Grampians Region
Palliative Care **Consortium**

Annual Report 2015

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)

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1. Chair's Message

Once again, 2014-15 has focussed upon specific strategies to improve 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 are the backbone of this provision, and we are delighted to have supported the continued development and provision of high quality palliative care services within the Grampians community. What is particularly evident this year is the commitment and dedication of all palliative care services within the region. The breadth of service provision has been remarkable and the innovative ways in which services have been able to meet the needs of their communities is commendable.

Financially, the consortium is well positioned to continue to implement core strategies in the future that will build upon strengthening palliative care initiatives and services within our region.

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. Finally I would like to thank Mr. Pete Marshall, Consortium Manager, for his excellence in coordinating and managing consortium initiatives.

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.

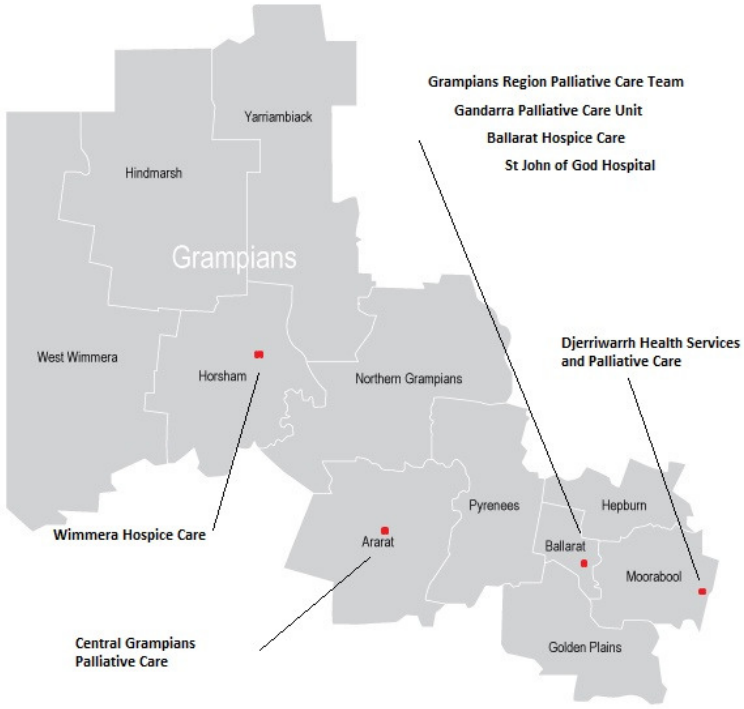
Table 1: *Population density and proportions of aged residents*

	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 palliative care for patients and carers. This is most readily achieved by improving the capacity and functioning of the funded services.

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 within the funded services and lightening the load on clinical service staff wherever feasible.

> Priority 1: Use available consortium resources to build sustainable improvements in effectiveness and efficiency within the funded services.

Most of the care given in a palliative approach to 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.

> Priority 2: Effectively educate health service clinical, social welfare and other support staff, at levels specific to their varied roles, in the importance of pain control and symptom management, and in turn, all the other aspects of a palliative approach.

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.

> Priority 3: Provide effective and relevant support and information for carers and communities about end of life, death and a palliative approach.

Over time, the Consortium has supported initiatives across the following four broad categories, which all contribute to a population that have their understanding of palliative care enhanced and their palliative care needs professionally addressed:

1. Support and training for staff
2. Supporting use and improvement of clinical tools
3. Developing client and carer resources
4. Community information and engagement

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 2014-2015

Chair: Denise Hooper, Director of Primary Care, Wimmera Health Care Group

Members:
Michelle Veal, Director Community Services, Ballarat Health Services (Deputy Chair)
Carita Potts, Executive Officer, Ballarat Hospice Care Inc
Peter Armstrong, Clinical Director, East Grampians Health Service
Julia Meek, Director of Nursing, Djerriwarrh Health Services
Pam Ryan, CNC Palliative Care, Djerriwarrh Health Services (Clinical Group representative, part)
Jane Bourman, Manager, Community Nursing, East Grampians Health Service (Clinical Group representative, part)
John Koopmans, Department of Health
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

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Gandarra Palliative Care Unit
Ballarat Health Services
102 Ascot Street South, Ballarat, 3350
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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: 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
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Web: www.wimmerahealth.com

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

6. Consortium Manager's Report

The focus of the 2014–15 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 approximately $150k in the 2014-15 financial year. Virtually all of this draw down has been matched by 'in kind' resourcing within the initiatives that have been undertaken, and the ultimate value of the $150k drawdown would conservatively be approx. $300k. Furthermore, if service development and staff upskilling, job satisfaction and ultimately retention were to be considered, the multiplier effect of innovative but judicious use of funding would be in the order of 2.5 ($375k).

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. And finally, I would like to thank Denise Hooper of Wimmera Health Care Group, for the support that she has offered over the year in her role as Consortium Chair.

Pete Marshall, Consortium Manager

7. Core Activities

7.1 Clinical Advisory Group

The Grampians Consortium Clinical Advisory Group (CAG) had 4 meetings during 2014-15, 3 of which were face to face meetings. 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 3 years now, and are building upon the individual frameworks and the resources developed during the previous years. During 2014-15, the consortium continued to offer funding support for small projects to earlier initiatives.

Ballarat Hospice has been committed to staffing their after-hours service, and they are the only community service in the region that is large enough to effectively do this. It does though, impose a significant cost burden, and so it is essential that it is well managed. The consortium has had an ongoing role on the After Hours steering committee for Ballarat Hospice, as it has methodically worked through the stages of their After Hours Service Development Project.

One part of the project is a retrospective audit of patients registered with BHCI and presenting to either BHS ED or SJOG ED after-hours, and following a phone call to the BHCI after-hours service. Following ED review, 84% of presentations were deemed necessary, in that interventions which were provided in ED could not have been provided in the home, and admission to hospital, or transfer to another care facility was required.

Over the 2 year audit period, less than 9% of BHCI patients attended ED after-hours, which indicates that BHCI processes in place are effective to allow patients to receive required support at home, and minimising demand on the ED after-hours. A subsequent review of the hospital records revealed that symptom distress, primarily distress resulting from multiple causes, was found to be the most common reason for ED presentations after-hours.

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, and this continued with the funding support for projects in 2014-15.

7.3 Aged Care Palliative Care

The Palliative Aged Care Resource Nurse (PACRN) role in the Grampians region is very clearly a resource & consultancy role, and specifically not a clinical role. It focuses on supporting each facility's link nurse/s to complete self-directed, online training and education learning packages; assisting link staff to conducting training in their own facilities; and building local sustainability for the palliative approach and End of Life (EoL) pathway.

The 2014–15 financial year has been one of consolidation, and the PACRN has individually visited and supported in some manner each of the 54 RACF in the Grampians region with their associated 24 health services. In order to provide an integrated approach across the whole region, this process has at times resulted in collaborative discussions with PACRNs in other consortia when health services cross regional boundaries.

The education aspect has been multi-faceted resulting in opportunities to speak at Palliative Approach workshops, Decision Assist workshops, Nursing Competency days, Personal Carers education sessions, Aged Care Study days and staff in-service sessions and more recently GP clinics. Rather than duplicating workshops and education sessions the PACRN has value-added to external resources/training such as Decision Assist by working closely with their support team to promote and encourage attendances to their sessions rather than being protective of our region.

Working in close co-operation with Decision Assist has resulted in an increased uptake of training for staff in RACF and therefore understanding of the 3 key processes. There have been five 2 day workshops with over 130 attendees.

In an attempt to assist each of the 54 RACF to further embed the Palliative Approach throughout, the PACRN has travelled approx. 18,700kms over last 12 months. There have been 183 meet and greet/education sessions in RACFs conducted in this role over the past 12 months, with over 500 participants attending sessions.

Barriers and Enablers

A key barrier to effective implementation of the palliative approach has occurred when members of health services and external providers have become over-protective of what they consider their space and knowledge, and been unprepared to relinquish some control over staff to enable a more collaborative approach. Barriers such as these are incredibly disruptive and destructive, and are rarely clearly stated, with the consequence that they waste resources. Part of the huge amount of travel and the large number of 'meet and greets' undertaken by the PACRN has been driven by a desire to be both seen and accessible across the more remote parts of the region, and consequently to reduce the chances of misunderstanding and mixed messages.

In addition, aged care staff are a scant resource across much of the region, and some of the RACFs suffer a regular 'churning' of key staff. In particular, the change of senior management in over 8 health services has resulted in some delay in the full implementation of the PA, and a subsequent need to re-establish connections and implementation strategies.

One of the enablers and most positive aspects of the role has been the PACRN either assisting in the setting up of, or the rejuvenation of 11 steering committees/working parties across the associated Health services. This has allowed each of the RACF involved to further embed the 3 key processes of Advance Care Planning (ACP), Palliative Care Case Conferencing (PCCC) and implementation of an end-of-life care pathway. Each RACF in the Grampians region now has access to the evidenced-based document entitled Residential End of Life care Pathway (RAC EoLCP), and over 98% of staff who have received education surrounding this document have felt that it is a significant resource in supporting and guiding the care of the dying person in their care.

To ensure sustainability of the project and assist in further embedding of the palliative approach into the aged care facilities, the PACRN role has involved a number of meetings with executive nursing staff, educator groups, individual and group sessions with facility managers, and meeting with link nurses and aged care staff to support them to learn and embraced the 3 key processes.

Education and Engagement

Unless valuable resources are delivered to RACFs and followed up by appropriate education and support, the resources often collect dust on shelves, or sit in cupboards unused. The PACRN has utilised 4 broad topics for education, which have been supported by the evidence based resources included in the Palliative Approach Toolkit:

1. The 3 key processes of Advance Care Planning, Palliative Care Case Conferences (PCCC) and implementation of an End of Life Care Pathway, which underpin the 3 trajectories that support the Palliative Approach model of care. These key processes of ACP and family meetings were often an informal part of the residents' care and often occurred in an ad hoc manner, with no routine to support the process, or appropriate documentation as to when and where this had occurred. RACF staff have stated that a well written ACP has reduced conflict over what care the resident receives as staff and family are aware of what their wishes are.

2. Recognising and understanding the signs of deteriorating health and the dying process, including discussion around appropriate referral and using specialist support services such as residential in reach, or the regional specialist palliative care services. This includes education around the use of the Residential Aged Care End of Life Care Pathway (RAC EoLCP) which meets the criteria of the 10 Core Principles for Best Care for the Dying Person. This has proven particularly beneficial for personal care staff (PCAs), who may have limited training, but have the most contact with residents, and if effectively utilised, are an important resource for recognising change.

3. Effective communication and family/carer engagement is the basis to providing optimal care of the resident. The importance of including family and carers in collaborative care planning such as palliative care case conferences or informal family meetings to inform them of changes in the residents' condition and explaining the meaning of the changes in an easy to understand way.

4. Symptom management is a very important aspect of education required for RACF staff, in particular the recognition and management of signs and symptoms of a resident with pain, nausea, dyspnoea, delirium and importance of excellent oral care. These are all aspects of care the PACRN has been particularly requested to provide to PCAs.

Additionally, education and co-ordination with GPs has been steadily growing, and has provided them with an increased understanding around the need for regular review of ACPs, importance of goal setting at PCCC and anticipatory prescribing for end-of-life medications. Although often very difficult to set up, these GP contacts are vital in rural regions if true coordination is to be achieved, and will continue to be a priority for the role.

Sharon Gibbens (PACRN)

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).

Given the limited EFT allocated, the project has had an initial focus on the central Grampians region which has a high level of disability housing. There are 29 Group Homes within the Stawell and Ararat region, and considerable effort has been put into more intensive support and interaction with those houses that are the most receptive to the palliative approach message, with the eventual aim that these houses and the staff in them will become accepted models for others. During the 2014–15 financial year, the major focus has remained on strengthening the palliative approach within the group homes in the central Grampians region, and focussed on the core outcomes of 'die in place of choice', 'advance care planning', 'palliative approach' and 'end of life pathway'.

The contract with the consortium for the disability palliative care funding expired on June 30th 2015, and based upon initial discussions with DHHS, 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 the consortium executive and EGHS have determined that a region wide consultation will occur in late 2015, 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 Nurse Practitioner Activities in the Grampians Region

The Consortium decided that 2012-13 funding provided for the support and development of Palliative Care Nurse Practitioner (NP) and Nurse Practitioner Candidate (NPC) resources would be used to support expanded capacity in the Grampians Regional Palliative Care Team (GRPCT), who already had a nurse practitioner in place working in a regional capacity. This contributed to the employment at 0.7 EFT of a nurse practitioner, Regina Kendall, by Grampians Regional Palliative Care Team.

Beginning with the 2013-14 financial year, funding is going straight to the GRPCT. Activities of this position include clinical, leadership, education, research and mentoring.

The Grampians region is well served by a highly skilled nurse practitioner, who in turn is part of an active and effective regional team. Combined with the medical specialists and other palliative care specialists engaged by GRPCT, we have both clinical and educational expertise which is quite exceptional for a rural region.

7.6 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 2014-15 the consortium secured PEPA funding to run Grief and Bereavement workshops for clinical staff in the region, and in conjunction with Grampians ML piloted Grief and Bereavement workshops for GPs, with a specific focus on short session interventions and referrals for unresolved grief. GPs are difficult to reach with this type of training, but are the health care professionals most likely to encounter and potentially support and/or refer the target group in an appropriate setting.

A combination of PEPA funding and consortium funding was also used to support the training initiatives in the region, as set out in the following section.

7.7 Consortium website

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

The consortium undertook a major review of both other consortia websites, and also other health related websites that had the design and functionality that we needed into the future, then produced a brief and engaged a local website designer to re-develop our own website. One major consideration of upgrading the website was that limitations on the staffing of the consortium meant that the website needed to be low maintenance, with few or no demands on website maintenance, design or functionality.

The 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 comparisons show:

- 25% increase in new users from '14 to '15
- 63% increase in No. pages hit from '14 to '15
- No. of Users increased from 296 to 2330 (687%)
- 207% increase in sessions coming from Grampians Region

Most pleasingly and importantly, the analytics demonstrate that increases are directly related to consortium activity, including increased use of website after PACRN education, Small Grant advertising, workshop registration and advertising of "Four Funerals" play.

8. Service Support Activities

8.1 Provision of Professional Training

The consortium has supported a total of 17 workshops run by external providers across the region in 2014-15, from which over 400 attendees have benefitted. 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, and a scan through venues below will illustrate how much of the training occurred in the West of the region.

Engaging in Effective Brief Contact or Single Session Bereavement Support

(Horsham and Ararat, delivered by the Australian Centre for Grief and Bereavement)

This workshop was aimed at community support staff and health care workers who have contact with bereaved and grieving individuals, even though their primary role may not be in the field of grief and bereavement. Nurses in particular are seeking quality training to help them in providing effective bereavement support. Nurses in the west of the region in particular often find such training very hard to access.

The workshop offered a simple framework and strategies that can be used to ensure effective bereavement support when only having brief contact with bereaved or grieving individuals. The workshop explored the idea that effective bereavement support can be offered or initiated via brief contact or a single session.

Dealing more effectively with grief and loss

(Ballarat and Horsham, delivered by Associate Professor David Pierce, Department of Rural Health, University of Melbourne)

(Training supported and organised through the network of the Grampians Medicare Local)

The primary target of this training was general practitioners, although other suitably qualified health care professionals were also able to attend.

Most bereaved carers and family members will move through the bereavement process with normal supports in place, and specific grief and bereavement interventions will have little impact on this. Therefore, the skill for health practitioners becomes identifying and focussing support on those for whom this is not the case. GPs are the professional group that many bereaved family and carers will be in contact with. In addition, GPs are trusted, but they are also busy, and face time pressures during a consultation.

Palliative care cases bring up different emotions for the doctors than most of their other patients. Not only do they bring up feelings around their own mortality and/or that of close family members, but they have likely been involved in some of the most profound conversations with the patients and their families, and likely a sense that they would like to have 'said more', 'done more' etc. So there is a residual of this when they see carers and family members, particularly if they are concerned about their bereavement. As we know, most bereaved people move through this period, and so if the GP felt that they could be more clear about the factors to look for in this process, and to more clearly target those that may be of concern, then they will feel more comfortable in their management of this.

While many GPs have undertaken mental health training over the recent past, many still report not having useful tools, training or guidelines to guide them with grief and bereavement. GPs are constantly confronted with the dilemma of providing bereavement support combined with the conflicting demand of limited time. Concise targeted training on this issue for GPs is both sorely needed, and provides a vehicle for adding on more advanced training at a later date. A search for provision of targeted training has turned up research calling for this specific training, but little evidence of actual training.

Experience indicates that GPs are less likely to attend clinical training supplied by non-medical trainers, and thus it was important to enlist a trainer with both the expertise in mental health, and the standing from a medical perspective to get the target group out in the evening, which is the most practical time for this group.

Palliative approach to dementia practice

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

Participants developed an understanding of palliative care for people with dementia in order to achieve improved quality of life, symptom control, and satisfaction with care for the person with dementia and their families.

Cognitive Screening and Assessment

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

Supported participants to further understand the process of cognitive screening and assessment and explore differential diagnosis.

Accredited Cert IV in Palliative Care

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

Described the knowledge and skills required to contribute to the development, implementation, evaluation and communication of a care plan for clients with dementia in a team environment using a dementia palliative approach.

Palliative Approach Toolkit

(Ballarat & Horsham, delivered by Brisbane South Palliative Care Collaborative)

A one day workshop specifically designed for RACF Managers and Registered or Enrolled RACF Nurses that focuses on practical, whole-of-facility strategies and resources to enhance the day-to-day palliative care of residents and their families.

Decision Assist

(6 workshops across Ballarat, Ararat, Warracknabeal, 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.

Culturally Responsive Palliative Care

(Ballarat, delivered by Judith Miralles & Associates)

This workshop will enable palliative care staff to move beyond "cultural awareness" to develop the confidence and practical skills to deliver effective and respectful services to people from culturally and linguistically diverse backgrounds.

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 Clinical audit

The consortium continued to work with the regional clinical group to support the common use of tools that were both reasonably accessible (ie. without significant price or permission issues), and were either in current use by the services, or were seen as potentially the most useful to introduce for their service. The services committed to introducing the following suite of tools into their clinical practice, and the consortium supported this by producing them in a replicable format:

- Problem Severity Score (PSS)
- Symptom Assessment Score (SAS)
- Australian-Modified Karnofsky Performance Scale (AKPS)
- Carer Support Needs Assessment Tool (CSNAT)

The consortium developed both paper-based and electronic audit documents for the four tools, and the actual audit results were consolidated and utilised as a discussion document for services at subsequent clinical meetings. There is a commitment to continuing this process of tool implementation and evaluation with the ultimate aim of a consistent cycle of effective tool use underpinning continual clinical improvement.

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 has been patchy, and feedback indicated that although the initiative was discussed and reviewed on numerous occasions, staff need time to fully engage with the concept and the process. Also, nursing managers indicated the new nursing award contains extra provisions for training support, which is being taken up as a first priority. However, awareness of the initiative is well established, and continues as an important support for professional development in the region.

8.4 Big Breakfast

The 'Big Breakfast' event has been run during Palliative Care week for the past 6 years, and has been funded by the consortium over this time. The promotion is health service based, and open to all staff and community that are in the health service on the morning. It provides an ideal opportunity to display and distribute palliative care resources, but perhaps more importantly it provides a relaxed and non-threatening environment to open discussions about death and dying, and about the services provided by palliative care.

8.5 ‘Attitude to Palliative Care’ Questions

The consortium has focussed on distinguishing sub groups both within clinical and community populations in terms of attitudes to palliative care, with the end point being a better understanding of factors impacting on the uptake of palliative care, and a better understanding of how to target messages. The ideal was to end up with 3 Qs that reliably did that easily and quickly.

The requirement around measuring attitude and attitude change was for questions that are validated, and quick, and could be utilised with a broad range of clinical disciplines within health services, and also ancillary staff (maintenance, food prep etc), and at community events. Experience shows that you get maximum engagement if people can truly see that filling it in will take a minute of their time. People are wary of being approached to do something that will 'take a minute', only to be still going 5 minutes later.

Extensive review of the research in the field revealed a dearth of well validated questions. The best option appeared to be the ‘Attitude to Palliative Care’, which are validated questions from a study by Bradley, EH, Cicchetti et al (2000). We chose a subset of six that were the most relevant across both clinical and community populations, to which participants responded with either Strongly agree / Agree / Neutral / Disagree / Strongly disagree. They were initially administered at each venue during the Big Breakfast promotions, and apart from being a great prompt for reflection and discussion, were analysed and adapted by the consortium to gather important attitude trends across both time and different groups.

An analysis for ‘medical’ vs ‘other’ showed that medical were more likely to disagree, and less likely to be neutral on two Qs. We followed this with other groups within the community and with aged care staff, and these two Qs retained reasonable ability to distinguish differences in attitude. Other questions showed little ability to distinguish attitudes with either mostly agreement or mostly disagreement no matter who you asked, and to this end were of little value to our focus.

While not realising it first up, the question ‘*Most elderly patients who are dying want their doctors to determine what care is best for them’* was problematic for medical and aged care staff, while in turn it may be great for community. What we found was that medical and aged care staff would find it difficult to answer separate to their role - ie their experience could be that most people could want their doctor to determine their care, while their personal attitude could be that most people don't.

The ‘Attitude’ questions are an ongoing project of the consortium, with the aim of providing indications of changes in the future associated with further community and professional education and information.

> *Bradley, EH, Cicchetti et al (2000) ‘Attitudes about care at the end of life among clinicians: A Quick, Reliable, and Valid Assessment Instrument’ in Journal of Palliative Care 16(1)*

8.6 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

8.7 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.

A call for submissions from funded services for potential project and resource development funding led to support for the following initiatives being approved by the consortium.

9.1 Carer Package for Subcutaneous Medications

Development and evaluation of a Carer package for safe administration of subcutaneous medications across the Grampians Region

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.

This study was designed to develop and evaluate a brief DVD intervention for carers in the home setting. The study involved 3 phases:

- Focus groups included previous caregivers and current health care professionals who reviewed a pilot DVD and action plan developed by Deakin Medical students and Grampians Regional Palliative Care Team (GRPCT). Feedback from these groups directed the redevelopment of a DVD and action plan.

- Palliative care providers were invited to participate in the pilot. Four rural and regional palliative care services, one metropolitan community palliative care service and one inpatient palliative care unit agreed to participate.

- Current caregivers were identified when patients were prescribed injectable medications for home use. Caregivers were invited to participate in the study and consented. Pre and Post questionnaires were given to current carers to evaluate the effectiveness of the intervention package.

Information obtained from focus groups assisted in redeveloping the DVD, prompt card and medication record. A ten minute DVD was developed, and divided into four sections: Assess; Prepare; Give; Review.

On evaluation, all carers felt the carer package had increased their confidence, reduced stress, and improved their skills. They felt the carer package was relevant to their needs and was a useful resource for injectable medications in the home setting.

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.

The project was managed by the Grampians Regional Palliative Care Team, and the Principal Investigator was Regina Kendall, Nurse Practitioner. A comprehensive project report from the initiative is available on the consortium website.

9.2 Profiling Lymphoedema in Inpatient Palliative Care.

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

<u>Proposed outcomes</u>

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

<u>Process</u>

We have completed a retrospective audit of the electronic medical records of 30 patients admitted to Gandarra. The purpose of this audit was to pilot our audit collection tool and to test the feasibility of performing a prospective audit to determine the prevalence of this issue in inpatient palliative care patients. This has helped to further define our research question, and allow for the audit tool to be piloted and modified as a result. In addition, a systematic literature review has generated a number of articles for closer review.

The project will require 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.

Education activities

While funding has not been used from this grant for the purpose of education, an additional benefit of this project is that it has stimulated and generated a number of education initiatives for ward staff regarding lower limb oedema, lymphoedema and its management. This has been a useful adjunct to the project and will in itself hopefully lead to improved patient care outcomes and increased recognition of lower limb oedema. It has also increased links between palliative care and lymphoedema services.

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

9.3 Death Café

The consortium funded 3 of these events in Bacchus Marsh. The evaluation of participants has endorsed the value of these, and the range of both age and sex of the participants has been quite a revelation. Attendees are broadly representative of the adult population, and they come along with a varied range of interests and objectives.

Updates on the latest event are shared at regional CAG meetings, and have spurned a lot of healthy discussion on this and other approaches to community engagement and initiating discussion of often difficult topics.

9.4 Telephone Triage Protocols Review.

The After Hours supporting documents were developed originally by Wimmera Hospice Care and further developed in 2010 as part of the combined Grampians Region and Loddon Mallee Region Consortium After Hours project. These current triage Protocols are supported by ‘generic’ triage protocols as developed by the then West Vic Division of GP, and are now no longer reviewed or maintained.

The Triage Protocols have also been taken up by The District Nurses Tasmania and they are regularly and, on an ongoing basis, engaged in review and further development.

9.5 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 framework is now well developed and effectiveness established.

A nurse-led initiative between BHCI and BHS-DC was implemented for patients choosing a supportive care pathway, ceasing dialysis or deteriorating despite dialysis. A successful multi-professional collaboration and coordinated approach was established within the development of an implementation framework.

This framework addresses the continuum of care from pre-dialysis with an integrated palliative approach, whilst patients are still actively dialysing, to a post dialysis setting and EOL care. New funding for 2015-16 will enable BHCI to continue to ensure the success and system sustainability of the project, with the following proposed outcomes:

- the introduction of nurse-initiated referrals to palliative care;
- to advertise and encourage PEPA placements, and explore options of reverse PEPA;
- to strengthen working relationships with the Renal Clinical Network and Department of Nephrology RMH;

- To support regional palliative care services and the satellite dialysis centres to implement the P-SOS Renal Version in cooperation with Renal Clinical Network and Department of Nephrology RMH;
- the implementation of a shared care model between renal services and palliative care services, including medical and allied health collaboration; and
- ensuring that systems are sustainably embedded focussing on supporting local palliative care services and Dialysis services to implement the P-SOS Renal Version.

The use of the POS-S (Renal) assessment tool to identify high-scoring symptoms has helped to open up conversations between staff and patients. Nurses report improved confidence in addressing ACP and EOL planning through completing Goals of Care documentation.

The project is supporting renal nurses and offering a system to assist patients and families identify the burden of treatment and disease. To date there have been presentations at Clinical Network Conference November 2012, Palliative Care Australia 2013 Conference and Palliative Nurses Association Conference 2014 with a publication in the Palliative Care Victoria Newsletter. Abstracts have been submitted and presentations made to Renal Society of Australia Conference (BHS Dialysis staff) and poster abstract to the Palliative Care Victoria Conference 2014.

9.6 Regional Conference

On the 7th and 8th of May 2015, 200 health care professionals from across our region and beyond met to discuss ***Sex, Drugs and Dying Well***.

The Grampians Regional Palliative Care Team (GRPCT) was extremely grateful for the generous sponsorship from the Grampians Region Palliative Care Consortium (GRPCC), Federation University, Grampians Integrated Cancer Service, Norgine and Mayne Pharma. We were honoured to have our opening address by Mrs Felicity Harte the daughter of Moira, who died at home surrounded by her family with the support of our palliative care services. We then were entertained by Amanda Hordern, who opened and closed our conference with her insightful and sometimes confronting thoughts on sexuality and ageing.

Associate Professor Michael McDonough, Director, Addiction Medicine & Toxicology Unit, Western Health discussed how addiction is regarded generally as a disease state, and for some patients, addiction may be a life-long condition that will impact on their choices (and capacity for choice) for treatment and personal preferences when it comes to making end-of-life decisions. Addiction also impacts on their experience of dying and those close to them, some having lost family contact.

Dr Deirdre Fetherstonhaugh, Director/Senior Research Fellow, Australian Centre for Evidence Based Aged Care (ACEBAC), La Trobe University presented on sexuality and ageing – the myths and the reality; including discussion of life in a residential aged care facility; issues of capacity and consent for people with dementia in respect to expression of sexuality; and possible ways forward for residential aged care services.

The calibre of our speakers was outstanding and the hot topics around sexuality and drug addiction were more than covered over the two day conference.

We now look forward to planning for the 2017 Grampians Regional Palliative Care conference: ***Location, Location, Location – Do we die well?***

9.7 Symptom Action Plans

The *Guidelines for Patient and Carers* were developed to assist patients and carers in managing symptoms after hours. These 'Guidelines' are written specifically for each patient, kept in the home and give guidelines on what to do if an expected symptom develops and the use of 'as-required' medications.

These tools were originally developed by Wimmera Hospice Care and further developed in 2010 as part of the combined Grampians Region and Loddon Mallee Region Consortium After Hours project. The purpose of the document is to provide advice for symptom management only, using medications that have already been prescribed to the patient by their doctor or nurse practitioner. This document contains suggestions for how to manage symptoms. It is not a prescription for medications.

In the past 12 months these Guidelines have been reviewed by the Consortium CAG with funding support from the consortium.

Following the review, the templates have been updated, the supporting 'Explanatory Notes' revised and the tool given a new name: Symptom Action Plans. It is proposed to take these documents to the Statewide PC Group for ratification.

Use of this revised tool is now underway across the region. We are also excited to see this tool being trialled with the District Nurses in Tasmania as part of their Hospice@Home program.

Ideally the templates will be adapted for use within the patient data management system. Quotes for this follow-on work have been received, but at this stage these costs are prohibitive unless they can be utilized across a significant number of services.

9.8 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, and is a resource that can be built upon and adapted as required in the future.

A broad range of nursing and allied health professionals within East Grampians Health Service were involved in this production, and the project had significant flow on effects in terms of raising awareness of carer needs, and improved job satisfaction.

9.9 '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.*

Information is presented in the form of guest speakers, written information and general discussion with questions. Often the sessions elicit questions which are generally asked tentatively and with uncertainty, and require a sensitive response e.g. "Can I kill my husband by removing the oxygen?" "Is it alright to hate my wife?"

These questions from carers can raise issues which can be sensitively responded to in the particular session that they were asked, but are not necessarily available in the palliative care resources. This means that responses to these 'whispered questions' are not necessarily available to other groups, and not available to those that do not attend face to face sessions.

The process is:

- 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 information identified will have potential:

- To be used as a catalyst for difficult questions within the Carers Education Program,
- To be given in a one on one session with carers that are unable to attend Carers Education Program
- To be the foundation for further research into the development of a validated Fact Sheet.

9.10 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 funded the purchase and trial of tablets for the Djerriwarrh Health Services 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

Other services in the region are exploring similar possibilities, and this project will have the flow on effect of helping to inform our combined expertise.

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-threatening 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-threatening 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.

In addition, the consortium sponsored 3 performances of the play 'Four funerals in one day' across the region. More information on all of these community based activities is provided below.

10.1 Information session for Hopetoun Healthcare Awareness Group

Accurate and professional palliative care information for older residents.

Melanie Hahne, Coordinator of Wimmera Hospice Care, provided approximately 20 members of our small community with valuable information on what palliative care is, how it has changed over the years and palliative care services in our region.

Assistance such as this is vital to our group as we operate wholly by volunteers with no financial basis at all. Our aim is to provide our community with information and support where requested and/or needed.

10.2 Wimmera Hospice Care Auxiliary, Lyn Bullock Memorial Quilt Auction

Quilt Auction & Display day with presentation by palliative care professional

A well-advertised event had over 100 quilt items donated which were auctioned. Over 400 people attended and every item was sold. Many more items were donated to the event than anticipated, helping to raise over $16,200 for Hospice, which ultimately feeds back into better services for palliative care patients in the Wimmera region.

The profile of Hospice Care and the auxiliary have been raised, with significantly broadened community awareness of advance care planning and palliative care options. This was a fantastic event which was far beyond our wildest dreams and shows the calibre of the community, the love of Lyn Bullock and the respect for our Hospice team. We could not have had this outcome without the fabulous grant. Thank you so much.

10.3 The forgotten ones: working with women affected by secondary cancer

Two forums for women affected by secondary cancer to find what supportive care is needed

The catalyst for the project was the current gap in peer support for women living with secondary cancer.

This collaborative project was led by Support4Cancer, a cancer peer support foundation, in partnership with Ballarat Hospice Care Inc, McGrath Foundation, Grampians Integrated Cancer Service and Ballarat Regional Integrated Cancer Centre.

Two local forums, one for women and the other for partners and family, had two intentions:

- The first aimed to create a safe, confidential and supportive environment to encourage participants to raise issues that most concerned them.

- The second was to present a suite of supportive care ideas from which to consider the development of tailored programs for these groups

The forums were facilitated by an experienced team of allied health and nurse professionals with experience in eliciting emotional cues and grief counselling. Many issues were explored and participation from the attendees is reflected in the issues raised. Sensitive issues were explored and addressed. The attendees also highlighted some quality improvement for health services to consider. These have been fed into a major consumer engagement project undertaken by GICS.

Positive feedback included ‘good to be able to speak out in a safe place', ‘enjoyed social aspect - would like more' and 'worthwhile discussion'. Participants also commended the capacity to share information and to discover the existence of supportive services.

The biggest challenge was reconciling the workshop content to the goals of the project. The short session time created limited opportunity to explore issues in great depth. The evening session time was a barrier for women's attendance due to fatigue. Extending the number and frequency of sessions, as well as changing the time of day are likely to minimise these challenges.

Outcomes

- Further programs in preparation for these target groups. These programs will utilise well developed content from specialised services in Melbourne and adapted for local need
- Greater understanding of issues and needs from local viewpoint
- Final report prepared with key themes identified for distribution to health services and GICS
- Explicit requests from attendees for further tailored programs

10.4 Conversations with the Community about Palliative Care Messages

Use the light-hearted Australian marmalade ‘Ashes’ challenge as the vehicle to get Palliative Care messages across to communities.

Mrs Jane Hasell-McCosh, Founder of the International Marmalade Awards, came to Australia to help promote the Buninyong Marmalade Association, and in particular the ongoing ‘marmalade challenge’ (the Ashes) between England and Australia. Mrs Hasell-McCosh is a great achiever and communicator as well as a tremendous supporter of British Hospice. The International Marmalade Awards, under her direction, has contributed £120,000 to these organisations over nine years. Funding for this initiative aimed to ‘value add’ to Jane’s visit, and together with Ballarat Hospice Care Inc. and other local palliative care specialists, engage in functions across the broader region with the aim of conducting a ‘conversation with the community’ in regard to the Hospice/Palliative Care messages.

An initial launch was held in the M.A.D.E. auditorium in Ballarat at which representatives from all community groups were invited. Media personality Sam Newman and Lady Potter both addressed the gathering as well as Jane Hasell-McCosh. The aim was to attract significant publicity to the forthcoming road show of community meetings in regional centres.

A road trip organised by chair of the Marmalade Association, Russell Luckock then proceeded to community meetings in Nhill, Mildura, Swan Hill and St Arnaud These were all addressed by local palliative care specialists in addition to the talks by Jane. They were joined on the road trip by Jane’s photographer daughter Hermione who acted as photographer/publicist. Local palliative care specialists gave detailed talks at each venue and were able to highlight their work amongst the local community at each centre. The Buninyong Marmalade Association has no paid staff, and this project was all run by volunteers.

Media coverage of the road trip and palliative care messages was significant with interviews being broadcast by ABC Radio Horsham and ABC Radio Mildura while local newspapers eg, Swan Hill Guardian, Sunraysia Daily also published photos and stories. The trip also featured on Hospice's website eHospice.

The program was very successful in using the light-hearted marmalade challenge to piggy-back the important community message being disseminated by palliative care organisations. We were able to elicit media attention that was then focussed on getting the message out to the communities about talking to family, friends and GPs about our end-of-life care wishes. Anecdotal evidence, however, indicated that people are reluctant to contemplate and discuss their end-of-life care, and that getting the community attitude to change seems a long slow process!

10.5 It's all about you

Informing and educating Harrow BNC clients in the advantages of Advance Care Planning

Harrow has an ageing population, and discussing ACP has stimulated thinking and discussion around a usually unspoken topic.

Harrow BNC holds regular monthly education and discussion days, and have used these as a vehicle for raising awareness of advance care planning in the community. Attendees were informed about ACP paperwork and given support to put their thoughts to paper. HBNC staff were available to assist with completing if required, and many participants took ACP paperwork home to discuss with their families. Advance Care Planning is now a regular item at these education days.

An initial group of clients have returned their completed forms and commented that they had been thinking about doing something like this but had never got around to it. They also commented that it was easier to do than they thought. During discussion sessions, participants have said that they have written their wishes in their wills, or have written it in a book in the kitchen drawer. This has been an opportunity to discuss that these arrangements will not necessarily honour their wishes, or indeed, who knows to look in the kitchen drawer?

Interestingly, there has been a substantial spin off for the centre and the staff:

- HBNC staff now have a clearer understanding of ACP and giving clients the opportunity to discuss end-of-life treatment issues.
- While previously staff thought this was aimed mainly at elderly people, they now understand that any age group (over 18) can write our wishes.
- 1 annual review will now involve reviewing/updating ACP forms.
- Staff have taken forms home to discuss with their parents/siblings/families.

10.6 Road show - When it is a tough road ahead ....we're here

Rural Northwest Health engaged community members and relatives of the residents in aged care with information and education about Advance Care Plans, the concepts of Palliative Approach and the use and benefit of Telehealth conferencing for specialist care.

Information sessions on palliative approach and advanced care plans were held with community members in the Yarriambiack Shire, with sessions at Warracknabeal, Hopetoun, Beulah and Woomelang.

The community was also informed of other services that RNH offered which are, Advanced Care Plans, the Cancer Support Nurse and Telehealth. Interactive conversations took place with the

Advance Care Planners and the coordinators who are also the palliative approach link nurse champions. Feedback from families and residents in attendance was very positive

10.7 Four Funerals in One Day

Four Funerals in One Day, developed by Alan Hopgood in collaboration with Molly Carlile, is a play designed to facilitate community conversations about death, grief and living. It brings a great deal of humour, matched with heartbreaking reality, to a much ignored topic of palliative care, and is designed to facilitate conversations about death, grief and living. When talking about developing the play, Alan realised that “you need comedy to make sure the men stay,"

In conjunction with local Health and Community Palliative Care Run services, the consortium supported a regional tour of the ‘Four Funerals’ play over three consecutive nights in the depths of winter, with excellent attendances:

- 9th June, Edenhope – 130 attendance
- 10th June, Ararat – 110 attendance, and
- 11th June, Daylesford – 110 attendance

Following each performance of the play, Alan was joined by a panel of local health care professionals to take questions from the audience. These questions inevitably bought up core issues which could be discussed to build upon the take home messages from the play.

Edenhope Community Nurse, Cath McDonald, felt the performance covered a number of messages that she wanted locals to take home:

- Have a frank discussion with family about death, which can be introduced at all ages, even to the young by talking about it in terms of pets.
- Write an advanced care plan, which outlines preferences for palliative care treatment, and update every 6 - 12 months.
- It is OK to talk about dying.

From an organisational point of view, Bay Street Productions were a delight to work with, and were very comfortable engaging with the small rural communities.

11. GRPCC 2014-15 Financial Statement

Income	
GOVERNMENT GRANTS	
DH GRANT - PALLIATIVE AGED CARE LINK NURSE	80,419.00
DH GRANT - PALLIATIVE CARE STRATEGIC FRAMEWORK	123,846.00
Total Income	**204,265.00**
Expenditure	
EXTERNAL CONTRACT STAFF	1,450.00
GRANTS RECEIVED & PAID TO OTHER AGENCIES	54,088.00
REPLACEMENT AND ADDITIONS- Computers and Comms <$1,000	6,363.64
OTHER ADMINISTRATIVE EXPENSES	30,278.37
COMPUTER - OTHER COSTS	596.63
RENTAL OF PROPERTY - OTHER	11,456.52
ADVERTISING	68.18
ADVERTISING RECRUITMENT	639.79
SECURITY COSTS	50.55
PUBLICATIONS - (BOOKS/JOURNALS) INC SUBSCRIPTIONS	1,022.68
LICENCE AND REGISTRATION (EXCL. MOTOR VEHICLES)	226.36
MEMBERSHIP FEES.PROFESSIONAL FEES.	695.45
POSTAL SERVICES	12.81
PRINTING & STATIONERY	2,064.32
TELEPHONE SERVICES	2,773.33
STAFF TRAINING AND DEVELOPMENT	3,705.87
CONFERENCES REGISTRATION AND ACCOMM	5,227.27
CATERING FOR MEETINGS	5,507.85
TRAVEL EXPENSES- OTHER	20,302.17
Total Direct Expenses	**146,529.79**
Salaries & Wages	
SALARIES	191,287.63
SUPERANNUATION EXPENSE	16,674.67
WORKCOVER - PREMIUM	1,499.44
Total Salaries & Wages	**209,461.74**
Surplus / (Deficit)	**(151,726.53)**
B/FWD - Total Program Surplus as at 30/6/2014	**334,643.49**
Total Program Surplus as at 30/6/2015	**182,916.96**