



Grampians Region
Palliative Care **Consortium**

Annual Report 2016

Members:

Ballarat Health Services
Ballarat Hospice Care Inc.
East Grampians Health Service
Djerriwarrh Health Services
Wimmera Health Care Group
St John of God Hospital Ballarat
Department of Health (non voting)

This report was prepared by:
Pete Marshall, GRPCC Manager.

On behalf of:
Grampians Region Palliative Care Consortium
Phone: 0428 737 330
Email: gpalcareconsort@gmail.com
Website: www.grampianspalliativecare.com.au

Copies of this report can be downloaded from the Grampians Region Palliative Care Consortium website at <http://www.grampianspalliativecare.com.au> or by contacting Pete Marshall – Consortium Manager, Grampians Region Palliative Care Consortium at the above email address.

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1. Chair's Message

Over the 2015-16 financial year, the consortium has again focused efforts upon the core objective of improving the quality of and access to palliative care services within the Grampians region. The report details a broad range of projects, all of which are aimed at supporting and enhancing the provision of quality palliative care. Our funded services remain a core focus, and we are delighted to have supported the continued development and provision of high quality palliative care services within the Grampians community. Both the consortium and the member services were well engaged with the End of Life Framework consultation that took place at the end of 2015. We look forward to supporting the implementation of the new framework into the future.

Financially, the consortium has continued to manage a moderate underspend to support our services to develop innovative and high quality resources. In addition, we continue to be able to assist smaller community based initiatives that fit perfectly with enhancing a broader end of life discussion.

I would like to take this opportunity to thank Mr. John Koopmans, Department of Health and Human Services, for his leadership and guidance throughout the year. I would also like to express my gratitude to my executive consortium colleagues whose time, commitment and dedication to regional palliative care services has resulted in raising the profile and delivery of palliative care services throughout our region. My sincere thanks to Mr. Pete Marshall, Consortium Manager, for his excellence in coordinating and managing consortium initiatives. I would also like to acknowledge our new Consortium Chair Ms. Michelle Veal who comes to the role with a wealth of experience, knowledge and skills, and who will be a considerable asset in leading the Consortium into the future.

Denise Hooper
Grampians Region Palliative Care Consortium Chair

2. The consortium focus in the context of the Grampians Region

The total area of land in the Grampians is 48,618 sq km, and only 1% (approx.) of land region is zoned for residential, business or industrial use, with most being rural (approx. 79%) or public reserve (approx. 20%).

Population growth in Grampians Region has been lower than average since 2000, and this trend is projected to continue to 2022. There are higher than average percentages of children under 14 years, and persons aged 45 plus, while the 15 to 44 age group is under-represented. The Aboriginal population is higher than average, but levels of cultural diversity are low.



The rate of volunteering is the highest of all regions. Grampians has higher than average low-income individuals and households and the highest percentage of unemployed throughout Victoria, but low levels of housing stress. The year 9 educational attainment is the lowest of all regions.

Grampians Region has the lowest GP ratio per 1,000 population, but the highest rate primary care occasions of service at over twice the Victorian average. Grampians Region ranks 2nd among regions for HACC clients aged 0–69 per 1,000 target population, and for those over 70 years of age, 26.3% are HACC clients.

In terms of health indicators, rates of asthma are higher than average across most of the region, as are rates of drug and alcohol clients and mental health clients. Some LGAs in the Wimmera have particularly high rates of overweight and obesity.

However, a breakdown into the broad areas of Wimmera (Horsham, West Wimmera, Hindmarsh and Yarriambiack LGAs), Central (Northern Grampians, Ararat and Pyrenees LGAs) and Ballarat (Ballarat, Hepburn, Moorabool and Golden Plains LGAs) shows significant disparities in local demographics.

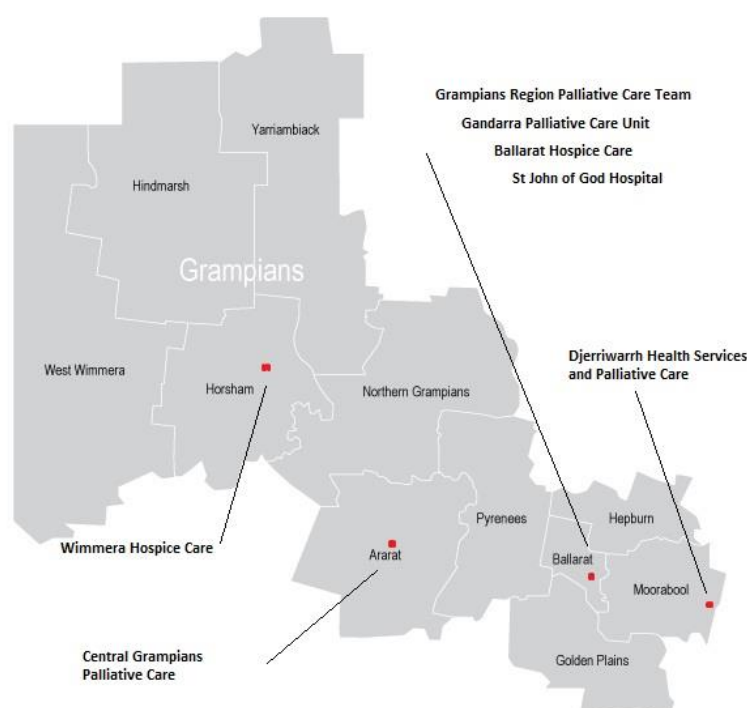
Table 1: *Population density and proportions of aged residents*

	Grampians Region	Wimmera	Central	Ballarat
Total population	220,878	16.5%	13.4%	70.1%
65+ (as % of popn)	16.4%	20.8%	20.6%	14.6%
Area sq. kms	48,618	28,222	13,370	7,026
% of Grampians area	100%	58.0%	27.5%	14.5%
Popn density (persons/sq km)	4.5	1.3	2.2	22.0

The Ballarat area has a vastly higher population density, accounting for 70.1% of the total population, but only 14.5% of the total land mass.

2.1 Factors impacting capacity to manage health issues into the future

The demographic data set out below (Table 2) shows that the Grampians region as a whole, and particularly LGAs in the central and western parts of the region, are facing significant issues that are likely to impact on the provision of palliative care.



A growing ageing population combined with reduced community working capacity lead to greater dependency.

This is currently reflected in high levels of people with need for assistance with core activities, and the percentage of persons aged 75+ who live alone, and exacerbated by high levels of disability support pension and age pension recipients, and high rates of those with profound disability living in the community.

On top of this, Grampians has a high rate of malignant cancers diagnosed, which is going to be one of the more significant drivers of increased need for palliative care.

Higher dependency ratios mean fewer people of working age. Dependency ratios for 2011 are higher than the Victorian average in all Grampians LGAs and are particularly high in Yarriambiack and Hindmarsh. This pattern will continue in 2021, with even higher dependency ratios. There is a general trend toward higher dependency ratios both now and into the future as you move across the West of the region.

Table 2: *Current (2011) and projected percentage population over 65 years of age, and proportion under 15 and over 65, compared with proportion of working age population (Dependency ratio).*

LGALGA	2011		2021	
LGA	65+	Dep Ratio	65+	Dep Ratio
Wimmera				
Hindmarsh (S)	24.1	0.71	29.7	0.86
Horsham (RC)	17.6	0.58	21.6	0.67
West Wimmera (S)	21.5	0.67	25.8	.071
Yarriambiack (S)	24.4	0.72	28.6	0.76
Central				
Ararat (RC)	19.7	0.60	23.8	0.69
Nth Grampians (S)	20.1	0.59	26.3	0.70
Pyrenees (S)	21.9	0.62	26.7	0.73
Ballarat				
Moorabool (S)	12.5	0.50	17.6	0.61
Hepburn (S)	18.9	0.57	23.6	0.66
Ballarat (C)	14.9	0.51	19.1	0.61
Golden Plains (S)	10.4	0.50	16.2	0.59
Grampians	16.1	0.54	20.6	0.64
Victoria	14.0	0.48	16.7	0.53

These issues are exacerbated by a high and growing proportion of people in the community who need medical and daily living support, as set out in Table 3.

Table 3: *Aged and disability characteristics, Grampians LGAs*

LGA	% with need for assistance with core activities	% with severe and profound disability living in community	% of persons aged 75+ who live alone	Disability support pension recipients per 1,000 eligible pop	Age pension recipients per 1,000 eligible pop
Ararat (RC)	7.1%	5.1%	39.8%	102.9	746.9
Ballarat (C)	6.0%	4.4%	42.5%	86.5	764.5
Golden Plains (S)	4.7%	3.9%	30.6%	55.1	766.3
Hepburn (S)	5.9%	4.3%	41.2%	97.3	760.4
Hindmarsh (S)	8.2%	5.1%	40.5%	107.5	684.7
Horsham (RC)	5.7%	4.2%	43.2%	81.9	728.6
Moorabool (S)	4.9%	4.2%	36.2%	56.7	736.2
Northern Grampians	8.2%	5.8%	43.8%	126.4	770.6
Pyrenees (S)	7.6%	5.9%	37.0%	127.4	764.5
West Wimmera (S)	5.9%	4.4%	41.5%	76.6	674.3
Yarriambiack (S)	9.1%	6.4%	41.4%	130.5	642.9

Grampians	6.1%	4.6%	41.0%	85.7	746.1
Victoria	5.0%	3.8%	35.9%	54.8	704.5

The consortium has focussed many of the supported initiatives on the west of the region. While population numbers may be smaller than in the east (closer to Melbourne) the proportion of the population that is aged and/or disadvantaged (in many cases both) is very high. The Index of Relative Socio-Economic Disadvantage (IRSED) indicates that four of the ten most disadvantaged LGAs in Victoria are in the Grampians region: Hindmarsh; Northern Grampians; Pyrenees; and Yarriambiack. Add to this the decreased access to training and professional support for health and welfare staff that comes with small centres, and large distances to services, make this an issue of addressing the relative disadvantage experienced in the west.

The percentage of persons with need for assistance with core activities is higher than the Victorian average (5%) in Grampians region (6.1%). All LGAs have a higher than average percentage of persons with severe and profound disability living in the community, with the highest percentages in the west and central part of the region. The percentage of persons aged 75+ and living alone is also higher than average, but ranges from 30.6% in Golden Plains to 43.8% in Northern Grampians. The rate of disability support pension recipients is well above average in all LGAs other than Golden Plains and Moorabool. The regional rate of aged pension recipients is also above average, with the highest rates in Ballarat, Golden Plains, Hepburn, Northern Grampians and Pyrenees.

Table 4: *Total malignant cancers diagnosed per 1,000 population, and for males and females, in 2011, Grampians LGAs*

LGA	Males	Females	Total
Ararat (RC)	4.79	6.42	5.58
Ballarat (C)	5.98	5.21	5.59
Golden Plains (S)	6.37	4.90	5.66
Hepburn (S)	7.58	5.55	6.55
Hindmarsh (S)	7.49	6.48	6.98
Horsham (RC)	7.77	4.45	6.09
Moorabool (S)	5.01	5.83	5.42
Northern Grampians (S)	7.12	6.10	6.62
Pyrenees (S)	8.53	6.61	7.58
West Wimmera (S)	13.13	8.17	10.73
Yarriambiack (S)	7.21	8.46	7.83
Grampians	6.45	5.56	6.00
Victoria	5.73	4.54	5.13

The rate of malignant cancers diagnosed (Table 4) is higher for males, females and total persons in Grampians region compared with the Victorian average. The rates for total persons are highest in West Wimmera but are above the Victorian average in all LGAs.

The Central Grampians area in particular has higher than average rates on disability indicators, with each of the LGAs having higher than average persons with severe or profound disabilities, and higher rates of those needing assistance with core activities.

Grampians region does not stand alone on many of these indicators, as numerous studies have shown high levels of health inequality across areas of rural Australia. The challenge is exacerbated by limited resources spread across large geographical areas, and well-recorded difficulties in attracting skilled health care professionals.

The palliative care services in the Grampians region are committed to offering a high level of care, and the consortium is committed to supporting them in this regard.

2.2 The consortium focus

The broad focus of the Consortium is supporting improved access to, and quality of, end of life care for patients and carers in the Grampians region.

A major part of this is improving the capacity and functioning of both the funded services, and the broader health and community sector. Services are time poor, with skilled staff at times struggling to meet the clinical load, let alone to have significant involvement in development of new initiatives. The Consortium is consciously focussed on supporting capacity building to provide sustainable improvements in effectiveness and efficiency, and as part of this, effective and innovative use of technology would always be a priority for consortium support, particularly in rural areas, within the funded services.

1. Priority 1 - Provide effective workforce support and professional development
 - Support enhanced use of technology,
 - Broader use of consistent tools and resources,
 - Enhanced capacity and skills within Aged Care,
 - Supporting specialist staff skill development and educational opportunities,

Most of the resources utilised in end of life care will not be provided by specialist palliative care services, but it is to be hoped that it will be informed by specialist palliative care. The next focus then is on broader sector engagement.

2. Priority 2 - Broader sector engagement
 - More understanding and acceptance of Advance Care Planning,
 - Up to date and effective website,
 - Regional Information sharing,
 - Local community education and initiative support

By far the most support for people at the end of life comes from the community. People at the end of life need a community that is well informed about the end of life, and the support to maintain their links to the community. The focus then becomes providing effective and relevant support and information for carers and communities about end of life, death and a palliative approach.

1. Priority 3: Better support for carers
 - Funding resource development

The consortium has been well engaged in the consultations that supported the development of Victoria's end of life and palliative care framework, and consequent discussions about an evolving role for consortia within this future vision for end of life care. The framework *'has a particular focus on services and asks everyone working in health, human social and community services to consider the role they play in delivering end of life care.'* The initiatives of the Grampians Region Palliative Care Consortium sit well with this focus, and we look forward to developing this even more within the new framework.

3. Other Specific Groups

CALD

A relatively small proportion of the Grampians Region has come from non-English speaking backgrounds. Community members now living in the Grampians Region, but born overseas, include

people from Chile, China, Croatia, Egypt, Germany, Greece, Holland, India, Iraq, Iran, Japan, Kenya, Lebanon, Malaysia, New Zealand, Nigeria, Pakistan, Philippines, Poland, Somalia, South Africa, Sri Lanka, Sudan, Thailand, Togo, United Kingdom and Vietnam and Yugoslavia.

Aboriginal and Torres Strait Islander

Data regarding the Aboriginal and Torres Strait Islander population can be found in the recent Department of Health publication - *Grampians Closing the Indigenous Health Gap Plan, 2009–13*.

Approximately 0.8 per cent of the region's population is Aboriginal or Torres Strait Islander, which equates to approximately 1,762 people (ABS 2006 Census), with numbers being broadly distributed across the region in a similar proportion as the general population. Table 6 shows approximate numbers associated with each of the Aboriginal community-controlled organisations (ACCOs).

Table 6: *Aboriginal and Torres Strait Islander population in the Grampians Region*

ACCO name	Catchment area local government areas	Number of Aboriginal persons (approx)
Ballarat and District Aboriginal Cooperative	Ballarat City Council, Golden Plains Shire, Moorabool Shire, Hepburn Shire	1,200
Goolum Goolum Aboriginal Cooperative	West Wimmera Shire, Horsham Rural City Council, Hindmarsh Shire, Yarriambiack Shire	350
Budja Budja Aboriginal Cooperative	Ararat Rural City Council, Pyrenees Shire, Northern Grampians Shire	200

Other data shows that the Grampians Aboriginal and Torres Strait Islander population is significantly younger than that of the non-Aboriginal and Torres Strait Islander population. Approximately 79% of the Aboriginal and Torres Strait Islander population is under 44 years compared to approximately 56% of the non-Aboriginal and Torres Strait Islander population.

The consortium welcomed the opportunity to provide an Aboriginal Health Worker scholarship for the PCV conference in July 2014.

4. Consortium Membership and Structure

Committee of Management for 2015-2016

Chair: Denise Hooper, Director of Primary Care, Wimmera Health Care Group (until May 2016)
Michelle Veal, Director Community Services, Ballarat Health Services (from May 2016)

Members:

Carita Clancy, Executive Officer, Ballarat Hospice Care Inc
Peter Armstrong, Director, Clinical Services, East Grampians Health Service
Jane Bostock, Manager, Community Nursing, Djerriwarrh Health Services
Jane Bourman, Manager, Community Nursing, East Grampians Health Service (Clinical Group representative)
John Koopmans, Department of Health & Human Services
Pete Marshall, GRPCC Manager

5. Member Services

Ballarat Health Services (BHS) - Drummond Street North, Ballarat 3350. The catchment area consists of the whole of (but not limited to) the Grampians Health Region.

Gandarra Palliative Care Unit is a nine-bed inpatient palliative care facility providing end-stage care and symptom management for patients and their families who have been diagnosed with a terminal illness. The multidisciplinary team comprises of medical, nursing, pastoral and volunteer support as well as allied health professionals such as occupational therapy, dietetics and social workers.

Patients and families are encouraged to actively participate in all aspects of the patient-focussed multidisciplinary care and planning. The environment enables patients and families to maintain as much as possible their normal routine within a specialised setting.

The Grampians Regional Palliative Care Team (GRPCT) facilitates the ongoing development of palliative care services in the Grampians Region through education, collaborative strategic planning, preparation of written materials, policies and procedures, quality improvement processes and consultation. The GRPCT is committed to providing a variety of quality education to a broad range of health professionals who strive for better palliative care practices.

Ballarat Hospice Care Inc (BHCI) - 312 Drummond Street South, Ballarat 3350. The catchment area consists of the City of Ballarat, Hepburn Shire, Golden Plains Shire, Moorabool – West SLA, and west of the Ballan-Daylesford Road and Geelong-Ballan Road within the Moorabool – Ballan SLA.

Ballarat Hospice Care Inc provides home-based palliative care services that are patient-focussed for people living with a life-threatening illness. A multidisciplinary team of specialist health professionals and trained volunteers deliver quality end-of-life care with understanding and compassion through symptom management and medication. BHCI continues to support families following a death at a time when people are emotional and feel vulnerable.

Experienced palliative care staff provide expert pain and symptom management as part of any ongoing treatment, with emotional and other practical support services for patients and families. The focus is on providing quality of life, to end-of-life care, with palliative care an adjunct to ongoing treatment, which can be delivered from diagnosis to bereavement.

Wimmera Health Care Group (WHCG) - Baillie Street, Horsham 3400. The catchment area consists of the Statistical Local Areas (SLA) or the Rural City of Horsham and the Shires of Hindmarsh, Yarriambiack and West Wimmera.

Wimmera Hospice Care, auspiced by WHCG, is a palliative care service that supports people living with life-limiting illnesses and their families and carers. The WHC team supports patients at home, in aged care facilities and in hospital. The team works closely with patients' local doctors, nurses and allied health care teams. The focus is not just on physical problems but also the emotional, spiritual and social issues that can occur as a result of illness. A bereavement support program is offered to families and carers and funding can be made available for specialist bereavement counselling.

East Grampians Health Service (EGHS) - Girdlestone Street, Ararat 3377. The catchment area consists of the Shire of Northern Grampians, the Rural City of Ararat and the Shire of Pyrenees including Skipton (ie. Beaufort and Skipton Health Service).

Central Grampians Palliative Care (CGPC) is a community-based service auspiced by EGHS, delivering health care and emotional support to patients, and their carers, living with life-threatening illnesses. CGPC aims to work with patients, their families and carers to achieve a level of care that optimises an individual's quality of life and to enhance dignity and independence. The service liaises with a number of local health and community services to assist in personal care, symptom management, home help and transport. It also loans equipment and aids to enable independence to be maintained and to make home nursing care easier. EGHS has one inpatient palliative care bed.

Djerriwarrh Health Services (DjHS) - Grant Street, Bacchus Marsh 3340. The catchment area consists of the Moorabool – Bacchus Marsh SLA and east of the Ballan-Daylesford Road and Geelong-Ballan Road with the Moorabool – Ballan SLA.

Djerriwarrh Palliative Care (DPC) is a community-based service, auspiced by DjHS. The palliative care program offers co-ordinated care services for people with a terminal illness and support for their family at home. Care and support is offered including pain relief and management of other symptoms. It aims to be flexible and sensitive to the wishes and needs of clients and their families. A range of allied health services are available and a counsellor co-ordinates volunteer and bereavement services. DjHS has two inpatient palliative care beds.

St John of God Ballarat Hospital (SJOG) - Drummond Street North, Ballarat 3350. The catchment area consists of the whole of (but not limited to) the Grampians Health Region.

SJOG is a member of the St John of God group, which operates an organisation-wide Palliative Care Strategy that embodies an holistic approach to palliative care as an integral component of inpatient, outpatient and community services. The focus is on building confidence and capacity to equip caregivers with the knowledge and skills to manage and care for people at the end of life. The ultimate aim is to offer patients, with the support of their families and other carers, the opportunity to die with dignity and respect while minimising pain and suffering.

The implementation of its Pastoral Services Strategic Plan 2010-2014 took place during the year. The main focus is on strengthening professional practice, information and education, and data collection. The Murdoch hospital developed bereavement resource packages for carers, which have been introduced across all hospitals within the SJOG group.

5.1 Contact Details

Grampians Region Palliative Care Consortium
Manager: Pete Marshall
Phone: 0428 737 330
Email: gpalcareconsort@gmail.com
Web: www.grampianspalliativecare.com.au

Central Grampians Palliative Care
Girdlestone Street, Ararat, 3377
PO Box 155, Ararat, 3377
Phone: 03 5352 9465
Email: cgpc@eghs.net.au
Web: www.eghs.net.au

Gandarra Palliative Care Unit
Ballarat Health Services
102 Ascot Street South, Ballarat, 3350
PO Box 577, Ballarat 3353
Phone: 03 5320 3895
Email: mareek@bhs.org.au
Web: www.bhs.org.au

Grampians Regional Palliative Care Team
Ballarat Health Services
102 Ascot Street South, Ballarat, 3350
PO Box 577 Ballarat 3353
Phone: 03 5320 3553
Email: info@grpct.com.au
Web: www.grpct.com.au

Ballarat Hospice Care
312 Drummond Street South, Ballarat, 3350
PO Box 96, Ballarat, 3353
Phone: 03 5333 1118
Email: eo@ballarathospicecare.org.au
Web: <http://www.ballarathospicecare.org.au/>

Djerriwarrh Health Services and Palliative Care
Grant Street, Bacchus Marsh, 3340
PO Box 330, Bacchus Marsh, 3340
Phone: 03 5367 2000
Email: pamr@djhs.org.au
Web: www.djhs.org.au

Wimmera Hospice Care
Wimmera Health Care Group
Baillie Street, Horsham, 3400
Phone: 03 5381 9363
Email: hospice@whcg.org.au
Web: www.wimmerahealth.com

St John of God Healthcare
101 Drummond Street North, Ballarat, 3350
Phone: 03 5320 2111
Email: liz.mcencroe@sjog.org.au
Web: www.sjog.org.au

6. Consortium Manager's Report

The focus of the 2015–16 financial year has been on effective use of available resources for improving palliative care provision in the Grampians region.

One of the main vehicles for improvement has been sector capacity building:

- Provide opportunities for staff to expand their skills by funding research opportunities and initiative development
- Provide support for external educational activities
- Supporting technology skills development and acquisition
- Region wide collegial support through the clinical advisory groups

The consortium has been fortunate to have the stewardship of a moderate underspend, and while there has reasonably been a focus on drawing that down, there has also been a strong focus by the executive on astute and targeted use of those funds.

The underspend has been drawn down by almost \$90k in the 2015-16 financial year. As was indicated in the 2014-15 annual report, by 'supporting', rather than just wholly funding initiatives, the draw down is matched by 'in kind' resourcing within the initiatives that have been undertaken. As a consequence, the ultimate value of the drawdown is effectively doubled, and if service development, staff upskilling, job satisfaction and ultimately retention were to be considered, the multiplier effect of innovative but judicious use of funding is even greater.

In addition, a quick look through the report will illustrate the wealth of resources that have been and are being developed to inform and support carers in the region. Similarly, we are delighted to have been able to fund a variety of initiatives targeting community understanding of, and attitudes to end of life care.

We are well supported in the Grampians region by professional and motivated specialist palliative care services, and it is to them that we owe the most credit for improvements in palliative care provision. The consortium role is to support them where we can.

I would like to thank the auspice, Djerriwarrh Health Services for their flexibility and support as we have worked through some of the structural changes required. I would like to particularly thank John Koopmans our Grampians Health Department rep, for our regular meetings, but also for the quiet way that he goes about supporting palliative care in the region. Thanks also to Denise Hooper of Wimmera Health Care Group, for the support that she has offered over the majority of the reporting year in her role as Consortium Chair. And finally, I would like to welcome our new chair, Michelle Veal of Ballarat Health Services. Michelle has an established background with the consortium, and is well placed to lead into the future.

Pete Marshall, Consortium Manager

7. Core Activities

7.1 Clinical Advisory Group

The Grampians Consortium Clinical Advisory Group (CAG) had 3 meetings during 2015-16, 2 of which were face to face meetings. One scheduled meeting was cancelled due to a significant level of unavailability.

Over time, the clinical group decided to both reduce the total number of clinical meetings, and where possible to have them face to face. Face to face meetings are held in Ararat, as that offers the best compromise on the need to travel from across the region. They are resource intensive, and for some participants will mean losing virtually a whole day from work. They do though, offer the greatest potential for networking and sharing, and the links and sharing occur at a much more significant level. In between these meetings, there is a more pronounced sharing online, and significant news, updates and discussions are utilised when appropriate.

Clinical meetings invariably have a full agenda, and face to face meetings are used to enable a particular focus. While far from exhaustive, the following list provides a snapshot of broad areas covered by these meetings and/or the online network:

- Support and sharing around consistent use of clinical tools
- Nurse practitioner input and feedback from the PCCN
- Information and support for involvement in statewide initiatives and central data collection
- Input into consortium planning activity and data collection
- Information sharing and input into implementation of statewide initiatives funded through the consortium
- Development and review of Grampians based consortium funded initiatives
- Concept development and design of future consortium funded projects

7.2 After Hours

Services have been directly receiving their after-hours money for 5 years now, and are building upon the individual frameworks and the resources developed during the previous years. During 2015-16, the consortium continued to offer support to earlier initiatives.

Individual services' approach to provision is quite varied in the Grampians region, and the consortium will be keen to receive the results of the current statewide review of after hours provision, with a view to supporting the development of a strategy that is more cohesive across the region.

The goal of business hours practice for all of the specialist palliative care services in the region is to pre-empt potential symptom distress concerns for patients. Interventions are aimed at patients and family caregivers being able to manage these situations, particularly in the after-hours period when usual supports are reduced or not available. Such interventions include relevant medications being made available, providing appropriate education and resources to patients and carers, and including and teaching family caregivers to be able to safely administer subcutaneous medications and low-flow oxygen. The low presentation to ED shows BHCI success with these measures, but even with these measures in place, symptom distress may persist which necessitates an ED review.

The consortium has long had a focus on supporting development of resources that will impact on after-hours care of palliative care patients.

7.3 Palliative Aged Care

The role of Palliative Aged Care Resource Nurse (PACRN) in the Grampians region has continued to be embedding a palliative approach and all that entails into the 56 Residential Aged Care Facilities (RACFs) through education, support and networking. This also includes providing training and support to newly established RACFs, as some have transitioned from low level hostel/supported accommodation to accredited RACFs. There has been constant change in management and care staff throughout the RACFs in the region, which has reinforced the need for ongoing and regular facility visits and ongoing support.

In rural regions in particular, it is imperative to fully utilise often scant resources. Broadly speaking, this involves two core thrusts:

- Increase the resources of the available RACF staff by expanding their skills and understanding via **education**, and
- Increase the resource base via networking and **integration**

Education

The PACRN has had 170 sessions with 600 contacts, including 250 attendees to workshops such as:

- Palliative Approach in Aged Care workshops across the regions, both 6hr and 3hr formats
- Presenting at Decision Assist study days.
- Supporting an Alzheimer's Australia workshop.

However most of the workshops have been localised, and specifically tailored to the individual circumstance, and I have used approx. 20 topics to challenge staff in their thinking and roles in care of our frail and aged in RACF. Topics have included recognising signs of dying, understanding the dying process, advance care planning, patient centred care, oral care, assessment of pain, dyspnoea and delirium. The focus of these sessions is focussed on the topic 'To treat or not to treat', underpinned by a phrase I have used extensively:

Treat the treatable, Reverse the reversible, Unless the burden of treatment outweighs the benefit.

This has provided a resolution to a great deal of angst often experienced by staff and families about when to treat and how much.

Education around the topic 'Understanding the Dying Process' has been extended to a broader range of staff, including environmental, cleaning, kitchen, reception and leisure and lifestyle. These 30 min sessions were well received with comments such as "It all makes a lot more sense now", "thank you for involving us as we often feel left out and we have become good friends with the residents", and "I was so upset when I entered to clean a room, not realising the lady had died and the family were gathered".

The staff attending these sessions often come up with their own suggestions about how to resolve some of these communication barriers. One simple tool was the use of a 'leaf' logo on the resident's door that indicates someone has been commenced on an End of Life Care Pathway (EoLCP). Also placing the logo with just a room number at the sign on point for staff and at reception (out of public view) and in the kitchen enables many staff to be aware without even having to say a word. This simple tool has enhanced communication across the facility so regular staff can acknowledge promptly that a resident is near death.

Another key opportunity has been to provide education to Personal Care staff whilst they are completing their Cert3 in Individual Support/Aged Care. My sessions discuss and debrief the trainees about their experiences caring for residents, both at end of life and as part of their routine care. Typical responses to this are "I wish we had this earlier, it has really made things clearer" and "it has helped understand the signs of dying". These PCAs will be care providers in the future and assisting in the education is a rewarding part of my role.

Integration

There have been ongoing requests by RACFs for onsite education and discussions around their local supports and resources. I have focussed in engaging local health services and other support services to attend workshops, or provided in-service education to address the direct needs of that facility.

The networking across the region has involved coordinated workshops and presentations with specialist palliative care services (SPCSs), West Vic PHN, Decision Assist and local GPs. This has been rewarding for all those involved as the GPs and SPCSs had the opportunity to discuss issues at the coal face, and education of staff has been further enhanced by the expertise of the presenters. Encouraging the ongoing networking and engagement of RACFs with their local specialist palliative care service and Hospital In Reach where available has resulted in a reduction in avoidable transfers to acute facilities, which in turn has raised patient satisfaction and improved outcomes.

A core component of this role has been expanding the educative resource role into providing sessions to acute staff who work in areas across a health service including emergency department and urgent care centres. This has been commented on by attendees as being beneficial for all involved and in particular in the care of residents presenting from RACFs.

The focus for 2016-2017 is ongoing education and resourcing for all staff in RACFs, including providing Advance Care Planning facilitation workshops in partnership with the Regional Palliative Care Team, and to continue to assist care staff in implementing each aspect of the palliative approach into their routine care. It has been a privilege to work alongside the dedicated aged care staff in the Grampians region and the relevant specialist services and I look forward to a further year of great networking.

7.4 Disability Palliative Care Project.

Formerly a consortium contracted project, from the 2013-14 financial year, funding for this initiative has been going straight to East Grampians Health Service (EGHS).

The contract with the consortium for the disability palliative care funding expired on June 30th 2015, and the consortium sought expressions of interest from the funded palliative care services in the region to operate the program for the next two (2) years - 2015-16 and 2016-17. However this approach was not able to be actioned as the funding for 2015-16 rolled over to continue with EGHS. Discussions with DHHS disability senior staff were held, and that the broad philosophy set out in the expression of interest will guide future development of the role. As such, I have included a section of the expression of interest below:

Realistically, this is a small amount of funding, and a big region. A project can either sprinkle small projects around and hope that some seeds, or try and make more significant change in a more focussed intervention. A focussed intervention does not have to be a geographical concentration - it may be specific provider groups, or specific levels of management structure across the region.

If the above were to be a region-wide approach, it would seem that the only way that we will make headway across the region with such a small eft is to target management, and provide regional education opportunities. The consortium will receive some PEPA funding to provide a disability education session per year, and we have some disability money in the budget to allow us to eke it out to 2 or 3 sessions, which would cover different parts of the region.

That leaves the funded role to then just target key management across both the private and public sector in the region. This person would also sensibly target management in other key services and enhance coordination with other services. It may be that the 'person' best suited to do this job will already have strong links with the disability sector, and quite possibly come from the sector.

The consortium believes that this approach offers a unique opportunity to the leverage that can be gained from what is ultimately a small amount of funding.

7.5 PEPA

The consortium has methodically worked through our available list of past PEPA participants, and gained verification of current contact details, or alternatively determined that contact details were no longer valid, and services within the region did not have current details. Using this list, all past PEPA participants are included in information regarding education and training activities.

During 2015-16 the consortium sponsored a PEPA workshop for GPs and other health professional associated closely with general practice. Pharmacists were also specifically invited in response to an ongoing issue of access to palliative care medications after hours, and particularly in rural settings. As a result, this became a core focus of the session, and set the scene for what will be an ongoing project to support broader access to such medications after hours.

7.6 Consortium website

The GRPCC website was originally established in 2008, however functionality was poor and information was limited in overall quality.

A renewed website went live in November 2013, and continues to be updated and utilised to the extent that it is now one of our major information tools. Analytics have been set up for the site, and these continue to demonstrate that increases in site visits are directly related to consortium activity, including increased use of website after PACRN education, Small Grant advertising, workshop registration and advertising of events.

8. Service Support Activities

8.1 Provision of Professional Training

The consortium has supported 3 workshops run by external providers across the region in 2015-16. The Regional Team is the major provider of training in this region, with a varied and comprehensive program, and the consortium has targeted training which is complementary to their program, rather than competitive.

In addition, the consortium has specifically aimed to take training out to the more rural communities, particularly in the West of the region.

The palliative aged care initiative has been our main training focus for this financial year, and this is reflected a smaller and more targeted support for external training.

Decision Assist

(2 workshops across Stawell & Horsham)

These are two day interactive workshops for health professionals working in aged care, allowing staff to enhance their skills and develop a better understanding about advance care planning and a palliative approach for older people living in residential aged care and those in the community receiving Home Care Packages.

Dementia Care Essentials/Dementia Care Fundamentals (CHCAC319A) - Provide Support for people living with Dementia

(Ararat, delivered by Alzheimer's Australia – Vic)

Dementia Care Essentials is a Commonwealth-funded initiative providing free-of-charge education to eligible aged and community care workers providing support for people with dementia. In this competency-based, accredited course, you will learn how to incorporate therapeutic communication techniques; apply a person-centred approach; and develop useful strategies to respond to behaviours that require intervention.

8.2 Advance Care Planning Discussion Resource

The consortium has developed a set of 'wish cards' which will be used to support advance care planning discussions into the future. Each of the 48 cards in the set has a different statement that expresses a wish that someone may have at the end of life. Examples are *'To be able to say goodbye to the ones I love'* and *'To know the truth about my condition, treatment options, and the chance of success of treatments'*. As currently structured, the activity takes participants through a series of stages until they end up with their 10 'most important' statements.

At this stage we have used the cards in group situations, as an adjunct to public events and individually, and the response has been enthusiastically positive across all formats.

We are trialling and gathering feedback on the cards and activity as they are currently configured, and will adjust the statements and/or process based on the feedback before producing them more professionally. All of the 'wishes' are numbered, and we do ask those who use them to anonymously record their own top ten wishes.

Although very preliminary data, an analysis 50 respondents shows the top 5 wishes that are most commonly chosen:

- To be free from pain;
- To maintain my dignity;
- To be able to say goodbye to the ones I love;
- To die within a short timeframe rather than lingering;
- To have my family and/or close friends with me.

Intriguingly, none of these are about where the person is at the end of life.

8.3 Support for Professional Development

The consortium agreed to support better access for palliative care staff working with palliative care patients throughout the region to attend conferences, seminars or educational workshops to further their knowledge and skills in palliative care.

The aim is to provide support such that both staff and agencies, particularly those with less immediate access to training opportunities, take up a greater range of options. The consortium recognises that the staff are our most valuable asset, and that training is critical for the continued quality improvement of services.

The consortium has done this in the past by responding to particular events or circumstances, but has not had a documented process in place. This initiative aims to make more training opportunities viable, and reduce the need for case by case decision making regarding what might be funded. The initiative also covers backfill, as this is often the most critical factor in decisions to release staff.

Uptake continues to be patchy, but an invaluable source of support when it is utilised.

Separate to the ongoing initiative, the consortium also funded 5 regional members to attend the PCV conference in July 2016.

8.4 Death Data

The consortium shared the funding of an initiative undertaken by Loddon Mallee consortium – the procurement of ABS death data for the years 2011, 2012 and 2013. The data was available down to SA2 level, and the consortium was then able to match relevant SA2s to the specialist service providers across the region. Loddon Mallee consortium did a great job of them matching the data to the relevant boundaries. The data was further broken down into deaths that would likely have been ‘applicable’ to receiving palliative care (hereafter called applicable deaths), and what were called ‘excluded deaths’ - those likely not to require palliative care services i.e. accidents, acute infections etc.

A number of analyses of the data pointed to it being quite stable across the 3 years, which in turn gave the consortium greater confidence in using it. There were over 2,200 applicable deaths across the Grampians region used in the analysis, which is more than enough to smooth out variations that occur in data of this sort.

The core findings from this analysis were that on average 73% of the applicable deaths were malignancies, and that on average 52% of applicable deaths were registered clients of the specialist palliative care services. Some similar analysis by 2 other regional consortia came up with a service rate very close to our 52%.

Of course, these figures do not tell us anything about individual circumstances, or about individual services, or about what percentage of people with a life limiting illness should be a client of a specialist palliative care service. Remembering that these are funded to be specialist services. If a particular specialist service registered 70% of those with a life limiting illness, would this be an appropriate level, or would it be over-servicing? If they have 35% of those with a life limiting illness registered, is this under servicing or the result of a lot of work with GPs, RACFs and generalist services?.

A reasonable search of research both from both Australia and world-wide failed to come up with comparable estimates of anticipated specialist palliative care servicing rates, but it is worth considering the 52% as a potential starting point.

8.5 Interactive PDF Forms

The consortium, in conjunction with the expertise of clinical advisory group, has supported and funded the revision and production of 2 key documents as interactive pdf forms for use by the specialist services:

- External referral form - For consistent referral to the specialist services
- Symptoms Action Plan – for use by the services, and adapted from the template: “Guidelines for Patients and Carers”, Wimmera Health Care Group © 2009

Following further review of this resource, the consortium has now printed the external referral forms in a tear-off pad format, which is one that health professionals are very familiar with. This does appear to be having an impact on more consistent use by some referrers.

8.6 Pop-up Service Banners

A number of the funded palliative care services in the region did not have suitable promotional resources, and in order to achieve a region-wide consistency the consortium co-ordinated and funded the design and purchase of a pop-up banner for each service provider. The bottom third of each banner was a section showing all of the services covered by the consortium.

9. Funding for Regional Service Based Initiatives

The consortium has been delighted to be able to provide funding support to a broad range of service based initiatives, all of which have relevance for improved provision of palliative care for the sector both within Victoria and more broadly across the nation. As pointed out earlier, the flow on effect of these investments is quite profound, not least in terms of professional development and professional job satisfaction.

Regular calls for submissions from funded services for potential project and resource development funding led to support for the following new and ongoing initiatives being approved by the consortium.

9.1 Extension of the Carer Package for Subcutaneous Medications

Timely access to medication (including injectable medications) to manage symptoms is vital to providing high quality end-of-life care in the community. The inability to control symptoms at home is a frequent reason for unplanned admissions to hospital in the last days of life. Anticipatory prescribing of medication for common symptoms at the end of life has been shown to avert symptom crises, increase the amount of time a patient can be cared for at home and improve the likelihood of dying at home.

One of the challenges in regional and rural areas is lack of access to health care professionals to assist in the administration of injectable medications in the home setting. Carers in the Grampians region are given verbal education about administration of medications by injection in the home, however there is currently no visual learning package available in Victoria to support this. It was proposed that an education package including a DVD would support carers when administering injectable medications in the home.

After successfully implementing the Carer package for safe administration of subcutaneous medications across the Grampians Region there has been a request for financial support to continue to provide this resource. Following consultation with the community advisory committee in early March 2016, the regional community palliative care providers requested that USB's and laminated reusable cards should be included. The original proposal did not include these products.

The consortium supported production of a further 150 packs including DVD, USB's, Laminated Carer Cards, medication log and clear plastic sleeve:

This resource builds on ongoing education with palliative care providers focused on supporting carers every day. The development of the package including Clinical Practice Guidelines will support compliance with state and federal legislation regarding safe administration of medications.

Although this is not the first package to be developed for the palliative care market in Australia, it is the first to be trialled in Victorian metropolitan, regional and rural community palliative care services. Responses from carers indicated that the intervention supported them in administration of medications, assisted in keeping a person at home, and reduced their stress and anxiety.

It is hoped that the package will continue to be used as standard practice. The package will need to be reviewed annually to ensure best practice. It is anticipated that we will apply to The Victorian Palliative Care Clinical Network for state-wide endorsement.

The project was managed by the Grampians Regional Palliative Care Team, and the Principal Investigator was Regina Kendall, Nurse Practitioner.

9.2 Profiling Lymphoedema in Inpatient Palliative Care.

Although initial funding from the consortium for this project was provided in 2014-15, it has a reasonably long time frame, and remains a current project.

The management of oedema in advanced disease is challenging especially in the absence of evidence-based clinical practice guidelines for this distressing symptom. The goals of treatment within the palliative care setting are different than the traditional lymphoedema treatment. Efficacious interventions for end of life oedema will make a very real difference to the quality of life for patients at the end of life.

This project involves a prospective audit of patients with malignancy admitted to Gandarra for the presence of lower limb oedema and its complications.

Proposed outcomes

- Introduction of policy and practice guidelines for management of lymphoedema
- Two journal articles published in peer review journals
- Educational materials for patients and staff

The project required identification and training of a number of key staff members in the assessment of lower limb oedema to ensure consistent reporting of clinical findings. Overall, it is estimated to take 6 to 12 months to recruit and review sufficient participants to generate meaningful data.

This project is an initiative of Gandarra Palliative Care Unit, Ballarat Health Services.

9.3 Carers in the Grampians

The consortium was delighted to be able to support the Carers in the Grampians project, which is an initiative of the Grampians Regional Palliative Care Team, Ballarat Health Services. The resulting resource is incredibly powerful, and will be a great resource for both carers and the community in general to broaden their understanding of the carer role.

The Carers project reveals the experiences of ten people caring for family members who were receiving palliative care. Talking openly about their parents, partners, siblings and children, the participants discuss what it's like to hear that there is nothing more the medical community can do, and the impact that had on their family member in palliative care, and on themselves. They reveal some of the joys as well as some of the challenges of caring for their family members, and what it was like for them dealing with grief. They share the benefits and difficulties of looking after their family members at home, and acknowledge how the experience has changed them.

The ten carers interviewed for the project live in regional towns such as Ararat, Horsham, St Arnaud and Ballarat, and others live on farms within the region. All participants in the project cared for family members who died prior to, or during, their engagement with the project. The familial relationships included children, siblings, partners and parents. All but one of the family members in this project died in their home, and all but one were heavily supported by their local palliative care team at the end of their lives.

There was a lack of regionally specific stories of carers of patients in palliative care. Specific issues such as isolation and distance from official support services, and a stronger local community mean that friends, neighbours and family often step into the gap. This project is designed to offer contextual support to reduce isolation of the carers by providing personal and honest accounts from carers in the same situation and region. The project has the capacity to reduce carers' feelings of

isolation and therefore reduce bereavement risk. The project will ensure that people know how to access local supports, and will build capacity in our local communities. The visual tools will provide a reference point for those embarking on a carer role in the future. And finally it links the Grampians region to state-wide projects such as The Dreamers, The Two of Us, and Palliative Care Stories 2016, also produced by digital storyteller Pippa Wischer.

The palliative care services which supported the participants in this project include Central Grampians Palliative Care, Ballarat Hospice Care Inc., Wimmera Hospice Care and Djerriwarrh Health Services.

9.4 Integrating Renal and Palliative Care

Since 2009 Ballarat Hospice Care Inc. (BHCI) and Ballarat Health Services Dialysis Centre (BHS-DC) have been developing a framework to integrate renal and palliative care to improve outcomes for patients in the Grampians region with Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD). The consortium has provided ongoing financial support for this project, and the following study (short summary) outlines the development to this point.

Evaluating nurses' action outcomes and exploring their perspectives of implementing Palliative Outcome Scale - Symptoms Renal (POS-S Renal) assessment tool: Addressing symptom burden, ACP and quality End-of-Life (EoL) care for patients, their families and carers undertaking haemodialysis.

Nurses working in haemodialysis settings in Australian regional and rural locations face challenges in facilitating Advance Care Planning (ACP), providing quality physical and psychological symptom care and discussing difficult and sensitive aspects of care at the End of Life (EoL), for a growing population of older and sicker people with End Stage Kidney Disease (ESKD). To assist nurses at a regional haemodialysis satellite unit to address these issues, a framework for integrating renal and palliative care was implemented including the introduction of the validated Palliative Outcome Scale-Symptoms Renal (POS-S Renal) assessment tool.

The study of this implementation showed that the introduction of the tool has provided a useful first step in the systematic identification of symptoms and actions, offering an entry point into more formal ACP processes and starting conversations about EoL. The existing nurse/patient dynamic is challenged when discussions highlight patient deterioration, and may lead to discussions about end of life. Discussing symptoms can raise personal concerns, fears and past experiences for both nurses and patients. While there is general acknowledgement that having these discussions is not easy, the implementation of the assessment tool has increased nurses' awareness of the need to talk about EoL earlier in the trajectory, and monitor deterioration and communicate with patients about EoL. The implementation and use of the tool has also brought to the surface the existing personal, cultural and structural obstacles nurses experience as they introduce palliative care into a regional dialysis setting.

Interestingly, this study suggests that nurses view the assessment tool as particularly useful for chronic symptoms but is not used when symptoms are acute. It would seem that tracking all symptom progression over time would provide more insights into the patient's trajectory. This study tracked pain and depression/anxiety in particular, because the evidence suggested that these are some of the most prevalent high rating symptoms for people undertaking dialysis. In reviewing the patient record it was observed that other symptoms such as itch, tiredness, nausea, restless legs and poor appetite also warrant further investigation, when considering quality of life.

Renal nurses in dialysis settings are well placed to play a role in facilitating and coordinating patients transitioning from a curative, restorative phase of chronic illness to a palliative, terminal phase, given adequate supports and assistance to identify and address personal, cultural and structural obstacles as they arise. Successful implementation requires leadership from management and a key conduit for nurses such as a Nurse Champion, and the implementation structure needs to be regularly reviewed to ensure that it is responding to the nurses' changing needs, confidence, awareness of the issues and barriers, and their willingness to increase their ownership of processes. The provision of specific advice and support to nurses is also important and could take the form of mentoring, role modelling and role playing, supported by collaborative partnerships with expert health professionals. In a regional context, this could be supported by access to a state wide Supportive Care Team via a combination of video/teleconferencing and regular visits.

These findings have provided useful insights given the recent Palliative Care Australia (PCA) and Kidney Health Australia (KHA) Joint Position Statement call for a "National implementation of a validated tool to objectively measure the symptom burden associated with ESKD with an associated quality improvement indicator" (PCA, 2013). The findings support the decision to implement the POS-S (Renal) tool and to use the tool as a method for not only identifying and tracking symptom deterioration and taking nurse led actions to address symptoms, but also as a prompt for commencing conversations about end of life. The use of the assessment tool has offered an entry point into more formal ACP processes.

The next phase of this project will expand the implementation of these findings across the Grampians region, and will continue education and publication opportunities to encourage an even broader implementation.

9.5 Palliative Care Navigation Project

In June 2016 Western Victoria Primary Health Network (Western Victoria PHN) held an aged and community care interagency forum called Connecting Aged and Specialist Palliative Care Services. The primary focus was on improving palliative care options (and the referral pathways) for people in the community. Issues identified during the forum were:

- GPs and other service providers unaware of available services and referral guidelines
- Lack of communication between service providers
- Lack of/gaps in palliative services in some regions
- Coordination responsibility blurred

It was evident that navigating the palliative care system in Western Victoria is complicated, and the Palliative Care Navigation Project developed from this to map out the intersect between specialist palliative care services, residential and community aged care services and general practice in the Grampians, with the aim of ensuring older people with palliative care needs have access to a coordinated and seamless pathway to access the right care at the right place and in the right time.

Specifically, the project will:

- Engage a palliative care project officer to undertake project
- Conduct service mapping in the Grampians region to identify service roles and responsibilities.
- Review systems and communication flow between aged and community care, general practice and palliative care service providers
- Development of a Palliative Care Quick Reference Guide
- Pre and post awareness evaluations conducted with stakeholders

Central Highlands Primary Care Partnership, Grampians Palliative Care Consortium and Western Victoria PHN have committed to work together to lead this project with the support of the agencies who attended the forum.

The desired project outcomes include:

1. An outline of the roles and responsibilities of specialist palliative care services in the Grampians region
2. Improved awareness of palliative care services available in the region
3. Enhanced understanding of what options exist and how to refer to palliative care services for different settings
4. Improved communications between general practice, residential and community aged care, palliative and specialist palliative care services
5. Improved health outcomes for patients through enhanced relationships of specialist palliative care service provision
6. An understanding of the gaps that exist in palliative care service delivery in the Grampians region

Project timeline: September – June 2017

9.6 A Guide for Caring for People at the End of Life

The consortium supported the Central Grampians Palliative Care team to develop a DVD and booklet which gives helpful advice for carers of those with a life limiting illness. The DVD sensitively broaches issues that are often hard to discuss, and real life experiences are shared in chapter format. This resource was launched to widespread approval at the Ararat performance of the 'Four Funerals' play in June 2015, and is a resource that can be built upon and adapted as required in the future.

The resource also had significant exposure at the PCV Conference held in Melbourne in July 2016, which resulted in widespread distribution across the state. In response to a request from other services, both within the region and more broadly, to have the resource for their own use, the consortium are currently re-designing the cover so that it can be branded for different regions and services.

9.7 'Whispered Questions' – Carers Education

Ballarat Hospice Care regularly conducts a facilitated Carers Education Program with the following topics: *Caring for the Carer, Medical and Legal, and Funeral and Bereavement*.

The consortium has supported Ballarat Hospice Care to undertake the following process:

- Identify the questions that are 'whispered'.
- Research the broader health literature and utilise the expertise of the trainers to develop responses.
- Share these with other sessions, and those that are not attending Carers Education Program.

The current state of the project is presented below:

Whispered Questions: identifying the confronting and often unspoken questions that provide valuable information to carers and patients requiring palliative care support.

What are 'whispered questions'?

These are questions which may be considered 'taboo' and are often difficult for carers and patients to ask anyone. We know that they are likely to be questions that others want answered too.

What did we do?

In 2015 we invited patients, carers and staff to participate in a survey and a focus group session to help us gather a list of 'whispered questions', find out why they are difficult to ask and determine what we can do to help patients and carers get the information they need at the right time.

What did we find?

A literature review was conducted and scant information was found to exist concerning confronting or taboo questions in palliative care. From the surveys and focus group, we found that people have a lot of questions and sometimes they don't know who to ask or may avoid asking 'whispered questions' altogether. We know that this can cause frustration and a sense of helplessness. We gathered a list of 66 questions, from 44 participants, relating to topics including medication, treatment, relationships, legal issues, emotions, death and dying and managing after death and found that the identified questions and themes are addressed in current education and resources provided through Ballarat Hospice Care.

Carers and patients may be reluctant to ask some questions because they:

- are new to palliative and don't know what questions to ask
- avoid asking because they are worried about the answer
- are worried what other people will think
- don't want to stir up their emotions

Providing information in a range of ways including face to face, one on one, in small groups and in written formats are all important.

What's next?

This research confirms the need for a suite of resources that address the common concerns of patients and carers. It is also important that information can be tailored to meet individual needs taking into account people's different roles, the timing of information delivery, capacity for processing information and accessibility issues. This will allow us to deliver sensitive information that is accurate and timely so that 'whispered questions' can ultimately become a thing of the past.

Thank you to the patients, carers and staff who participated in this research.

9.8 Telehealth and Mobile Tablets for Community Palliative Care Use

Admission and ongoing home management of clients requires a significant amount of paperwork, the vast majority of which needs to be transferred to the Uniti patient management system. The consortium has previously funded the purchase and trial of tablets for palliative care staff to record this data directly in the home, and reduce the burden of double and at times triple entry of the same information, in turn enabling staff to spend more time with clients. The tablets also allow access to up-to-date information in a timely manner.

Direct effects are

- More efficient use of nursing hours
- Move to computer-based notes for clients with minimal paper work left in the homes
- All team members will be able to access information in real time
- Improved client outcomes
- Security of staff due to inbuilt tracking systems
- Cost saving due to inbuilt phone and tracking

In addition, the consortium has prioritised a focus maximising the often stretched specialist services across the region by judicious use of telehealth consultations. Understandably, discussions on this topic are often tough, as more distant services have a justifiable concern that the introduction of telehealth consultations could mean that they will become the norm, rather than an additional support.

9.9 Remembrance Services

The consortium has been delighted to be in a position to support the specialist services in their remembrance initiatives.

10. Community Based Initiatives

The Consortium set up a process to offer small grants for a maximum of \$4,000 to community groups looking to manage a local initiative that meets the consortium strategic objectives. Background research on the experience of the Foundation for Rural and Regional Renewal (FRRR) and the Mercy Foundation, which both offer grants up to \$5,000, is that over hundreds of small grants the average amount funded is approx. \$2,500 - \$3,000. This has been the experience of the consortium as well, with successful applications averaging funding of approx. \$3,200. The small grants had the following focus:

People with a life-limiting illness spend most of their time with family, friends and acquaintances in their own community at home, including disability and residential aged care facilities. Building community capacity in relation to life-threatening illnesses, dying, death and bereavement leads to better support and positive outcomes for people with a life-limiting illness.

Benefits of a community awareness approach to palliative care include avoiding unwanted hospitalisation/treatment, making and communicating appropriate care plans before future potential loss of decision-making capacity, appointing a decision maker for a person's best interests, putting in place enduring powers of attorney, making advance care plans, relieving family burden, dispelling myths and improving understanding of facts, personal peace of mind, autonomy and dignity at the end of life.

This initiative has generated new and innovative partnerships between local communities and the palliative care services, and significantly 'value-added' to the provision of excellent and responsive palliative care across the region.

More information on these community based activities is provided below.

10.1 Dying to Know

St Arnaud campus of East Wimmera Health Services proposed a community event with the aim to bring to life the conversations about death, in order to encourage their community members plan for end of life. This included assisting their community members to write down their future health care wishes in advance.

The forum was presented by Molly Carlile (the Deathtalker). Molly has extensive academic qualifications in health, end of life care, counselling, education, and healthcare management and over 20 years of experience in the field. Molly supports people to become informed about death and grief in order to live life to the full.

Aims were to encourage our community to:

- Consider making their end of life plans.
- Share these wishes with their families
- Be informed about end of life and death care options such as dying at home.
- Equip our community to support their family and friends experiencing death, dying and bereavement.

The community event was an adjunct to the existing EWHS implementation of the Advance Care Planning and Palliative Approach project across the health service.

This project has recruited: Advance Care planners who will work within the five East Wimmera health rural hospitals, and in the communities of Birchip, Donald, Wycheproof, St Arnaud and Charlton. This will ensure that the Victorian Health -Advance Care Planning - “Having the conversation” Strategy is embedded into practice. EWHS has also appointed 5 Palliative Support Nurses into our 5 residential aged care facilities to support our residents with advance care planning, person centred case conferences and end of life pathways. This approach is based on the Palliative Approach toolkit.

This event will support our community to understanding that death is a part of life and to feel confident to have those much needed conversations about planning for death.

10.2 Getting to Know Us Before You Need Us

Getting to Know Us Before You Need Us: A Conversation about Dying at Home with the Help of Ballarat Hospice

Adults and seniors residing in the Shire of Hepburn face the same health challenges as those in Ballarat, but are often unaware that they may have a choice to have end-of-life care at home. This is especially important in Hepburn Shire, as if hospital care is required, family members often have long drives to get to the hospitals in Ballarat, hence limiting their ability to support their loved one at this critical time.

The project will design the program and hold it in at least three towns in Hepburn Shire: Daylesford, Creswick and Clunes, with the expectation of reaching at least 100 people over the three programs, and via those people, their neighbours and friends.

Activities to be held: We will engage the help of local storytellers, musicians, poets and artists to present a conversation about life, death and dying, which at the same time tells Hepburn Shire residents about how Ballarat Hospice works (services offered, costs, etc.) and what it takes to become involved with Hospice. The program will take place in an afternoon or evening, over a period of 2 hours. The program will be able to be moved from town to town, so that the smaller communities in Hepburn Shire can also benefit from the conversation and receive the information. The program could be held in any of the communities that Ballarat Hospice serves.

Participants’ benefits to be gained: Participants will be able to think about end-of-life care in an engaging way and will learn about what Ballarat Hospice is and does. Participants will be able to talk with local residents who have had Ballarat Hospice help a loved one in their home so that the information will be personal and directly relevant to them and their community. By the end of the program, participants will know how to access Hospice services and will know how end-of-life care can be managed in one’s home.

Evaluation Activities:

- Feedback will be invited at the end of each program, in order to improve subsequent offerings of the program and to find out whether the information has been helpful and effective.
- Participants will be invited to join the mailing list of Ballarat Hospice, and for those who do so, we will send out a small evaluation of the program in order to gain feedback for future occasions of the program.
- Ballarat Hospice will review the number of referrals from Hepburn Shire in the 12 months following the program to see whether more Hepburn residents are accessing their services, possibly as a result of increased awareness of Ballarat Hospice due to the project.

10.3 End of Life Education Forum

In conjunction with Ballarat Hospice Care, the Australian Catholic University and the Creswick Medical Centre, the consortium supported Hepburn Health Service (HHS) to put on a full day end of life education forum. The morning half of this workshop was open to all, and covered the following topics:

- Advance care planning and the delivery of palliative care
- End of life care for people with dementia
- Advance care planning from the consumer's perspective
- Palliative care for the LGBTI person

An additional afternoon program was specifically for HHS staff and volunteers:

- Palliative Care in Residential Aged Care – the Link Nurse Project
- What do our teams do well?
- What can our teams do better?

The event was attended by 50 staff and 30 community members, and feedback responses indicated that the LGBTI presentation was particularly appreciated.

11. GRPCC 2015-16 Financial Statement

<u>Income</u>	
GOVERNMENT GRANTS	
DH GRANT - PALLIATIVE AGED CARE LINK NURSE	81,625.00
DH GRANT - PALLIATIVE CARE STRATEGIC FRAMEWORK	125,704.00
Total Income	207,329.00
<u>Expenditure</u>	
EXTERNAL CONTRACT STAFF	
GRANTS RECEIVED & PAID TO OTHER AGENCIES	51,131.82
OTHER ADMINISTRATIVE EXPENSES	4,582.38
COMPUTER - OTHER COSTS	194.53
RENTAL OF PROPERTY - OTHER	11,523.60
MEMBERSHIP FEES.PROFESSIONAL FEES.	722.73
POSTAL SERVICES	72.62
PRINTING & STATIONERY	1,115.18
TELEPHONE SERVICES	2,213.48
STAFF TRAINING AND DEVELOPMENT	1,963.70
CONFERENCES REGISTRATION AND ACCOMM	1,330.77
CATERING FOR MEETINGS	748.09
TRAVEL EXPENSES- OTHER	14,375.22
Total Direct Expenses	89,974.12
Salaries & Wages	
SALARIES	186,711.27
SUPERANNUATION EXPENSE	18,041.69
WORKCOVER - PREMIUM	1,461.44
Total Salaries & Wages	206,214.40
Surplus / (Deficit)	(88,859.52)
B/FWD - Total Program Surplus as at 30/6/2015	182,916.96
Total Program Surplus as at 30/6/2016	94,057.44