Commonwealth Department of Health and Ageing

Local Palliative Care Grants Round 5

The Amaranth Project : Your Mind Does Matter

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EXECUTIVE SUMMARY

The funding for this project, from the Commonwealth Department of Health and Ageing, Local Palliative Care Grants, was for the integration of mental illness into palliative care.

The ***Your Mind Does Matter project*** aimed to deliver a "Social Work Palliative Care Case Management" approach for the delivery of a "Packaged" model of care. This project built on previous action research projects undertaken by the author and principal researcher on two previous Local Palliative Care grants rounds - one with the Riverina Division of General Practice, and the other with Intereach, a regional not for profit organisation that auspices the Riverina Commonwealth CareLink and Carer respite program.

The Your Mind Does Matter action research project developed an evidence based social work model of care planning, case management and trialled several appropriate mental health screening and assessment tools as well as the delivery of evidence based brief therapeutic interventions for a range of identified mental health problems and issues.

The successful strategies implemented and evaluated throughout the project included:

- The development of a **social work palliative care interventionist 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 and current evidence;
- **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.

Over 80 percent of individuals and their families participated in Advanced Care Planning conversations, using the Amaranth ACP document, that is based on he Respecting Patient Choices literature and documentation. The reason for the high uptake of these conversations were that they occurred as part of the normal work undertaken by the social worker, and occurred in a narrative, theraputic framework. This meant that the focus was on the individual and their families' individual needs and concerns at this time, and not just focussed on obtaining a legal document.

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. Our 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
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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. Screening 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.

[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.