC and MI Resource and Information Guide” in the identified Riverina, Murrumbidgee and Murray rural communities

We have implemented evidence based screening and assessment tools for psychological distress and MI that have been validated in this population group as well as PC specific assessment tools (such as Kanofsky and Stages of Illness). These tools are being used regularly with clients, families and carers. Although we have not yet trialled the Resource Guide, we plan to do an evaluation of it once available to health professionals in order to receive feedback.

The assessment, PC and MH tools include:

- Phase Definitions
- Karnofsky (Australian) Performance Scale
- Hospital Anxiety and Depression Scale (HADS)
- The Distress Thermometer
- DASS21
- The Mini-Mental State Exam
- MDT/Care Plan Checklist: Stable Phase
- Case Conference Guide
- Multidisciplinary Care Plan: Terminal Phase
- Patient and Carer Checklist

- Psychological Assessment

The Guide contains information about the appropriateness of and pathways in using the Medicare Items for the delivery of psychosocial and psychological support and interventions for people requiring palliative and EOL care.
Information regarding indepth discussion relating to ACP, EOL planning and helping people find Hope and Meaning using therapies such as Dignity Therapy, Interpersonal Therapy and Narrative Therapy is also contained in the resource. This will be added to over time, and as clinicians evaluate its effectiveness.
Due to requests for training for MH clinicians in primary health care and specialist palliative care units (SA teams), Amaranth has decided to hold a “Supportive Care in End of Life” Symposium in November this year. This will be a two day symposium, with Master Classes in Narrative Therapy and “Compassionate Conversations in EOL Care”. Mark Gordon (Clifton Centre for Narrative Therapy) and Michael Barbato (Palliative Care Specialist) have been invited to offer the Master Classes, and many expert and leading SW clinicians have been invited to participate and present over the two days. Expressions of interest have been received from over 50 social workers, psychologists and counsellors in Queensland, WA, SA, Vic and NSW. This event will be evaluated and will be a regular feature on the Amaranth education calendar.

Objective 9:

- Plan, develop and coordinate community engagement and education events that support the community to care for and understand issues in PC and MI.

The Community Roadshows enabled us to educate the community, carers and patients about the issues in PC, EOL care and MI, as well as survey the community, carers and patients to identify the needs of the community. As mentioned above, the Leeton roadshow resulted in the development of an ongoing CoI, the Leeton Health Expo, as well as the partnership with the NSW Ambulance to address the issues of afterhours EOL care. Members from other communities such as Cootamundra have also been attending the Leeton meetings in order to take information back to their communities and bring together a group of people to meet in a similar fashion to the Leeton CoI.

The Leeton Health Expo will be a platform for further engagement and education of communities in the Riverina in regards to issues in PC and MI. We have also provided ad-hoc community talks to groups requesting information around EOL, PC and MI. We have been promoting PC standards, psychosocial support strategies, assessment options, the link between PC and MI, community supported bereavement, death and dying and care planning protocols within these communities.

Rationale for change (if applicable):

A number of barriers were faced throughout the project which forced some of the objectives to be changed. These include:

- Delay in commencement of the project due to delayed receipt of funds from the Department.
- In April 2010 the Federal Government announced that access to the Mental Health rebates for Social Workers and Occupational Therapists under the Better Access program would be cut by the end of the year. If this was the case, the sustainability of this model and the referral pathways as well as resources that had been developed would have been obsolete. Therefore, much time was spent lobbying against this decision, writing letters to and travelling to Canberra to meet with the Health Minister, speaking on ABC radio, writing and seeking support and signatures for a petition. This work took time and effort which consequently took time away from some deliverables such as the trial of the resource and information guide.
- There was some opposition from existing clinical palliative care services, that felt that our model was a duplication of the supportive care provided by the Palliative Care CNC’s and CNS’s due to a lack of understanding about what our service provided. A MOU with the Area Health Service is being pursued, and hopefully will be in place in early 2012.
- There was the impression that screening and assessment of psychological distress in a situation where it is anticipated and considered normal (ie people who are dying), could further increase the distress.
- There was a lack of understanding and awareness of social work skills and competencies, as well as a lack of appreciation and understanding of Mental Health Social Work accreditation and competency standards. Therefore, more time than expected was spent putting forward and

justifying our qualifications and organisation's credibility. This lack of community and professional awareness has been recognised by the AASW and OSWA, and Amaranth has been involved in public awareness campaigns and writing submissions in regard to SW skills and competencies.

- There was a lack of willingness for local GPs to make the time to meet with us, as well as a lack of willingness for local GPs and other health care professionals to take on an 'external' organisation's services, resulting in initial disregard for our organisation.
- The Project Manager resigned half way through the project, leaving the community development work to be completed by a 0.4FTE and backed up by the CEO and the SW clinicians which also saw time constraints placed upon some of the deliverables.

The changes in objectives are outlined below:
Objective 2:
The rationale for the change in objective 2 included the poor attendance at the inaugural and subsequent two steering committee meeting and the perception of duplication with the RDGP project. The Board supported the development of Focus groups to gain expert advice on specific issues and resource development, as well as the input from the local University and social work students to support their taking over the project management in lieu of a steering committee.

Objective 5:
Amaranth provided as much education, training and support as possible to those who were interested in this information. However, due to a number of health care professionals and service providers being 'wary' of a non traditional palliative care primary health care provider , it was at first difficult to engage these professionals and develop a working relationship with them. Education and training around PC was not seen as a need by these professionals, therefore no formal training days were set in those communities. In other communities, service providers and health professionals welcomed us warmly and monthly clinics were promptly established. In these communities, we were requested to provide training and education to different health care professionals and service providers. The community and aged care sectors welcomed the opportunities that Amaranth provided for their agencies and fully supported access to staff and training opportunities. The community based aged care sector continually refers to Amaranth for psychosocial support for their clients, and the Foundation has been involved in assisting several organisations in the development of quality projects in relation to prognostication and the implementation of ACP for their clients and their families.

Objective 6:
The concept of Road shows, whist successful in some communities where positive engagement had occurred with Amaranth, was not as successful in other communities where the Community Development had not been fully integrated into the community and the community and PHC services were not as aware of the Foundation or the services they offered. This was due to different approaches undertaken by staff across different communities and the positive relationship building that occurred with different communities. Changing the focus of the presentation to ones that had ownership by the community created a positive change for the Amaranth presentations, and enabled the community groups and PHC services and agencies to better welcome the information provided. This provided some important lessons in the different needs of different communities across the region.

Objective 7:
The uptake by GP's was delayed due to the interruption to this aspect of the project by the Australian Government's decision to cease access to the Medicare Better Access rebate for social workers. This decision and the subsequent lobbying undertaken by the CEO meant that the referral pathways and information regarding sustainability beyond the project could not be undertaken until after the decision was revoked. Since the July Road Show, which included visits to individual GP clinics and talks with Practice Managers, Practice Nurses and GP's, the referral rate has dramatically increased. GP's are more supportive and understanding of the referral process and usefulness of the Medicare Better Access program for the delivery of specialist MH support for their palliative care patients. This process is slow, however, it is believed that the Better Access referral rate will increase as more individual contact is made with GP's.

Objective 8:
The Resource guide is a work in progress, and the first draft is completed. This resource will be advertised in the Amaranth Newsletter and made available on the website. There have been many

requests for assessment tools from SW from a range of services, as well as the Care Plans, and discussion pathways. It is intended that this Resource will be evaluated over the next six months, and changes made depending on the usefulness and appropriateness of the information to mental health clinicians, working in both specialist and primary health arenas. This Resource Guide will be launched at the Symposium in November.

Objective 9:

Many rural communities and service providers were quite receptive of our organisation due to reasons outlined above, while others perceived duplication and were less receptive . We implemented 'roadshows' in a number of communities and had varying attendance rates. As a result, we decided to work with interested communities which has seen the development of the Leeton Health Expo and the AND protocol with the NSW Ambulance Service. We also offered to do presentation at locally owned groups and meetings which saw an immediate uptake from such organisations.

Key activities:

Objective 1:

- Employ project staff that meet core competencies required of Social Work PC Professionals through advertising and recruitment processes
- Employ appropriately qualified project staff through advertising and recruitment processes
- Define SWPCCM roles and responsibilities
- Identify and access appropriate professional development (PD) opportunities to enhance SWPCCM skill set in delivering psychosocial assessment and care planning
- Provide in-house training to SWPCCM in PallCare Packages policies and protocols
- Provide orientation to new staff in Amaranth Foundation policies and procedures

Objective 2:

- Formally invite key stakeholders to be members of the steering committee
- Determine the Terms of Reference (TOR) and chairperson of the committee at the inaugural meeting
- Formally minute each meeting and monitor attendance and input from stakeholders

Objective 3:

- Host a stakeholder engagement roadshow event to introduce the project and SWPCCM approach to the practices and existing PHCP that utilise the current "PallCare Packages" model in Cootamundra, Junee, and Temora
- Identify and liaise with existing link nurses in each practice and community health setting and other existing PC service providers to determine MDT procedures for the provision of ongoing psychosocial support services
- Communicate procedures and pathways with all stakeholders, PHCP and the wider community
- Develop and implement a "Priority PC pathway and referral process" in each community, based on successful outcomes and learnings of the Top End "Diamond Register"
- Develop a communication pathway (to ensure seamless and continuity of care within each identified community) with identified PHCP
- Implement quality planning tools (using the Clinical Practice Improvement Process tools such as PDSA cycles matching standards from PC Aust, Case management Aust Standards, HACC standards, AASW standards) to improve or modify processes that enhance the management of PC patients/families at the general practice and primary health care level
- Evaluate the implementation of the model, utilising methodology identified in „A guide to the evaluation of PC service and programs", with an emphasis in rural practice
- Develop and utilise a "Primary Health PC Resource and Information Guide" (PHCRIG) based on best practice, outlining:
    - The palliative approach
    - Business Case and referral pathway for enhanced primary care MBS items
    - Forms (symptom assessment scale; Karnofsky scale, phase of care definitions; problem severity score; referral to SPPCT for case management; referral to CRCC; care plan proformas; Case Conference guidelines and checklist; MD care plan;, psychosocial assessment tools, carer strain assessment tools, quality of life self assessment tools, Clinical Care plan; patient and carer checklist)

Objective 4:

- Utilise a Community Development approach to research, identify and map existing PHCP and other appropriate PC service organisations in the rural communities identified
- Liaise with Murrumbidgee and Murray Divisions of General Practice and coordinate a stakeholder engagement roadshow event to introduce the SWPCCM approach and project to the participating practices and existing PHCP in the "PallCare Packages" model
- Assess each practice capacity to implement the model, identify procedures that require change and work with the practice to enable this change using a quality improvement cycle of care
- Identify and liaise with existing link nurses in each practice and community health setting and other existing PHCP to determine MDT procedures for the provision of psychosocial support services
- Communicate procedures and pathways with all stakeholders, PHCP and the wider community
- Develop and implement a "Priority PC pathway and referral process" in each community, based on successful outcomes and learnings of the Top End "Diamond Register"
- Develop a communication pathway (to ensure seamless and continuity of care within each identified community) with identified PHCP
- Implement the model
- Evaluate the implementation of the model

Objective 5:

- Research and determine clinical and non-clinical education and training needs of the PHCP and key stakeholder groups
- Identify appropriate training packages and organisations to deliver clinical and non-clinical PC training that promotes the uptake of the PC approach within the primary care setting
- Provide ongoing support and education to practices and PHCP to enable them to implement and use appropriate MBS billing items for effective patient management
- Provide ongoing support and education in the use of client/carer data management systems for effective information management between and among the MDT and PHCP

Objective 6:

- Liaise with key stakeholders within each community and establish a pilot project team
- Develop a community research plan and time frame
- Collect and analyse available clinical and service use information and data
- Survey stakeholders to identify needs
- Complete community research in identifying asset rich community development resources
- Analyse results using triangulation
- Report back to the community and stakeholders
- Set priorities
- Determine responses to the needs identified that support the community to care for PC and mentally-ill patients and their families

Objective 7:

- Research and adapt, or develop local PC policies and frameworks that include appropriate MI standards in PC case management and care planning and based on the outcomes of the needs analysis
- Develop partnerships with existing MH services; equipment provider/s; community service sector and MH respite sector; and existing PHCP to identify improved integration pathways and referral tools based on the frameworks identified
- Research and refine mental health practitioner involvement in the MDT for PC
- Identify and adapt aspects of "PallCare Packages" model of care planning that is appropriate to people with MH problems and trial these together with the pathway and integration tools within the communities where "PallCare Packages" are being implemented
- Develop prognostication guidelines with regard to PC, mental and chronic illness
- Provide ongoing education to PHCP on the implementation of the frameworks in order to change the culture of existing case management and care planning of PC patients with a MI
- Promote the frameworks and protocols to the wider community and stakeholders at the local level
- Liaise with Divisions of General Practice to facilitate social work PC structures within the "Access to Applied Psychology Services" (ATAPS) framework

Objective 8:

- Research and identify suitable tools for MH self assessment, QOL, depression and anxiety scales. Identify and adapt where necessary, the usefulness of existing clinical and psychosocial tools (within the guide) in the identification of MI signs and symptoms as well as psychological distress
- Review the Amaranth, Rural Primary Health PC Resource and Information Guide
- Trial the revised guide in the rural communities engaged in the "PallCare Packages" model

Objective 9:

- Hold focus groups or survey the community, carers and patients to identify education and training needs
- Utilise existing and develop appropriate training resources that address identified needs
- Deliver education to the wider community and stakeholder groups, based on these needs
- Promote PC standards, psychosocial support strategies, assessment options, the link between PC and MI, community supported bereavement, death and dying and care planning protocols within the communities

Identified outcomes:

Outcomes:

- A social work led primary health care model of psychosocial and supportive care as well as screening and assessment for MI and psychological distress was trialled for over 100 patients.
- An additional 250 family members and care givers were assisted over the 12 month period.
- Outreach clinics from Corowa were established in Leeton, Griffith, Coolamon, Cootamundra, Tumut and weekly Mental Health clinics held in Henty and new clinics are being established in Howlong, Albury, Culcairn, Chiltern (Vic), Wangaratta (Vic) and Beechworth (Vic).
- Screening and Assessment tools were implemented and evaluated.
- Discussions commenced with National bodies regarding Practice Standards for social workers in EOL and PC. Small research project commenced with involvement with OSWA and AASW.
- A "Rural Primary Health PC and MI Resource and Information Guide" based on best practice models was developed.
- Excellent relationships and partnerships with many aged care facilities offering ACP, EOL supportive care, counselling and bereavement support for their clients, their families and care givers were developed and will continue.

Unexpected outcomes:

- Reaching double the number of patients and family members that we set out to support.
- Developing a partnership with the NSW Ambulance Service in a P1 Protocol Care Plan pathway for rural Palliative patients and extending the NSW Ambulance Palliative Paediatric Protocol into the rural communities of Leeton, Griffith and Narrandera.
- Integration of Respecting Patient Choices ACP protocols into the SW suite of options provided for patients, their families and care givers and training of all Amaranth staff as facilitators in ACP.
- Working with Rural Adult Mental Health Teams in supporting their team and clients with suicide ideation and desire for hastened death with people with terminal illnesses and their caregivers.
- Partnerships with Rural Support Workers from Centrelink and Department of Primary Industries in drought affected communities identifying people at risk who are caring for or who have life limiting illness.
- The development of "Compassionate Conversations" that are part of the psychological and supportive care that the Amaranth SW model provides.
- Inclusion of Dignity therapy, Hope and Meaning discussions, Advance Care Planning, Mindfullness and Acceptance and Commitment therapy into the suite of psycholofgical supportive care offered to all patients and their famileis.
- Support by the AASW for the development of National Competency Standards for End of Life and Palliative Care.
- The development of a Communities of Interest group which was responsible for the organising an Amaranth-led community health expo around 'Planning for a Positive

Future'.
Performance indicators: **See Appendix One**

Part 3 – Evaluation

While there is no provision for an overarching national evaluation of this project, it would be most helpful if you could provide information about the following aspects of your project to aid planning for future funding directions.

Project title 'Your Mind Does Matter'	
Keywords	End of Life, Palliative Care, Social Work, Rural Outreach, Advance Care Plan, Mental Illness, Psychological and psychosocial care and support, Therapeutic Interventions for EOL care, Bereavement
Project organisation	Amaranth Foundation
Partner organisations	
Project funding	$593,169.00 (Inc GST)
Project timeframe	12 months
Were there any issues in designing the methodology?	Changing the Packages concept (PallCare Packages) to a Specialist Social Work Primary Health Care approach that included a range of supports and interventions. This approach had been untested and there was limited research as to the effectiveness of such a model of care in primary health care.
Were there any issues with governance in the course of the project?	Initially yes. These were due to: - Existing Rural Palliative Care project run by the RDGP and a perception of duplication by HCP - Hesitation and lack of familiarity of model by specialist Palliative Care providers - Commonwealth Government decision to cease SW accessing Better Access Medicare rebate leading to insecurity in determining sustainability of the project - Initial difficulty in engaging mental health clinicians to the SC due to poor understanding of their role in palliative and end of life care. - Difficulties in obtaining a MOU with the AHS
Comments on what worked	Development of specific focus groups (consumer, social work professional and mental health clinicians) to support the Board in the management and acquittal of the project Engagement with the Aged Care sector, both community

	and residential aged care service providers Engagement with consumers, family members and care givers across all rural communities Development of excellent resources that cover ACP, EOL care and planning, therapeutic interventions that were well accepted and requested by patients, families and care givers such as narrative therapy, dignity therapy, interpersonal therapy. Mindfullness and Acceptance and Commitment therapy Development and use of self management and psycho educational aids such as home diary, carers kits, mindfullness resources Development of an excellent working relationship with the regional equipment supplier and OT for the provision of timely and appropriate equipment to support people to be cared for by the people and in the place of their choosing for as long as appropriate Development of the collaboration with the Austin Respecting Patient Choices program and the development of the Foundation's resource for ACP. Endorsement by NSW Ambulance for the Foundation's ACP pathway and the collaboration with this service in the implementation of the Palliative Care P1 Protocol with the Foundation clients across the Riverina. Development and use of the EOL planning resource, and the endorsement by the Slim Dusty Foundation and Don Walker for the use of the lyrics and song title "Looking Forward Looking Back" as the title of the resource Positive engagement with Palliative Care Social Work Practice Groups in West Aust, Victoria, South Aust and NSW as well as the AASW in the development of draft competency standards for social workers working in Palliative and EOL care. Engagement with Charles Sturt University Social Work department in the support of student placements and participation in focus groups for the development of resources and projects as well as the identification and use of screening and assessment tools.
How was the project evaluated?	Evaluations were conducted by the Social Worker, Community Development Worker, SW students and CEO, using a variety of qualitative and quantitative methods. Surveys and semi-structured interviews were conducted throughout the life of the project at regular intervals and after information and education sessions. Semi-structured interviews were conducted with consenting families to elicit the effect and impact that Amaranth's services had on their family and their experience of living with or caring for a person with an advanced disease. Interviews with health professionals and service providers helped to gather information regarding their perceived impact that Amaranth had on a family compared to how a family seemed to be coping prior to Amaranth engagement. Qualitative, informal, semi structured interviews with

	bereaved carers and family members has identified that programs like this should be continued, and they have commented that their **distress had been greatly reduced, and their coping in the bereavement period enhanced** due to having access to the professional support that the social workers provided. Patients report that they benefited from : - Having someone to coordinate their care - Having someone to anticipate their equipment and support needs - Having someone to advocate for them in navigating the health and community care system - Having someone available to talk that is not afraid to talk about the "hard "stuff – like is there a God, why should people suffer, how can I have hope? - Having someone that will answer their questions honestly - Having someone that considers the family and care givers as equals in the care team - Having someone that is respected by their other health care professionals Service providers stated that the **care planning and timely access to equipment packages and financial support** were key successes of the project, providing much needed support. Carers and families that had been referred to Amaranth and used the service indicated they **valued the psychosocial support provided by the specialist social workers.** Amaranth Foundation used tools such as **PDSA cycles** from the Clinical Excellence Framework and evaluation tools developed by the University of Wollongong and available on CareSearch, such as **Dissemination Log and System Impact Tool.** PDSA cycles were developed and used at critical points along the project to evaluate the effectiveness and usability of resources and tools.
Was the project completed on time and within budget?	An extension was requested and granted from the Department for the project, due to the late commencement, the delay in implementing the referral pathways due to the uncertainty of the Medicare rebate for social workers, and the late development of the collaboration with the NSW Ambulance department with the incorporation of the Palliative Care P1 protocol into the Amaranth ACP Pathway. The Budget was well managed by the Business Manager, the CEO the skills based Board and the accountant. Other than the Project Manager resigning in August 2010, and difficulties in recruiting to this position, there were no unexpected expenses.

Were there any factors which impacted the cost of the project and its purpose?	None identified
Were there things which, in hindsight, you would have done differently?	Even though there were challenges with the implementation and changes to many of the stated objectives, the project successes could be attributed to the alternative activities developed. These challenges allowed the Foundation to look outside the traditional provision of palliative and end of life care in the community, and engage with non traditional providers who were openly responsive and very willing to engage with the Foundation and the work we provided. Moving forward having overcome these initial challenges has enabled us to develop very robust and sustainable as well as evidence based tools and resources. Developing a Community Of Interest in place of a Steering Committee has worked well in another Commonwealth funded project that we were delivering and enabled a mechanism for an ongoing group of interested health care professionals and service providers to meet regularly and at minimal cost beyond the life of the project. In hindsight this may have worked well for this project instead of a Steering Committee.
Were there any unexpected issues or unintended consequences identified in the course of implementing this project? List the positive and negative issues.	Positive: - The willingness of the community care sector for end of life and palliative care education and support. - The Residential Aged Care sector welcomed every opportunity for support for their clients and their families. The ability of the MH SW to access Medicare and to provide psychological as well as specialised EOL conversations as well as bereavement filled an important gap for many of their families. - The partnership formed with the Austin Hospital and RPC - The partnership formed with NSW Ambulance - The development of a CoI and Health Expo in Leeton Negative: - Delay in commencement of the project due to delayed receipt of funds from the Department. - In April 2010 the Federal Government announced that access to the Mental Health rebates for Social Workers and Occupational Therapists under the Better Access program would be cut by the end of the year. If this was the case, the sustainability of this model and the referral pathways as well as resources that had been developed would have been obsolete. Therefore, much time was spent lobbying against this decision, writing letters to and travelling to Canberra to meet with the Health Minister, speaking on ABC radio, writing and seeking support and signatures for a petition. This work took time and effort which consequently took time away from some deliverables such as the implementation of the referral pathways and trial of the resource and information guide. - There was some opposition from existing clinical palliative care services, that felt that our model was a duplication of the supportive care provided by the Palliative Care CNC's and CNS's - There was the impression by many people in specialist palliative care services that screening and assessment of

	psychological distress in a situation where it is anticipated and considered normal, could further increase the distress. - There was a lack of understanding and awareness of social work skills and competencies, as well as a lack of appreciation and understanding of Mental Health Social Work accreditation and competency standards. Therefore, more time than expected was spent putting forward and justifying our qualifications and organisation's credibility. - There was a lack of willingness for local GPs to make the time to meet with us, as well as a lack of willingness for local GPs and other health care professionals to take on an 'external' organisation's services, resulting in initial disregard for our organisation.
If the project involved contact with people with dementia or mental illness and their carers/family/friends, was there positive/negative feedback?	The project involved contact with many people with dementia and/or mental illness, as well as their carers and families. The following are examples of positive feedback we received: "I was hoping a semi trailer would just hit me" When my husband died of dementia in a facility, I thought that I couldn't go on. I thought that I just couldn't handle life without John. The GP sent me to the Amaranth Social Worker. I really gave thanks for that day they came. They gave me a sense of being normal and having hope. I could talk about John's dying and how I had cared for him for so long. They understood when I told them I felt I had failed him..." Jean (husband died of dementia in a RACF 6 months ago) "I was told to stop work and get my things in order. I was told that I may have 12 months. The Amaranth Social Worker has helped me to work through any anxiety, to be mindful, to break feelings down to what they really are. I am more hopeful now. I know that being anxious about leaving my children and feeling that I have no control are just feelings and thoughts. I can take charge and not just let things happen. I am not dying, but living with dying. That's what our conversations have shown me." Christine (mother 42, with ovarian cancer and 2 teenage children)
Was there any feedback from other groups of people impacted by the project?	There was much feedback from other groups of people impacted by the YMDM project. Some examples include: "This program offers something different – good psychosocial support for the families when they need it... Time to talk to families is so important, it allows us to do the nursing better and worry more about symptom control. Having a social worker was crucial to the success of the psychosocial supports and advance care planning. They knew when to refer and we worked well as a team. That's the best approach – working as a team. " Claire (Community Nurse) When my mum, Maree, was told she was palliative it was like we had entered a big black hole. Heading in to a rural community where palliative care appeared to be outside everyone's boundaries, along came Amaranth and without your endless support, both emotional and social, my family would not have been able to care for mum at home. Through your guidance mum was able to die with peace and dignity and surrounded by her family at all times and we were so proud to be able to do this for such a beautiful lady and mother. I am so happy to see you have Amaranth in place and I know that you will help so many more families out there who are swept in to this 'black hole'. Lynette (daughter of Maree who died of Melanoma and secondary's)

	The feedback from the Leeton Community of Interest Group : "Amaranth is like a catalyst for change." **What did help?** "Things that enabled living. The strategies that helped, the artful conversations, the equipment, the advocacy for services, planning the death and what comes after death... .....I don't put things off now. I have become a bit of a risk taker I wouldn't have had the choice to do that if we hadn't had those conversations". (Sue and Anne)

Part 4 – Future directions

Please use the following sections to describe:

- the extent to which the project or the outcomes achieved by the project will be sustainable beyond the timeframe for the project funding received under the Local Palliative Care Grant Program Round, including comments on contributing factors or barriers to sustainability
- issues that impacted on the achievement of the intended objectives of the project, overall Program design, and suggestions for improvement to the Program in the future
- any additional comments you would like to make.

Sustainability
Our model of sustainability included referral from GP's and specialists for mental health social work utilising the Chronic Disease and Better Access Mental Health Medicare items. As this is a relatively new concept for the GP's and the education has not come from their own traditional sources of education, or from Government sources, then the acceptability of the appropriateness of such a referral for people living with the effects of a terminal illness, their families and care givers is taking more time than anticipated. Where such a referral has been made the feedback from the GP's and other clinicians has been very positive. More referrals are coming in, and the Foundation is working on a document for patients and their families to provide to the GP's if they feel a referral is required. We believe that this will enable the GP's and patients to have a clearer idea of what is required to make an effective referral and what to expect form a MH social worker in this context. We have developed a comprehensive web page and will be adding resources and more information to this over the ensuing weeks. There has been a 150% increase in people accessing the website over the past months, and an increase in the number of people downloading resources, including the advanced care plan and the EOL resource – "Looking Forward, Looking Back". Having evidence based resources on the website and promoting its use across the region, will ensure that such resources are available to a range of consumers and HCP. An additional twelve months of funding for this project would: 1. **Enable the NSW Ambulance Palliative Care Management Plan – Pre Authorised Care Plan P1 initiative to be really bedded down** across each of the 8 rural communities where we have outreach clinics. 2. **Evaluate the effectiveness of the P1 protocol, in combination with the Amaranth ACP and emergency care list**, in reducing psychological distress at EOL, ensure that people's EOL wishes were respected, that unnecessary resuscitations were undertaken on people at the EOL, that fewer people were transferred to hospital when they preferred to be cared for at home or die at home, that fewer people died upon arrival at hospital. 3. **Build up the Foundation's credibility with GP's and other PHCP** as being a quality organisation primary health care organisation that was sustainable, provided evidence based

screening, assessments and therapeutic interventions, was relevant to people requiring palliative and EOL care, and worked in a collaborative and interdisciplinary manner across the PHC interface.

4. **Measure the effectiveness and appropriateness of using the Better Access Mental Health Medicare items** for the provision of evidence based therapeutic interventions and ACP for people at EOL.
5. **Complete the development of draft Competency Standards for social workers in EOL and PC** and present this to the AASW for national endorsement
6. **Plan and deliver a series of symposia or conferences for social workers and psychologists**, in line with the Competency Standards, in primary health care to better equip this part of the workforce to deliver quality and evidence based EOL and Palliative Care within the community setting. This is a very under resourced aspect of quality Palliative and EOL care.

Issues and suggested improvements related to Program design

1. Longer funding periods – 2-3 years

2. External evaluation program - such as University of Wollongong

3. Planning to allow for all project officers / researchers to meet early in the project period to share information, resources, skills and develop partnerships

Additional comments

Over the course of the project, issues arose that put the sustainability of the project in jeopardy and caused much duress for the organisation and staff. These have since been resolved, however put our time lines behind by several months. **Overall The Amaranth Project: "Your Mind Does Matter" has been a very successful project, and deserves ongoing funding**. In the new rural health care context with changes to the Commonwealth and State mix of services, as well as reforming of primary health care, Amaranth is forging relationships and collaborative partnerships that will ensure that the primary health care sector is well equipped to understand and support the EOL needs of the population.

FINDINGS:

- **Enormous gaps exist in the provision of appropriate, timely and evidence based psychosocial interventions** for people with life limiting illness, their families and caregivers across all rural communities
- People with MH issues or those with psychological distress **felt that these issues were not adequately addressed** by existing services
- Primary health care professionals stated that they **felt unskilled when working with people with terminal illnesses, or with grief, loss and bereavement**, and that symptom management was paramount or took precedence in palliative care
- **Lack of understanding of the psychological and psychiatric needs of people** with terminal illnesses, their families and care givers.
- **Lack of knowledge and awareness of appropriate screening and assessments tools** to identify psychological distress for people with terminal illnesses, their families and care givers
- **Lack of care planning and referral pathways for people requesting hastened death** or requesting euthanasia.
- **Referrals for psychological support occurred late in the disease trajectory** and were then acute or crisis driven
- **Advance care planning conversations and recording of statement of wishes was poorly done** across all communities. NFR orders were only discussed at end of life and only relevant for each admission.
- **Values and issues related to dignity, finding hope and meaning** were seldom well addressed.
- **Paucity of literature regarding primary health care psychosocial or psychological**

interventions for people with mental health issues and co existing terminal diseases or conditions.

Rural Palliative Care Project

2008 - 2010

Riverina Division Of General Practice

Project Officer:

Julianne Whyte

CEO Amaranth Foundation

julianne.whyte@amaranth.org.au

www.amaramth.org.au

Phone: 0408 388533

Executive Summary

The Riverina Division of General Practice and Primary Health (now the Murrumbidgee Medicare Local Ltd) is committed to ensuring that quality palliative care service across all tiers of care is available to all people that require it regardless of geography and socio economic status. The Division in partnership with Amaranth Foundation has been instrumental in implementing, evaluating and working on developing a sustainable primary health model of palliative care, with particular emphasis on rural and remote communities.

The previous palliative care projects highlighted that applying a one sized approach to service delivery and project planning would only further alienate rural and remote communities and their people. Rural and remote populations have many other factors that influence prosperity and economic stability. They also have larger client capture areas, smaller populations, larger geographic areas, poorer reported health outcomes, lower life expectancy, fewer primary and specialist health care professionals and a very complex and occasionally disjointed community care system.

This model developed has taken into account that a one sized approach would not be accepted nor be sustainable across many rural communities. The model incorporates many components of a 'packages' model of community care, with strong linkages and partnerships with local and regional clinical palliative care services. The model worked on developing a specialist allied and primary health role in palliative care service provision, whilst recognising that the region had excellent specialist nurse practitioners and consultants as well as visiting medical specialists supporting patients, their families and care givers, in a consultative capacity, along their palliative journey.

Then model utilised a professional evidence based social work strengths and systems approach to case management and care coordination, with a particular emphasis on the patient, the family and significant care givers as the 'unit of care'. The case management approach also worked with patients, their families and care givers in developing personal and individual goals of care, including advanced care planning that integrated social, emotional, psychological and existential goals and needs. This model of case management is built on a social work model, incorporating elements of clinical competencies essential for social workers working in palliative care. (see appendicies for a list of clinical competencies for social workers from Canada and the UK used as a framework for this role).

The packages model has some additional core components to the individualised case management and care planning. These are:

- patient home notes
- carer support and education
- advance care planning
- patient centered, goal orientated and individualised multidisciplinary care coordination, where the MDT is orgsanised around the patient, family and care giver needs
- flexible brokerage of equipment appropriate to the disease trajectory and prognosis
- general practice and primary health care support

This project has successfully provided support and case management to over 120 patients and an additional 350 family and care givers across small rural communities in the Riverina.

The Division and Amaranth has been building on the strengths of their previous Department of Health and Ageing Local Palliative Care Grants (Rounds 3 and 4) and believe that their model of rural primary health palliative care with its emphasis on strengthening primary health care and community capacity is a sustainable and innovative model.

Primary health care, supported by Medicare, is for many people the first point of contact with the health care system. Strengthening this area of care for the majority of Australians whose palliative and end of life care needs will be met by this level of care will ensure that these people will have real choice in determining their place of care and involvement in decisions regarding their physical care needs.

Enabling people in rural communities the choice as to who cares for them and where, as well as having confidence in their decisions as to how and where they will die, will ensure, in the words of Dame Cecily Saunders, that people can and will " live until they die".

Introduction

The Riverina Division of General Practice Rural Palliative Care Project is an enhancement of the palliative care packages model of community and primary health care that was developed and implemented across rural communities by the Division in the Riverina since 2006. This project was implemented with support from Amaranth Foundation Mental Health Social Workers, that had developed a comprehensive model of psychosocial and psychological support and intervention.

The Division has developed strong partnerships with local and regional rural community organisations as well as the Area Health Service to deliver quality community based palliative care to over 120 patients and a further 350 family care givers across the Riverina. This project is an enhancement of the previous packages model (Round Four Local Palliative Care grants) and included education about and integration of Palliative Care care planning into the General Practice Enhanced Primary Care Initiatives and data collection.

Due to the success and positive evaluations of the Round 4 Local Palliative Care Grant project, and also the success of the colloborative partnership with Intereach NSW, and Amaranth Foundation, in their action research palliative care project, the Division decided to include patient centred case management and individualised equipment brokerage into this project's aims and objectives. Families and carers had indicated that they appreciated having a person that was available and provided education and resources specifically for them and their needs. They indicated that the individualised equipment brokerage enabled them to remain at home longer, with greater choices and involvement in decision making. Bereavement support and counselling, provided by the social work case manager was also commented on as recognising and supporting the personal and ongoing needs of the family and care givers.

The case model was built on the research and evaluations undertaken during the Round Four projects, where the model was successfully trialled. Initially this model caused some concern from existing specialist palliative care providers who were unfamiliar with the theoretical perspectives and core competencies of social work practice in primary health and in palliative care. (this uncertainty and concern still exists).

Patients, families and care givers responded positively to the use of home notes, so these were continued with minor changes reflecting the evaluations received. The name and purpose was changed to Home Notes or Home Diary ,from Patient Held Records, due to issues that emerged regarding privacy and eventual ownership. Patients and families commented that they wished to retain these folders for their own records so these new folders - Home Diary or Home Notes, became the sole property of the patient and family.

The project therefore included the following elements:

- the development of a strong governance model - to ensure local ownership and sustainability
- strong links, partnerships and collaboration with the regional clinical palliative care services
- continuitation of the social work model of case management and 'packaged' approach to service provision and equipment brokerage
- collection of relevant data
- integration of the strategies into the general practice environment utilising the Enhanced Primary Care initiatives

- implementation and further refinement of the patient home notes, in collaboration with the Area Health Service and community care organisations
- development of education events
- development and support for patient centred multidisciplinary teams

The project is built on an understanding that flexibility and an understanding of local needs of each community and its people is essential for the success and acceptance of any project or initiative. Therefore the governance Group decided that several elements of the initial project project plan would be dropped, such as link nurses and on going education. The other aspects of the project have been successfully implemented, with local variations depending on availability of primary and specialist health care professionals, engagement of local general practice staff, and rate and location of patient or carer referrals for case management or support.

Project area demographics

The project receives referrals for case management and project implementation in all the smaller rural communities outside the major township of Wagga Wagga. These include : Cootamundra, Coolamon, Adelong, Junee, Henty, Temora, Batlow, Tumut, Tumbarumba, The Rock, West Wyalong, Lockhart, Gundagai and Tarcutta.
Some communities had greater involvement and 'buy in' to the project towards the end of the project - such as Cootamundra, Junee, Coolamon, Gundagai and Henty. This was due in part to the acceptance of the project by local community and primary health care providers and willingness of the local clinial staff to work collaboratively.

Ethnicity

Australian born people make up 94.4% of the Division's population. Of the 3.1% from English speaking countries, 2% were from the UK, Scotland and Ireland.
The major birthplaces of the people from non English speaking population come from Germany and the Netherlands.

Some smaller communities have a higher than the NSW State average Aboriginal population including Brungle, a small town near Tumut.

Major Achievements

The RDGP Rural Palliative Care project has been an innovative and successful project. It has used the results of two successful projects that researched and developed a model of case management in palliative care and integrated the successful elements of these projects into this new project. The close partnership with Amaranth Foundation and Intereach Inc, ensured that all aspects of care provision were included in the model and care provided to patients and their families. The result of this was a seamless transition between short term funded projects and a continuation of the trust and collaborative partnerships that had been developed over many years between small rural communities and service providers. Every opportunity was made to ensure any initiatives planned and delivered were evidence based and well researched. Consultation with members of the Governance Group were held outside of scheduled meetings if issues arose or difficulties were encountered. This ensured that problems were addressed quickly and effectively.

A problem solving, capacity building approach was employed by the project team to ensure the success of the project.

An effective and collaborative relationship was built up with two equipment providers, servicing the region. These businesses provided a quality service to all the patients and families that had equipment brokered on their behalf. They guaranteed a 48 hour delivery time frame, provided advice to the project team, patients and families regarding appropriate and available equipment, sourced additional items when required and worked out of hours to ensure that patients had access to appropriate and timely equipment. Both providers showed a great degree of sensitivity to the needs of the patients and families and ensured that a respectful service was always provided. They also ensured that equipment was picked up after the death of the patient in a timely and respectful manner. The partnership with these providers and their professionalism and commitment to a high quality and respectful service ensured that this aspect of the project was enormously successful. Patients, families and service providers commented positively on this aspect of the project on many occasions.

“ .....to have someone know what we needed before we did. This made the difference in being able to care for as long as we did”. Debbie – daughter of father with metastatic prostate cancer.

“ My parents are only pensioners. We could not have afforded the equipment – beds, chairs – what we needed before we did. This made all the difference”. Marie – daughter of mother with MND.

“ Dad didn’t need the bed for long- but it meant that he could stay home another week. That made all the difference”. Bernadette – daughter of father with metastatic prostate cancer

Early Prognostication

Of significance was the implementation of the Wattle Register. This was a register trialled in the Cootamundra Medical Centre. Patients that had been diagnosed as palliative by their general practitioner and in consultation with the practice nurse and case manager were placed on a register at the Cootamundra GP practice. This enabled the patients, their families and significant care givers to have priority access to a GP of their choice, if available, or to a practice nurse with an interest in palliative care.

This initiative was based on the Diamond Register which was a successful initiative developed in the Northern Territory by the Division of GP’s. The purpose of this initiative was to support sustainability within the GP practice, and to enable GP’s and practice nurses to become familiar with prognostication for palliative care especially with patients with non malignant conditions. It also enabled patients, their families and care givers access to clinical support when they required it, including after hours support.

Anecdotal evidence from the project indicated that patients were protective of their doctors and did not feel they could ring for minor complaints. Also, patients under the care of oncologists in the regional centres did not realise that they could also access their local doctor for clinical support so many waited until their next specialist appointment for clinical advice when it could have been resolved locally and in a more effective manner. The preliminary results of this initiative have been very positive from both the practice staff and patients.

Home Records

At the commencement of the project Patient Held Records were implemented for all patients by the social work case manager. These were well received in some communities, and did contribute to seamless communication and transition of care where used by all health care professionals. As the research suggests, Patient Held Records are only as successful as the service providers that use them. The project team found that the cost and effort to continue to use them for all patients could more effectively be used on other strategies. Patients, however, did gain much benefit as they used them to record pain, treatment, personal comments, and also as a resource folder. Because of this, changes were made to the folder and patients and carers were provided with a Home Diary that contained individualised forms and resources. Such forms were: centrelink forms and advice, advance care plan, pain chart, chemotherapy record, chronic disease records, information on grief and loss, meditation, distress and depression, emergency care plan, daily and episodic medication charts and a comments or communication/diary section. Additional resources were provided depending on the patient or carer circumstances and need. In some instances families reported that this became a permanent record of their loved ones final journey, and a record for the family members that could not share the journey. In some communities, especially Cootamundra, Coolamon, and Junee, service providers and community nurses and general practitioners used them to enhance communication, ensure continuity of care and avoid duplication.

Social Work Model of Case Management

The Social Work Case Management model (Amaranth Foundation model of Specialist Mental Health Social Work) developed over the previous palliative care projects and further enhanced by this project has been informally **commented by health care professionals and families as being singularly valuable.** Having a professional model of social work case management ensured that comprehensive and holistic assessment occurred in a timely manner consistent with the patient and carer identified needs. The model also ensured that assessment of 'distress' or complicated psychosocial needs occurred in a timely manner and that appropriate focussed interventions could be delivered or appropriately referred on. It is important to note that the skill set and competencies required by Mental Health Social Workers is inclusive of screening, assessment and care planning for a range of psychological an psychiatric interventions, including grief, loss and coping with change.

The social workers employed by Amaranth were also trained in the **Respecting Patient Choices®** Advanced Care Planning program, Psychosocial aspects of Palliative Care, Dignity Therapy, Cancer Counselling, and Chronic Disease Self management strategies.

MDT’s

The Multidisciplinary Team care planning was developed around a patient centred, strengths and capacity building model. As many rural communities do not have a full range of primary health care providers providing local services, but often provide limited outreach service, and there is limited regional specialist palliative care services, a successful model of locally orientated patient centred MDT was implemented. This model used the case manager, local community nurses, local community care service providers, local general practice nurse and the patient's general practitioner as the core MDT, with relevant regional health care professional or community care service dependent on the patient or carer need and stage of patient journey. The MDT was therefore created around the ‘unit of care’ and pulled together at key transition points along the patient or carer journey. Discussions had commenced around trialling the Modified Kanofsky Scale and Phases of Illness Data set as a means to formally identify the timeliness of MDT’s and measure their effectiveness, however this was not implemented.

Education of Community Care and HACC workers occurred through out the project. Working in close partnership with the community care sector has enabled the case manager to identify with regional and local managers a range of education needs for their community care staff in working effectively and compassionately with their clients with palliative care needs. This has also assisted in these workers being familiar with terminology used in palliative care, and appropriate referral pathways that could assist their clients.

Carer Support

Another sustainable initiative of the project has been the reinforcement and enhancement of strong partnerhips and referral pathways with the Commonwealth Respite and CareLink Centre (CRCC). This partnership has ensured that carers accessing the CRCC for short term or emergency respite have had access to early identification and referral to palliative care case management, and also ensured that eligible carers have had access to 24 hourly emergency and short term carer support, respite and education as required. The sustainability aspect of this has been the willingness of the service coordinators of the CRCC to be educated in referral pathways for palliative care, and theoretical perspectives relating to grief and loss, death and dying. Resources have been provided for their staff, and information regarding Care Search and other electronic palliative care resources have been provided.

Education and Support for General Practice

The development of a dedicated Palliative Care section on the RDGP website, with regular updates has been another sustainable initiative of the project. Local forms, such as advance care planning, referral forms to specialist and primary health care providers, care planning templates, EPC pathways for general practice utilising appropriate Medicare items. Policy documents are also included including certification of death , NSW Palliative Care Plan, NSW documents regarding advance care planning and legal issues are included. Appropriate linkages to other Division templates and information are also included. The Division IT department have made a commitment to ensure that these forms and policy documents are regularly updated and practices and GP’s notified when changes occur.

DISCUSSION OF MAJOR POINTS FOR THE REPORT

Please provide additional GP data information to further explain the quantitative data reported above.

1. GP's have reported that they are often confused as to the referral pathway for community based services. They commented that the eligibility criteria can be confusing for not only themselves but for the patient and caregivers. They commented that they were not aware of wait times and the impact this had on service provision. GP's generally commented that they did not use the CRCC, as that service preferred the carer to make contact, but that did recommend many carers to use this service. They commented that many carers reported that they were deemed to be ineligible when they contacted the CRCC themselves.

2. GP's in discussions have indicated that they believed that the level of palliative care delivered by the primary health care team was excellent in most circumstances. The GP's and practice staff work hard to ensure that clients with obvious end of life and palliative care needs had their needs met by both the local practice and local hospital staff, including local emergency care staff. Where they were aware of patients, they delivered care that was patient centered, and responsive to their needs, including assisting to plan for a home death if this was preferred. Some of the difficulties identified with specialist support was that this was episodic and if the community nurses had referred a patient to the CNC or CNS, the GP may or may not know about this until the specialist nurse made contact, or the patient gave them a report. The medical specialist, even though she had made it clear that she would like to assist the small rural communities better, was not called upon to do so. Efforts had been made to improve the communication pathways and input from the specialist team to the MDT, this was only slowly improving at the time of writing this report.

Another barrier has been the identified capacity of the local rural or regional outreach allied health staff to understand the nature of end of life and palliative care symptoms and best practice guidelines for treatment or support to enable the patient's goals of care to be respected. One local OT made a clear undertaking to understand the different disease trajectories and ensure her assessments were timely and apporpriate to the patients current and future needs. In some instances the speech therapists and dietitians were unrealistic of carer capacity or the level of communtiy support available deciding appropriate treatment regimes. There was unanimous support for ongoing education in end of life and palliative care by all these service providers.

3. The GP's interviewed stated that in many cases they were unclear as to the criteria for determining palliative care, and if they referred for local palliative care services, (ie: community nurses) often there was not a clearly identified role for the community nurses to undertake.

4. As the project has become established and developed a criteria and business plan for the use of GPMP and PN reviews, the GP's have indicated that they are keen to improve their involvement in data collection and the development of MDT care plans for their patients and carers. All of the GP's indicated that they saw improved patient outcomes and their conversations regarding advance care planning (ACP) and end of life care with patients, families and care had been enhanced. One GP referred to the case manager regularily to commence the ACP discussions and then continued the medical discussions in a team approach.

Describe the patient held record model. In the model description include: needs planning and analysis, research of models and tools undertaken, consultation process and dissemination strategy. (600 words)

The patient held record was developed after a comprehensive literature search looking at communication models, chronic disease self management tools, patient diaries. Previous and existing models were examined such as the GSAHS Patient Notes, Adelaide Hills RPCP and the GAPs PHR. Common themes emerged as to what data and tools patients found useful and supported MDT communication, as well as improved patient and carer communication. The most common theme was the notion that PHR provided the 'glue' between all services [2] and that the information and communication follows the patient.

The PHR had been trialled in the previous Palliative Care project (Rd 4) and a model that was accepted by all health care providers and evaluated by patients and carers as being useful and enhanced communication was implemented in this project.

A sub committee of the Panel was formed early in the project life, to examine the contents to ensure ongoing suitability and appropriateness for this project. The RDGP agreed to have copies available for use in all communities and to have them available for other health care workers.

Information regarding the PHR was circulated to all community nurses, primary health care nurses and GP's via email and monthly reports to the GP's.

Copies were available whenever case meetings or discussions / education sessions were held, in order to familiarise other health care professionals in their use.

A copy will be included on the RDGP web site when the new site is completed. Separate pages will be available to be downloaded as required, such as pain management, communciation.

Describe in detail the processes and results for testing the PHR and any modifications made as a result of the testing process.

The sub committee met 3 times from 2008-9 to discuss the appropriateness of the PHR and also looking at coordinating the various health records that patients have in the home (HACC, Community Nurses, RDGP).

The discussions included the following decisions and actions:

- the sub committee felt strongly that the process had to be streamlined and seamless for the patient and that all health care professionals had to work together in a constructive and positive manner
- It was agreed that if the community nurses had previously implemented a PHR for the patient with a chronic illness, then the Case Manager would add palliative care specific pages such as pain management, symptom control, legal issues, to the existing file.
- if the Case Manager was the first health professional to work with the patient and family, then the RDGP PHR would be implemented, and the community nurses and

other community care workers and health professionals would use this record, and add their relevant pages, if different

Over the past 6 months, there have been some issues with consistency of the PHR used by the AHS in some communities. Also with changes in AHS staff, there were issues with awareness and cooperation in the use of a consistent model for the patient and their family. It was decided by the Advisory Panel that in these situations the RDGP PHR would be used as well as the AHS PHR if the patient and their family felt that it would be benefitial. To differentiate this record from the AHS PHR, the Advisory Panel agreed with the name change to Home Diary and Resource Folder. The focus has also changed here in that the PHR is then owned by the patient and is not considered the property of the Division or the AHS. THis change also impacted on the interchangeability of the Home Notes with the AHS PHR. The AHS PHR is the property of the community nurse, not then patient, and it was felt that the RDGP Home Notes would have a greater emphasis on the patient's own record keeping, and communication. They were encouraged to take this when consulting other health providers, and to record personal comments regarding care, symptoms, thoughts and feelings.

Describe in detail the evaluation framework and results of the evaluation.

No formal evaluation has been conducted of the home notes. General quantitative information as gathered from community services, GP's and patients and carers. The general consensus was that the home diaries were favoured by the patients and carers as they felt that this was their record and they had more control over its contents. When patients brought the Home Notes to GP consultations the communciation page was used, and also consulted with medication and other treatment sections of the Home Notes Folder.
The HSM of one facility stated that she encouraged all patients in her community that she was aware of with Home Notes to bring them to hospital with them, especially with emergency calls.

Describe in detail the strategies and activities undertaken to ensure the PHR is sustainable beyond the RPC Project.

The Home Diary and Resource Folder will be loaded onto the new RDGP web site, so that GP's and practice nurses can download the folder or resources from it when working with specific patients and families. Templates of various tools have been electronically provided to AHS staff in many rural communities on request. These will also be available on the RDGP web site and staff updates regularly by the IT manager and chronic disease team.

Describe in detail the MDT meetings model. Include needs planning, research of model, consultation process, testing and evaluation strategy and results thus far. (900 words)

The model utilised for the MDT in this project have been drawn from a range of sources. The most significant is the Multidisciplinary Tool Kit, taken from Cancer Australia web site, and also informed by the action research project conducted by JWhyte for Intereach (2009) that trialled MDT in rural communities.

We were aware that the Comprehensive Cancer Centre (RCCC)in the regional centre of Wagga had MDT meetings for their cancer patients, however, attendance at this was confined to staff at the RCCC and Wagga clinicians. No rural allied health workers or patient GP's were involved in these discussions. Neither were care plans shared with teams outside the regional centre.

We decided that as the project was designed to support all patients with a palliative disease trajectory not just those with malignancies, and that our focus was improving the care in smaller rural communities outside the regional centre, the nature of the MDT had to reflect this. Whilst the research was mostly describing formal and stationary MDT, with a set membership, this structure did not always suit the smaller rural environment, where many of these specialisations were not present.

A small pilot of a formal, structured MDT was conducted early in the project in Cootamundra, however the number of patients identified as having palliative care needs was spasmodic and in some months there were no new patients identified. This made the need for the monthly MDT questionable, especially as some practitioners and health care professionals, who work part time or had to travel long distances to attend, question the validity and usefulness of such meetings.

Another model was developed where the MDT was created around the patient, based on need and complexity. If a patient was referred to the case manager, after an assessment was conducted and the clinical and psychosocial needs assessed, usually in conjunction with the community nurse, the MDT was created based on identified need. The MDT was also designed to be flexible to suit the rural environment, in that a variety of mediums were used to support engagement and interaction. A combination of teleconferencing, email, individual face to face, small group discussion, and GP appointments/phone calls, were used to ensure the most appropriate and available health care professionals and community care organisations were involved in developing a holistic and comprehensive care plan. This was very labor intensive, however once the pathways and communication channels were developed and entrenched in the project the work load decreased.

Describe in detail the strategies and activities undertaken to ensure the MDT meetings model is sustainable beyond the RPC Project.

The Case Manager has worked hard to encourage each discipline to engage with the MDT process. Using a patient centered approach, where the MDT is focussed on the patient disease trajectory and complexity of need, and is pulled together when required ie: when there is a change in care needs, then it is expected that there will be a greater acceptance of the role a MDT can have in patient care.

Other disciplines have started initiating the MDT which is evidence that this may be a model that is sustainable.

A resource book has being developed that will support health care professionals and community care workers in the purpose, use and management of a MDT. This will also include information and examples of how a MDT becomes the basis of a new care plan. This information and resource has been included on the RDGP web site under a section dedicated to Palliative Care / End of Life care.

Sustainability

- GP Palliative Care Resource Guide - This resource is intended for the Practice Nurses and GP's in utilising the EPC items for identified Palliative care patients and their families and care givers. It also includes a range of resources to assist GP practices in developing quality projects to identify and support their patients who may benefit from a palliative approach. This resource is available on the RDGP website
- Carer Involvement and referral to CRCC - The relationship with key stakeholders in understanding the role and nature of the funding mix for CRCC's to support people requiring a range of supports and services will be ongoing. The CRCC also have

accessed information and support for their service coordinators and managers in understanding the complexity of a palliative diagnosis

- Equipment availability - The equipment supplier across the region has a greater understanding of the needs of people with a terminal illness and is aware of the range of health care providers in each community. They have a relationship with the Cancer Support and other patient support programs, which will continue.

  Home Notes and Resource Folder - this resource is available in electronic form on the RDGP website.

Barriers

Discuss challenges or difficulties (if any) encountered during the project and the actions undertaken to overcome these challenges. Detail any slippages in timeframes.

There have been several barriers to the project that have impacted in varying degree to the success of all deliverables. These can be listed as follows:

- Slow buy in from the Area Health Service - Changes in staff and lack of awareness caused many delays and multiple meetings in the implementation of deliverables such as patient held records, after hours pathway, referral to specialist teams, regional forum, education events and link nurses.

- Large geographical region. This is always a problem for projects that target a whole geographic region with part time staff. Developing relationships is an important part of building a successful project and the trusting relationships that have to occur. Due to the large region, with over 13 communities, and referrals for case management, as well as project deliverables, made this project very labour intensive, with great travel time involved. As the project evolved, 6 communities emerged as wanting to work collaboratively and implement changes or initiatives from the project. It was decided, after discussion with the Advisory Panel that whilst we would work with the other communities, if patient referrals came from those areas, or requests were made for resources or information, efforts would be concentrated in the 6 main communities.

- Another major barrier was the lack of familiarity with a social work role in Palliative Care as it applied to rural practice. This caused some confusion as to role delineation, where the social worker in a Metropolitan specialist team has very clear and identified roles, where as in a rural context the social worker has to undertake a multiple of tasks, including comprehensive, systemic and patient centred approach to care planning.

- Lack of familiarity by the specialist palliative care team of the Medicare EPC items and their application to end of life and palliative care. This caused some confusion and lack of support for the psychosocial assessments and care planning conducted by the Mental Health accredited Social Work case manager and practice nurses for patients, their families and care givers requiring end of life or palliative care.

Additional Comments & Recommendations

Provide any additional comments relevant to your project. This could include recommendations for project improvements and / or suggestions for policy development and implementation.

The Case Management focus of this project has seen great improvements in the capacity of rural communities to be able to plan for and deliver quality palliative care into small rural communities. This component of the RDGP's palliative care projects since 2006 have been highly successful and evaluations of previous projects have indicated that staff in rural communities greatly appreciate the support and involvement of the case management role.

It has, however, made this project very labour intensive, with regard to the number of deliverables agreed to in the business plan, and the part time nature of the staff. Whilst the agreed deliverables have all been worthwhile components of a quality palliative care project, the professional, dedicated role of Case Manager working across many rural communities appears to be singularly benefitial to patients, their families and caregivers, health care professionals and community care services across rural communities. The model, based on a 'packaged' model of care, but utilising a professional social work model of case managment, has been informally and formally reported as being able to deliver appropriate and timely care for patients, their families and care givers and much needed educational, resource and practical support for the health care professionals working often in isolation, across all the rural communities in the region.

The implementation of effective MDT's into rural practice will be an ongoing dilemma for rural practitioners, and also for practice nurses who will be continuing with the Priority Pallitaive Care Initiative. Alternative, flexible, patient centered models of MDT care planning, need to be encouraged to be developed, with a strong evidence base to ensure that this is effectively planned for a developed in consultation with the patient's GP, the patient, their family and care givers, and determined based on the complexity of both clinical, psychological, and existential needs.

It was my observation that the utilisation and updating of patient care plans was spasmodic, when undertaken by professionals other than the case manager, whose role is dedicated to the task. Education and further support may need to be undertaken in regards to making these documents dynamic and reflective of current patient and family need, and not just a once off document with little relevance to ongoing care requirements.

Dedicated funding for rural palliative care case managers will be required for the positive outcomes of this and other RPCP to be sustained. An alternative model may be the increased utilisation of EPC items for chronic disease, and referral to social work for case management and care planning. This would be an innovative project to implement and evaluate especially in regard to the primary health developments being discussed nationally.