



Grampians Region
Palliative Care **Consortium**

Annual Report 2018

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

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1. Chair's Message

Throughout the 2017-18 financial year, the consortium has continued to focus our efforts on the core objective of improving the quality of and access to palliative care services within the Grampians region.

This report details the three priority areas that have underpinned the work of the consortium over the last 12 months.

1. Provide effective workforce support and professional development
2. Broader sector engagement
3. Better support for carers

The consortium has continued to be fiscally responsible, resulting in the achievement of a surplus at the end of the 2017 – 18 budget cycle.

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 and the consortium administration officer for their time, commitment and dedication to regional palliative care services throughout our region. I appreciate the support that they have given me as Consortium Chair over the last twelve months.

I would also like to acknowledge the support of the clinical group who work closely with the consortium to facilitate our shared objectives.

A last big thankyou to all staff who work in the palliative care services across the Grampians region for their ongoing dedication and commitment to patients, families and carers.

Michelle Veal

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.

Section 2 & 3 information source:

- ABS data/2016 census
- Victorian Cancer Registry 2019
- DHHS 2012 Regional Health Status Profiles (Grampians region)

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.

Compared to the Australian Population, the population in the West of the Grampians health region are on average 9 years older, and earn 23.5% less average total annual income. (ABS 2016 census)

	West Grampians	Vic	Australia
Median Age - Persons (years)	47.3	36.8	37.4
Median total income (excl. Government pensions and allowance) (\$)	36,504	46,984	47,692

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 this regions three areas: **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.

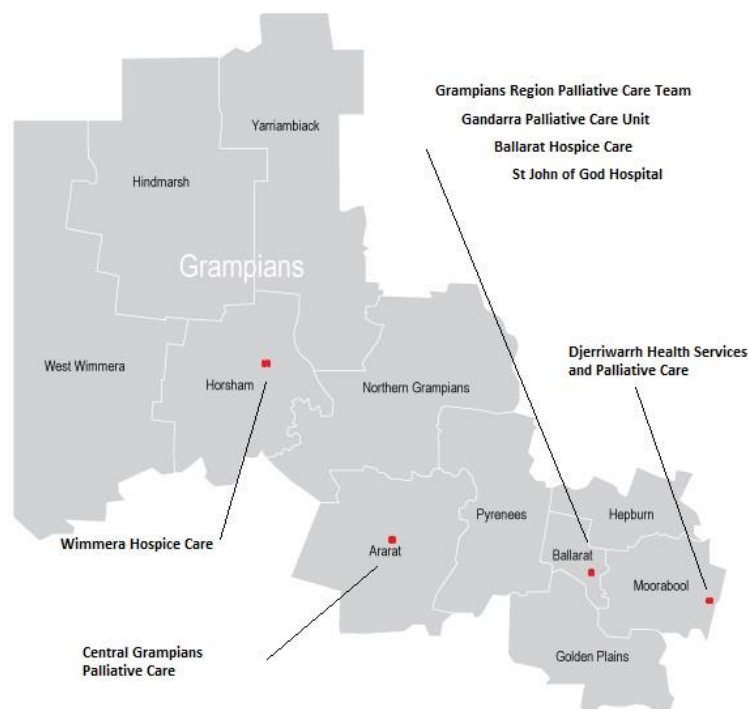
Table 1: (Current ABS data–June 2017) *Population density and proportions of aged residents*

	Grampians Region	Wimmera	Central	Ballarat
Total population	243,909	14.8%	12.6%	72.6%
65+ (as % of popn)	18.5%	22.5%	23.6%	16.7%
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)	5.02	1.3	2.3	25.2

The Ballarat area has a vastly higher population density, accounting for 72.6% 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 2021 are projected to remain higher than the Victorian average in all Grampians LGAs and are particularly high in Yarriambiack and Hindmarsh. 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: 2011 ABS figures and projected 2021 % population over 65 years of age, and proportion under 15 and over 65, compared with proportion of working age population (Dependency ratio).

LGA	2011		2021	
	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	0.71
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 (% of pop'n)	Age pension recipients (% of pop'n)
Ararat (RC)	6.5%	5.1%	39.8%	5.6%	15.5%
Ballarat (C)	6.2%	4.4%	42.5%	5.0%	11.8%
Golden Plains (S)	4.6%	3.9%	30.6%	2.8%	8.5%
Hepburn (S)	5.9%	4.3%	41.2%	4.8%	15.8%
Hindmarsh (S)	7.7%	5.1%	40.5%	5.7%	17.1%
Horsham (RC)	6.0%	4.2%	43.2%	4.6%	13.3%
Moorabool (S)	5.1%	4.2%	36.2%	2.9%	10.1%
Northern Grampians	7.6%	5.8%	43.8%	7.1%	17.8%
Pyrenees (S)	7.0%	5.9%	37.0%	5.9%	17.1%
West Wimmera (S)	5.0%	4.4%	41.5%	4.3%	15.6%
Yarriambiack (S)	8.9%	6.4%	41.4%	7.8%	17.5%
Grampians	5.8%	4.6%	41.0%	4.7%	12.6%
Victoria	5.1%	3.8%	35.9%	2.9%	9.6%

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: Northern Grampians; Yarriambiack; Ararat and Hindmarsh. 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 (5.1%) in Grampians region (5.8%). 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 Northern Grampians, Yarriambiack, Pyrenees, and Hindmarsh.

Table 4: Total new malignant cancers diagnosed (actual incidence) in 2017, for Grampians LGAs

LGA	Males	Females	Total
Ararat (RC)	46	48	94
Ballarat (C)	350	288	638
Golden Plains (S)	80	55	135
Hepburn (S)	58	62	120
Hindmarsh (S)	28	28	56
Horsham (RC)	78	72	150

Moorabool (S)	119	86	205
Northern Grampians (S)	52	45	97
Pyrenees (S)	34	16	50
West Wimmera (S)	11	15	26
Yarriambiack (S)	27	22	49
Grampians Total	883	737	1620

The rate of malignant cancers diagnosed (Table 4) is on average higher for males than females. Grampians region has the third highest rate of cancers across Victoria.

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 focus of the Consortium has always been, and will continue to be 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 & Disability Residential 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 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 and a Palliative Approach to care,
 - 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 family/carers and 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.

3. Priority 3 – Better support for carers
 - Funding resource development
 - Update existing resources

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

Approximately 1.3 per cent of the region's population is Aboriginal or Torres Strait Islander, which equates to approximately 3,313 people (ABS 2016 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 (2016 census)*

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	2,331
Goolum Goolum Aboriginal Cooperative	West Wimmera Shire, Horsham Rural City Council, Hindmarsh Shire, Yarriambiack Shire	493
Budja Budja Aboriginal Cooperative	Ararat Rural City Council, Pyrenees Shire, Northern Grampians Shire	489

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.

4. Consortium Membership and Structure

Committee of Management for 2017-2018

Chair: Michelle Veal, Operations Director Community Programs,
Ballarat Health Services

Members:

Tony Tuohey, Acting Director of Primary Care, Wimmera Health Care Group

Carita Clancy, Executive Officer, Ballarat Hospice Care Inc

Peter Armstrong, Director, Clinical Services, East Grampians Health Service

Amanda Edwards, Director of Nursing & Midwifery, Djerriwarrh Health Services

Melanie Mattinson, (Clinical Group representative)

John Koopmans, Department of Health & Human Services

Vacant, 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 an eleven-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 clinical consultation, education, collaborative strategic planning, preparation of written materials and quality improvement processes. 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-limiting 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 is a specialised palliative care service run by WHCG, 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 specialist palliative care service run by EGHS, delivering health care and emotional support to patients, and their carers, living with life-limiting 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 specialist palliative care service, run 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) – 101 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 a 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 SJOG publication 'Our Vision 2015 – 2019' outlines its vision, mission and guiding principles which strengthens their excellence in care, governance and management of resources, formation and leadership, and social justice.

5.1 Contact Details

Grampians Region Palliative Care Consortium
Manager: Vacant
Phone: 0428 737 330
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Web: www.grampianspalliativecare.com.au

Central Grampians Palliative Care
East Grampians Health Service
Girdlestone Street, Ararat, 3377
PO Box 155, Ararat, 3377
Phone: 03 5352 9328
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 Inc.
312 Drummond Street South, Ballarat, 3350
PO Box 96, Ballarat, 3353
Phone: 03 5333 1118
Email: admin@ballarathospicecare.org.au
Web: www.ballarathospicecare.org.au

Djerriwarrh Palliative Care
Djerriwarrh Health Service
Grant Street, Bacchus Marsh, 3340
PO Box 330, Bacchus Marsh, 3340
Phone: 03 5367 9137
Email: palliativecare@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: elizabeth.mcencroe@sjog.org.au
Web: www.sjog.org.au

6. Consortium Report

The focus of the 2017–18 financial year has continued to be on effective use of available resources promoting a collaborative approach to improving palliative care provision including end of life care in the Grampians region.

The main areas for improvement have been:

- Provide opportunities for staff to expand their skills and knowledge through ongoing education/conferences
- Provide support for external events and initiatives
- Provide resource planning to identify regional priorities
- Supporting technology skills development
- Region wide collegial support/networking through the clinical advisory group
- Assist with the implementation of the Victorian Government's end of life and palliative care framework

In the absence of a manager during this financial year the consortium has continued to maintain a focus on 'supporting' initiatives where possible, and any funding provided is matched by 'in kind' resourcing within those initiatives. The consortium focus continued on service development, staff upskilling, job satisfaction and ultimately retention and further resource development. The positive outcomes of what was achieved this year proved to be an innovative but judicious use of funding.

In addition, a quick look through the report will illustrate the wealth of resources that have been developed or are being upgraded to inform and support carers in the region. Similarly, we are delighted to have been able to support 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 consortiums role is to support them where possible.

I would like to take this opportunity to thank Michelle Veal of Ballarat Health Services, for all the support she has given me over the reporting year, as Consortium Chair she took on a far greater role during the extended period without a Manager. I would like to thank the auspice, Djerriwarrh Health Services for their assistance and support over the past 12 months. Also a very big thankyou to John Koopmans our Grampians Health Department rep, for his knowledge and support in assisting us whenever we needed it, also for the efficient and timely way he goes about supporting palliative care in this region.

Christine Hocking, Consortium Administration Officer

7. Core Activities

7.1 Clinical Advisory Group

The Grampians Consortium Clinical Advisory Group (CAG) had 6 meetings during 2017-18, which were all face to face meetings. These have proven to be extremely valuable networking time for all who have attended and face to face also proving to give greater representation from all areas of the region.

These meetings are held in Ararat, as this offers the best compromise on the need for members to travel from across the region. They are resource intensive, and for some participants will mean

losing most of their day from work. They do however; offer the greatest potential for networking and the sharing of knowledge occurs 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 offer invaluable sharing of knowledge and skills. 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
- Feedback from representation on external advisory groups
- Information and support for involvement in state-wide initiatives and central data collection
- Input into consortium planning activity and data collection
- Information sharing and input into implementation of state-wide initiatives funded through the consortium
- Information sharing around implementation of the new Advance Care Directives & the MTPD Act 2016
- Development and review of Grampians based consortium funded initiatives
- Concept development and design of future consortium funded projects

7.2 Palliative Aged Care

The role of the Palliative Aged Care Resource Nurse (PACRN) has been ongoing support and education to embed a Palliative Approach in 59 Residential Aged Care Facilities (RACF) in the Grampians region. The role is clearly a resource and consultancy role which works closely with aged care staff and Specialist Palliative Care Services (SPCS) staff in this region. The PACRN has continued to focus on supporting RACF link nurses, members of steering committees and their staff to complete self-directed online training and supporting them to conduct training in their own facilities using aspects and resources from the Palliative Approach Toolkit.

Onsite education and discussions around local experiences have continued throughout 2017-18 around topics such as recognising signs of dying, understanding the dying process, advance care planning, patient centred care, oral care, pain assessment, diagnosing dying and a palliative approach. Multiple education sessions/workshops with over 380 attendees and/or contacts, interacting with Managers, Clinical Care Coordinators, and colleagues in the field included: -

- 1 (6Hr) Palliative Approach in Aged care workshops
- 3 (6hr) ACP Facilitation Skills workshops (co-facilitated with the GRPCT)
- 3 WestvicPHN GP education sessions (co-facilitated with the GRPCT)
- 35 education sessions (1-3hr) aspects of a Palliative Approach in Aged care
- 8 ACP Community events
- 2 Forums presenting the 'Wishes Activity' cards data
- 3 Resident and family meetings (update on ACP)

The challenge for managers and educators is to support the staff in the recognition when a resident is entering the terminal phase and the associated documentation that was needed to be included in an end of life care pathway, rather than trying to transfer to an acute facility. Mostly the education was around subjects such as implementing a Care Plan for the Dying Person (CPDP), Advance Care Planning. In particular, the new legislation of Advance Care Directive documents included in the Medical Treatment Planning and Decision Act 2016 (MTPD), with completion of these new forms to guide residents' medical care into the future being well supported throughout the region.

On 12th March 2018, the (MTPD) was enacted in Victoria and the PACRN was part of the Implementation Working Party. This was a valuable opportunity to network with leaders in Victoria

in advance care planning and to put forward concerns and thoughts from a rural aged care focus. This change in law meant a significant need for updates with both care staff and residents and families in RACF. The main changes regarding the process of discussions in Advance Care Planning were moving from acting in the “best interests” of individuals to providing care that was consistent with their Values and Preferences, in particular when they were no longer able to speak for themselves. In aged care it was about supporting residents who no longer had decision making capacity to be supported in having their values and preferences documented.

Another focus of education has been to support and encourage the ongoing links between RACF and SPCS in the Grampians region. These connections are invaluable to staff and residents in RACF to support the provision of care in the facility. This also gave an opportunity to promote the [quick reference tool for referral to SPCS in the Grampians Region](#) which is a navigation tool that was completed in July 2017 and continues to be updated regularly. This support assists in avoiding unnecessary transfers to emergency departments and admission to hospitals and thus reduces both caregiver and resident’s distress as they are able to be cared for in their own facility.

A further tool used in PACRN education sessions are the “Wishes Activity” cards recently developed by the consortium. These have been utilised in discussions around an individual’s values and preferences for end of life, to encourage individuals to **“Have the conversation”** with family. Interim data results were shared by the PACRN at the Palliative Care Nurses Association Conference in Brisbane, May 2018 and also at a forum at the Victorian Advance Care Planning Conference in Melbourne, November 2017. The 48 Value statements can be accessed on the [Grampians Palliative care consortium website](#). The consortium is now looking to have these professionally developed so copies can be distributed to all SPCS and RACF throughout the region.

During the last two years, the PACRN has co-facilitated with Jade Odgers, Manager, Grampians Regional Palliative Care Team, Advance Care Planning Facilitation Skills workshops across the region. These were often booked out within a short time-frame, were always well attended and valued by participants. From feedback, participants felt more confident to be able to conduct advance care planning discussions with residents and their families with the skills that were introduced at these sessions.

In addition to the core activities the PACRN experienced valuable and rewarding opportunities that further enhanced the networking of this role, which were:

- Supporting a successful small grant initiative by Rural Northwest Health (RNH) called the ‘Dying to Know’ forums during August 2017 in the rural communities of the Wimmera and Yarriambiack regions. This allowed approx. 80 attendees to learn more about ACP’s, complete the wishes activity, discuss a medical support person and meet Wellbeing Coordinators from RNH.
- Speak at both TAFE and Universities in the region to students completing either their Certificate in Individual Support or Diploma of Nursing. This allowed for discussion of student experiences during placements in RACF and how the Palliative Approach is the key to understanding how to support residents in their care and to recognise deterioration.
- International attendee at the inaugural Supportive & Palliative Care Indicators Tool (SPICT) conference in Edinburgh in February 2018. The SPICT™ is an excellent resource and can be used to identify people at risk of deteriorating and dying with one or more advanced conditions for palliative care needs, which was a key resource often used in education.

Regular staff changes at a senior management level in RACF such as CEO’s, CCC’s and NUM’s meant that a significant part of the role was to continue conducting site visits, being aware of the increasing number in the region, both public and private and meeting new management. This relatively

frequent change often meant that the embedding of a palliative approach and the 3 key processes of advance care planning, family case conferences and timely commencement of end of life care pathways became at times difficult to achieve. This reinforces the need for the PACRN role to continue with ongoing facility visits, looking at systems/processes to create organisational change and strengthening the organisations capacity in palliative care.

The consortium would like to acknowledge and congratulate the passionate care staff at each of the RACF for providing excellent nursing care. Together we will continue supporting the community at large but in particular each of the dedicated care staff and residents to embed a Palliative Approach to care in each of the 59 RACF in the Grampians region.

7.3 Disability Palliative Care Project

Formerly a consortium contracted project, for the 2013-14 and 2014-15 financial years, East Grampians Health Service (EGHS) took on this initiative and funding went directly through to them. After no Expressions of Interest were received to operate this program for 2015-16 and 2016-17 funding continues to rollover to EGHS.

In 2016-17 after extensive research to determine the key stakeholders required to drive this project the Grampians Disability Palliative Care Project Steering Committee (GDPCSC) was formed. This committee is made up of representatives from our Specialist Palliative Care Services (SPCS) as well as the Disability sector and DHHS. In 2017-18 the GDPCSC focused on employing a person that could drive the project further and give the biggest impact from what is ultimately a small amount of funding. In August 2017 after much discussion around project outcomes that were required a position description was finalised and the position advertised. The GDPCSC decided that it was more important for this role to have a greater disability background and would therefore be able to develop and implement strategies that were workable within the disability sector. The funds were transferred to Ballarat Hospice Care Inc. as the fund holder.

In November 2017 the Consortium engaged the services of Uniting Ballarat who had a part-time employee with exceptional knowledge and skills to build capacity of Residential Disability staff in the Grampians region. An agreement was drawn up between the consortium and Uniting Ballarat for a 12 month contract and Kathy Steenhuis commenced as the Grampians Disability Palliative Care Project Worker on 2nd January 2018.

The GDPC Project Worker was engaged to build capacity of Residential Disability staff in the Grampians region, to provide an effective and appropriate palliative approach to care for residents. This involved clarifying the respective roles of both residential disability and palliative care staff as part of the project, so they both understood each other's scope of practice, limitations, etc., and to support staff to adopt a palliative approach and improve end of life care for residents.

Main points:

- A regional approach underpinned by strong links and networks
- Identifying key staff within facilities who will participate in the program
- Engagement with service provider senior managers
- Engagement of specialist community palliative care services and the Grampians Regional Palliative Care team to support the provision of specialist palliative care as required.

From January – June 2018 GDPC Project Worker worked very closely with the GDPCSC members, key stakeholders and the Residential Disability Services sector to develop a set of documents that could be implemented by Residential Disability staff when a resident requires a palliative approach to care.

As these documents were finalised, it was with extreme regret that the consortium received the resignation of GDPC Project Worker, as she had resigned from Uniting. However the consortium is extremely grateful to both Kathy Steenhuis and Cathryn Ryan, Manager – Client Enhancing Services, Uniting as without their insight into the disability sector this project would never have progressed to where it is today. Unfortunately Uniting have no capacity to continue the project worker role, which leaves the consortium currently looking to restructure where this role best sits in order to move forward.

The consortium and the GDPCSC continue to work towards trialling these documents with the Disability Residential Service providers as a strategy towards improving a palliative approach to care for residents.

7.4 PEPA

The consortium received PEPA funding specifically targeting Grief and Bereavement education for the region. A workshop was held in Ballarat in November 2017 with an external facilitator from the Australian Centre for Grief and Bereavement. (see 8.5 for more details)

The consortium received an additional amount of PEPA funding during 2017 to further enhance skill development for staff who had undertaken a previous placement. This was utilised in many different ways giving opportunity and variety to staff from across the region. The consortium supported fifteen sponsorships for post PEPA placements and staff to attend the GRPCT Palliative Care conference in November 2017. The consortium also subsidised a 'Non-malignant Conditions in Palliative Care' study day held in Ballarat May 2018 with seventy-one attending and a 'VCCCP Communication Skills Train the Trainer' two day workshop in Ballarat March 2018 with palliative care staff from across the region attending.

7.5 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 on a regular basis to the extent it has become a valuable information tool for many people from within the Grampians region. Analytics demonstrate utilisation is increasing from within the Grampians region, with approx. 30% of people accessing the site from this region, 45% from other regions and 25% other countries. It continues to demonstrate that increases in site visits are directly related to consortium resources and/or activity, including Aged Care education, Small Grant & Events advertising, workshop registrations and our 48 values statements. A frequently accessed resource is the link available to the [Navigation Project Quick Reference Tool](#), to quickly access the Specialist Palliative Care Services and the referral process for this region which is regularly updated. Also two important resource additions this year was direct links to the [Medical Treatment Planning & Decisions Act 2016 documents](#) which were implemented from 12th March, 2018 and our list of [48 Values Statements](#) which have proven to be a popular advance care planning tool for conversation starters.

8. Service Support Activities

8.1 Provision of Professional Training

The consortium has run workshops across the region during 2017-18. The Grampians Regional Palliative Care Team (GRPCT) is the major provider of training in this region, with a varied and

comprehensive program. The consortium has co-facilitated some training with the team, as well as targeting training's which are complementary to their program.

The palliative aged care initiative has been our main training focus for this financial year. The consortium in conjunction with the regional team have run a further three very successful Advance Care Planning Facilitation Skills workshop's which were held in Ararat, Ballarat and Horsham. All attendees indicating this was a valuable topic which gave them more confidence to go away and have the conversations, and a much needed area for ongoing training.

The consortium previously sponsored the GRPCT to run two Clinical Skills Workshops specifically aimed at palliative care nurses from all four Specialist Palliative Care Services. The second of these workshops were held in November 2017 which was also very well supported, with some attendees travelling long distances and requiring overnight accommodation in order to attend.

8.2 Advance Care Planning Discussion Resource – ‘Wishes Activity’

The consortium has developed a set of ‘Wishes Activity’ cards that offer health and aged care facilities a resource to support end of life and advance care planning activities. 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’*. Participants sort the cards until such time as they end up with the top 10 statements that best reflect their end of life wishes.

The cards were used in group situations, during education sessions, as an adjunct to public events and individually, and the response has been enthusiastically positive across all formats.

Feedback on the cards as they are currently configured, identified an overwhelming positive response. The main feedback is this activity gets people thinking and talking about the conversations that need to be had, especially with loved ones. All of the ‘wishes’ cards are numbered and used anonymously to record their top ten wishes.

Analysis data from over 500 respondents continues to show the top 5 wishes most commonly chosen are:

- To be free from pain;
- To maintain my dignity;
- To have my family and/or close friends with me.
- To be able to say goodbye to the ones I love;
- For my family, friends and caregivers to respect my wishes even if they don't agree with them;

Being free from pain is a clear standout in this list, and it is clear that there will be little quality at end of life if your pain is not managed. Similarly, there were other areas such as being relatively free from anxiety, treated with cheerfulness and to not be left alone. But fascinatingly, while 74% of respondents had pain in their top 10, virtually every respondent chose an area associated with the themes of dignity, respect and family and friends. This therefore points to the absolute importance of services paying close attention to providing what could be termed the ‘psychosocial’ aspects of palliative care.

The data also points to the ‘dying at home’ theme as being a nice thing if it can happen without significantly impacting on my family and self-determination – in other words much more nuanced than just ‘I want to die at home’.

The consortium is looking to have these professionally developed for distribution throughout the SPCS and all RACF in the region so they can be utilised as an excellent tool for starting the conversations. The 48 Value Statements can be accessed via the [Grampians Palliative Care consortium website](#).

Always Remember – the most important thing is to have the conversation

8.3 Support for Professional Development

The consortium recognises palliative care staff are our most valuable asset, and that training is critical for the continued quality improvement of services. Therefore where possible, agreed to support better access for 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 has done this in the past by responding to particular events or circumstances on a case by case basis. This initiative aims to make more training opportunities viable, by either assisting with registrations and/or staff backfill.

During 2017-18 the consortium assisted with staff attending the PCA conference in Adelaide, September 2017 and the PCNA 2 day conference in Brisbane, May 2018. Both events had representation from the specialist palliative care services and the regional team. Two staff from this region presented their research findings at the PCNA conference, and both found this to be a valuable experience personally.

The consortium once again was delighted to support the GRPCT with sponsorship for their bi-annual Palliative Care conference – ‘Location, Location, Location’ held in November 2017. The sponsorship assists the team with being able to offer a subsidised cost for participants to attend. The conference was attended by 120 staff from across this region as well as some from other regions. It was a very well-received conference with many engaging presenters and guest speakers, giving all who attended a greater level of professional development as well as a networking opportunity with colleagues from the palliative care sector.

With the assistance of additional PEPA funding the consortium was able to further support professional development of staff in the region with sponsorships to the GRPCT bi-annual palliative care conference, subsidised places at a Non-malignant Conditions in Palliative Care study day and also VCCCP Communication Skills Train the Trainer opportunities.

8.4 International Conference – A time for Reflections: A time for Visions

Vicky Smith, palliative care nurse at BHCI, attended the 10th World Research Congress of European Association in Palliative Care (EAPC) in Berne, Switzerland in May 2018. The conference was an opportunity to join 1500 delegates from 40 countries to share knowledge and learn from world class researchers for best evidence care.

The theme was: “A time for Reflections: A time for Visions”.

Research topics covered were:

- Integrating routine early palliative care,
- “Future Proofing” Palliative Care through research, education and clinical care,
- Nursing Research in Palliative Care.
- Challenges in design and application of economic evaluation in palliative care research.

This is on a background of a growing impetus and imperative for a more integrated, holistic and person-centred health, incorporating aged and disability services at a time of unprecedented increases in need and efforts to manage expenditure.

The international Keynote Speaker, Dr Irene Higginson, Kings College, UK, highlighted the need to explore “short term” integrated palliative care to assist with the increasing aging population over the next 20 years.

Australians were well represented with oral presentations and posters including the Early Research Award going to Dr Anna Collins from St Vincent’s, Melbourne. Anna presented her research in early integration of palliative care, using “trigger” points in the course of the disease for routine consideration for referral. Early palliative care interventions data correlates with an increase in home deaths.

With the global trend to de-hospitalise the dying, community palliative care nurses were seen as the “glue in the community”, giving security, presence and competence. There was a call by researcher presenters to build evidence of the community nursing impact on home palliative care to achieve and maintain sustainable models of care.

Vicky and Kate Wise submitted an abstract which was accepted for publication in an online special edition of Palliative Medicine by Sage “Evaluating Nurses’ Action, Outcomes and Exploring their Perspectives of Implementing the POS-S (Renal) Assessment Tool for Haemodialysis Patients”. The conference highlighted the global need to continue to promote research to deliver the best clinical care to improve patient outcomes, therefore “Future-proofing palliative care”.

“Without data you are just another person with an opinion”

The conference gave Vicki an opportunity to network and form connections with international colleagues, gaining insight and knowledge for them and promoting Ballarat Hospice Care as a place of excellence in home based palliative care service.

8.5 Grief and Bereavement

In early 2017 the consortium received a small amount of PEPA funding specifically for the purpose of running a Grief and Bereavement workshop which was eventually held in Ballarat in November. This was facilitated by one of the counselling team at the Australian Centre for Grief and Bereavement and covered the following topics:

- Understand the concepts of Disenfranchised Grief, Anticipatory Grief and Complicated Grief
- Support families impacted by one or more of these types of grief
- Identify effective self-care strategies.

As this proved to be an extremely popular workshop and booked out within 3 weeks the consortium ran a second workshop further up the region. Consequently this was duplicated in Horsham giving palliative care staff from more remote areas access to the education without needing to travel such extreme distances. Between both sessions approx. 80 people from across the region enjoyed a full day of interactive education and went away with increased skills and knowledge. Feedback indicated the need for more Grief and Bereavement training in the future, specifically understanding how to give families and carers support over the phone.

With such strong feedback coming from these workshops the consortium ran a further two specifically designed to address the training need for ‘over the phone support’.

These were held in Horsham in June 2018 and Ararat in July 2018 and were very well supported, with approx. 50 staff from across the region gaining valuable skills and knowledge, with the following learning outcomes:

- Describe the benefits of phone counselling in supporting the bereaved.
- Understand the theoretical principles of telephone support/counselling.
- Identify and implement effective strategies to support grieving individuals over the phone.
- Offer grief support across a number of sessions over the telephone.
- Understand when to refer to specialist grief and bereavement services for ongoing support.

The consortium would like to acknowledge and thank the Wimmera Hospice Care Trust for their very generous donation which supported the running of the Horsham 'Bereavement support over the phone' workshop.

The need for grief and bereavement education and support is not limited to those who have accessed a palliative care service but impacts on all members of our community at some stage in their life.

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.

Previous calls for submissions from funded services for potential project and resource development funding led to continued support this financial year by the consortium for the following ongoing initiatives.

9.1 MND Changeover

With the retirement of Jennifer Noonan from WHCG, in 2017 the Motor Neurone Disease Shared Care Worker (MNDSCW) role has seen changes across this financial year. The consortium expressed their appreciation of Jennifer's professionalism over many years filling the MNDSCW role for our region and wished her well in retirement. The MNDSCW role covers the full region, and in particular is one that is best suited by being stable over a number of consecutive years. In line with the procedure for all changes in program auspice arrangements the consortium called for an expression of interest (Eoi) from our funded specialist services to manage the role into the future.

The management of the role is for the next four financial years (2017-18, 2018-19, 2019-20 and 2020-21), dependent upon the role continuing to be funded.

An Eoi for future management of the program were called for, and the Grampians Regional Palliative Care Team became the auspice, employing an RN to the role for the region which commenced in Sept. 2017 as a one day per week. Unfortunately, due to unforeseen circumstances the position became vacant towards the end of 2017.

The consortium then agreed that the role was best suited as an addition to a specialist palliative care nurse position with one person from each end of the region ideally to share the role, hence reducing costs of resources. With a further Eoi called for, management of the position and funding then transferred across to Ballarat Hospice Care Inc. with the new MNDSCW commencing in the role from

1st March 2018. The consortium is still keen to employ another person from the west end of the region to assist in sharing this role into the future.

At the end of 2017, there were 15 people living with MND in the Grampians region (as registered with MND Vic). A look at the figures for the past 5 calendar years shows that the numbers regionally can vary significantly, but the overall trend across Victoria has been increasing numbers.

Year end	Grampians region	Victoria
Dec 2013	19	315
Dec 2014	15	379
Dec 2015	13	380
Dec 2016	17	372
Dec 2017	15	393

The current years funding is \$19,417 and although the overall numbers may seem low, it can readily be seen that travel across the region is quite challenging, both in terms of time and cost, within that overall budget. This confirms the consortium strategy to eventually employ two people to share the role due to the vast distances within this region.

9.2 Carer Package for Subcutaneous Medications

This is an ongoing resource available within the Grampians Region and is managed by the Grampians Regional Palliative Care Team. After successfully implementing the Carer package for safe administration of subcutaneous medications across the Grampians Region in 2014, this resource was financially supported by the consortium in 2016 to reproduce an additional 150 packs.

As this has proven to be such a valuable resource, the clinical advisory group have recommended having it included in 'A Guide for Caring for People at the End of Life' carers resource due to be upgraded in early 2019.

9.3 Carers in the Grampians

The consortium previously supported the Grampians Regional Palliative Care Team in the 'Carers in the Grampians' project. This ongoing resource is incredibly powerful and a great tool 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.

This continues to be a valuable resource for carers in our region and copies are available for families that may benefit from reading these ten amazing experiences of what others have gone through with their loved ones. Copies are available from any of the specialist palliative care services, the regional team or the consortium.

Thank you to the palliative care services which supported the participants in this project which 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).

A research article by Ballarat Hospice Care Inc. staff was published in the Renal Society of Australia Journal, earlier in 2017.

Evaluating nurses' action outcomes and exploring their perspectives of implementing the POS-S (Renal) assessment tool for haemodialysis patients.

This publication showed that between 11% and 24% of patient (n=54) indicated moderate to severe symptom burden. The progress notes showed that there were actions taken by the nurses to address symptoms as identified using the POS-S (Renal) tool. Focus groups revealed increased confidence/willingness to take ownership to effect change with in nursing roles, co-existing with prevailing persona, cultural and structural barriers which create a sense of powerlessness to effect further change. The conclusion highlighted that the POS-S (Renal) Tool is useful for identifying and tracking symptom deterioration, supporting nurse led actions to address chronic symptom burden and as a prompt for commencing conversations about End of Life (EoL) care. Renal nurses in regional dialysis settings face many challenges and require ongoing support and assistance to progress towards the adoption of timely advance care planning and the provision of patient-centred EoL care to their patients.

The consortium has previously given financial support to this project and looks forward to continuing with ongoing support to expand the skills and knowledge of renal dialysis nurses in the region. The Clinical Advisory Group is currently planning a Renal Study Day for later in 2018.

9.5 Palliative Care Navigation Project

July 2017 saw the completion of this joint project between the Consortium (GRPCC), Central Highlands Primary Care Partnership (CHPCP) and the Western Victoria PHN to develop a clear referral pathway tool for easy access to specialist palliative care services (SPCS) across the Grampians region.

The aim of this project was to:

- Improve patient outcomes and service delivery.
- Reduce avoidable transfers to the emergency department (ED).
- Improve the connections and enhance the patient journey between services.

The information from both SPCS and the survey data was used to inform the development of a quick reference tool, with a focus on making it easy to use, accurate, consistent and succinct. It was determined that the quick reference tool should include the following information:

- Referral process for each service, including triggers for referral, referral criteria and tips
- Map showing SPCS catchment areas
- List of other services which support SPCS

The quick reference tool was uploaded to the Western Victoria PHN website, and the [link to the tool](#) was then launched via the extensive email lists of the partners.

To be effective into the future, the tool continues to maintain currency and relevance. A feedback process is and will remain in place, and staff resources are still required to update and maintain accuracy of the tool. The quick reference tool can also be accessed via the [consortium website](#).

9.6 A Guide for Caring for People at the End of Life (video)

In 2015 the consortium supported Central Grampians Palliative Care to produce this carer's guide video which has been very well received, not just on a client/carer level, but more from other Palliative Care providers who were searching for easy to access, compact training tools.

In August 2016, Palliative Care Australia featured an article about the resource that in turn generated more than 130 requests for a copy. The requests came from many health services and individuals from around Australia and also overseas- Scotland, Thailand and Ireland. A poster detailing the videos development and research was presented at the Victorian Integrated Cancer Service conference in May 2017.

Youtube has proven to be a valuable media for sharing information. One of the video segments "when death is near" has had over 319 000 hits. Other popular segments include practical advice such as using an overnight catheter and what to do when you have breathing difficulty have had over 32 000 hits, also problems with a syringe driver and hair washing in bed attracted audiences of up to 10 000.

As this has proven to be an extremely valuable carer's resource, in 2018 the entire 40 short videos were uploaded onto the consortium website for easy access across the region. The consortium is progressing to fund an upgrade ensuring a more regional focus and producing copies on USB's. This will allow for updating sections, such as the MTPD Act 2016 and the new advance care directives, as well as include 'Carer package for safe administration of subcutaneous medications' resource.

9.7 'Whispered Questions' – Carers Education

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

In 2015, Ballarat Hospice Care Inc. (BHCI) staff (Educator – Integrating Palliative Care and Supportive Care Team Counsellor) undertook a research project surrounding 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. These have been identified as 'Whispered Questions'.

Patients, carers and staff participated in a survey and a focus group session where sixty-six questions were identified to assist with creating a list of 'whispered questions'. The topics included medication, treatment, relationships, legal issues, emotions, death and dying and managing after death. The researchers discovered that by providing information in a range of different ways including face to face, one on one, in small groups and in written formats were all important ways to address common concerns of patients and carers.

The staff submitted an abstract to Palliative Care Nurses Australia (PCNA) to present their Whispered Questions research at the 2018 PCNA Biennial Conference. This research was conducted in conjunction with the BHCI Project Manager. Their abstract submission was accepted – Mel presented their research findings to approximately 40 people at the Conference, held in Brisbane on May 20-21, 2018. The audience asked questions at the end of the presentation with feedback validating research as interesting and important with scope to extend research further. This

presentation was described by Mel, this being her first conference presentation, as a positive experience. She valued the support and feedback provided by BHCI staff following opportunities to practice the presentation prior to the conference. Emeritus Professor Margaret O'Connor encouraged BHCI staff to publish their research findings, further validating the research undertaken.

Thank you to the patients, carers and staff who participated in this research project. The consortium will continue to be supportive of this valuable resource.

9.8 Clinical Skills for Community Palliative Care Providers

The Grampians Regional Palliative Care Team ran the second of their clinical skills workshops in November 2017 that was specifically for our palliative care nurses across the region who were unable to previously attend, including staff from our inpatient palliative care unit. This was also a very successful day with attendees from across the region able to increase their skills and knowledge. The consortium was delighted to be able to support the regional team in providing these workshops for the region.

9.9 Remembrance Services

The consortium has once again supported the specialist palliative care 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-limiting 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 medical treatment decision maker to provide care that is consistent with your values and preferences, putting in place an advance care directive, 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 community based activities is provided below.

10.1 RNH – Dying to Know

From June – August 2017 Rural Northwest Health (RNH) ran five community events with the aim of starting more conversations about death and dying in order to encourage their community to start a conversation with their loved ones. These were held in Woomelang, Hopetoun, Beulah, Brim and Warracknabeal and were reasonably well supported by community members. Considering the remote areas of some rural townships RNH staff reached out to approximately eighty-seven of their community over all five events.

Session information covered enduring powers of attorney, palliative care, advance care planning and an interactive component where people were given the ‘wishes activity’ cards to identify the 10 wishes that were most important to them when planning their advance care plan. A ‘bucket list’ enabled people to add their most important wishes to it.

As well as financial support for this community initiative, the consortium staff also supported with a presentation at each of these sessions, which was very well received by RNH and the community. A static display and printed resources to take away were available. The sessions also provided the opportunity for the RNH Wellbeing Co-ordinators role to be promoted as they can assist people with completing an advance care plan.

The benefits identified from these sessions were:

- Importance of appointing a Medical Treatment Decision Maker
- Explanation and discussion informed participants about advance care planning
- The ‘Wishes Activity’ cards created interest among those who participated. Some participants found it challenging to narrow their wishes down to 10 from the 48 listed
- Promotion of the RNH Wellbeing Coordinators and their availability to assist with completing an ACP has seen a number of community members in Woomelang take up this offer.
- The Manager of the Woomelang Bush Nursing Centre reported that participants were still talking about the session the following day
- Verbal feedback from participants at the Warracknabeal session – reported the session as being excellent and that it was just what they wanted to know
- Bucket list wishes included – train from Perth to Sydney; fly to El Questro; trip on Ghan and to listen to my opera; Travel Australia, stay positive health, keep living, keep fit, days not long enough, don’t be a burden on family; see some grandchildren married; have no more room on my present bucket list sorry!; to get my wellbeing information in order; to go to Canberra and back to Broome; to be alive for my grandchildren.

Rural Northwest Health found these sessions to be extremely interactive with the community and an excellent source of promoting the importance of having an Advance Care Plan in place. They acknowledged the financial and staff support given by the consortium in assisting with the positive outcomes from these community events.

10.2 Compassionate Communities

Although not a consortium funded small grant, this is still very much a community initiative which originated from a few passionate people who attended a Compassionate Communities Symposium held in Queensland a few years ago. Upon their return a group of dedicated people was formed to create a compassionate community locally, to which the consortium has had two members on this since its formation.

Members of the Central Highlands Compassionate Communities group have continued to meet regularly. Members – Dr Allison O’Neill and Dr Claire Hepper (Shannon’s Bridge), Annie De Jong

(Ballarat Cemetery Trust), Dr David Brumley and Mel Mattinson (Ballarat Hospice Care Inc.) and Sharon Gibbens (Grampians Region Palliative Care Consortium) have been conducting community forums and are currently planning a Compassionate Communities Symposium to be held in 2019.

Two successful community forums titled 'Let's Talk about Dying' have been held, both at The Lost Ones Basement Bar, Ballarat. The first forum was held in November 2017, as part of the 'Romancing the Skull' exhibition at the Ballarat Art Gallery. Approximately 30 people attended the forum. Short presentations from members were held, and then attendees were able to participate in a range of activities around Wishes Cards and Values; Advance Care Planning, and Whispered Questions. The second forum was held in May 2018, coinciding with National Palliative Care Week. Guest speaker, Libby Moloney (It Takes A Village) opened the forum which was attended by approximately 15 people. Following Libby's talk, people then participated in activities, similar to those offered in the first forum.

Central Highlands Compassionate Communities has had representation at the 'Compassionate Cities Charter Community Forum' hosted by Ballarat Health Services (BHS). The group are looking to strengthen their relationship with BHS and other groups in Ballarat who are working towards building a compassionate community.

11. GRPCC 2017-18 Financial Statement

<u>Income</u>	
GOVERNMENT GRANTS	
<u>DH GRANT - PALLIATIVE AGED CARE LINK NURSE</u>	84,092.00
<u>DH GRANT - PALLIATIVE CARE STRATEGIC FRAMEWORK</u>	129,504.00
<u>Total GOVERNMENT GRANTS</u>	213,596.00
<u>OTHER INCOME</u>	
<u>Y7503-57051 Ballarat Health Services Scholarships</u>	1,136.36
<u>Y7503-57051 Wimmera Hospice Bereavement Support Training</u>	2,727.27
<u>Y7503-57051 Trybooking Education Sessions</u>	6530.00
<u>Total OTHER INCOME</u>	10,393.63
<u>Total Income</u>	223,989.63
<u>Expenditure</u>	
EXTERNAL CONTRACT STAFF	
<u>GRANTS RECEIVED & PAID TO OTHER AGENCIES (ACTUAL)</u>	-
<u>REPLACEMENT AND ADDITIONS- Computers and Comms <\$1,000</u>	271.83
<u>OTHER ADMINISTRATIVE EXPENSES</u>	4,123.63
<u>COMPUTER - OTHER COSTS</u>	530.28
<u>RENTAL OF PROPERTY - OTHER</u>	8,307.98
<u>ADVERTISING RECRUITMENT</u>	2,992.20
<u>MEMBERSHIP FEES.PROFESSIONAL FEES.</u>	766.36
<u>PRINTING & STATIONERY</u>	416.55
<u>TELEPHONE SERVICES</u>	1814.33
<u>STAFF TRAINING AND DEVELOPMENT</u>	12,999.99
<u>CONFERENCES REGISTRATION AND ACCOMM</u>	3,377.27
<u>CATERING FOR MEETINGS</u>	915.45
<u>TRAVEL EXPENSES- OTHER</u>	3,807.85
<u>Total Direct Expenses</u>	40,323.72
<u>Salaries & Wages</u>	
<u>SALARIES</u>	118,368.04
<u>SUPERANNUATION EXPENSE</u>	13,269.76
<u>WORKCOVER - PREMIUM</u>	2,616.00
<u>Total Salaries & Wages</u>	134,253.80
<u>Surplus / (Deficit)</u>	49,412.11
<u>B/FWD - Total Program Surplus as at 30/6/2017</u>	107,352.52
<u>Total Program Surplus as at 30/06/2018</u>	156,764.63