Summary and analysis

As our members will recall, we undertook a member survey over the Christmas/new year period. I am pleased to report that we received 128 responses. Thank you so much to all who responded, we really do appreciate the time you have taken to help us to set our priorities for the next two years.

We used your feedback to inform our recent Strategic Planning session and the results of that planning session in terms of work plan have been finalised with new mission and vision statements to go with our soon to be launched new website.

Continued on page 6.
President’s Report

Welcome to the April 2017 edition of Pallium. I can’t believe we’re almost in May already, what a busy start to the year!

We have been working very hard to develop our new Strategic Plan and Workplan for the next two years and held a very productive and intensive planning afternoon at Mona Vale in February. We have fine-tuned our purpose, vision and mission statements and here they are:

**Purpose:** Promoting quality palliative care for all.

**Vision:** To be the peak body and leading voice in NSW promoting quality palliative care for all.

**Mission:** To promote awareness of palliative care through education and networks for the health workforce and broader NSW community.

We have agreed on five focus areas for the next two years to tie in with those statements and they are:
- Awareness
- Partnerships (including Memberships)
- Leadership
- Governance
- Funding

We believe that these five focus areas will provide a strong platform in which to guide the work of the association.

Linda Hansen our ever hard working Executive Officer, has developed a clear work plan that will focus on those five areas and we look forward to reporting to you regularly via our new electronic only version of Pallium as well as our regular email updates.

We believe that these five focus areas will provide a strong platform on which to guide the work of the association and provide our membership and the general public with a clear understanding of the role of PCNSW, the peak body for Palliative Care in NSW

I am very pleased to see the new Health Minister taking up the cause and instigating a series of palliative care round tables across the State. We are keen to meet with him outside of that opportunity to to give him the results of our member survey and discuss with him on your behalf what is important now and in the future in terms of palliative care service planning and care provision.

Linda and I attended the April 10th Q&A program featuring author Nikki Gemmell, bio ethicist Professor Margaret Somerville, University Notre Dame, Australia, activist Billy Bragg, Federal Minister for Communications Mitch Fifield and Opposition Senate leader Penny Wong. One of the topics for discussion was euthanasia within the context of Nikki Gemmell’s recent publication *After*, a book she wrote following her mother’s suicide.

We did submit questions to the show’s producers in the attempt to provide some informed and balanced discourse about specialist palliative care but unfortunately our questions were not selected. Unfortunately there is no ability to counter or comment on any of the panellist’s commentary during the show. Linda continues to be active on various social media platforms and as part of PCNSW’s focus areas especially awareness and leadership, we will continue to attend any public forums where we can attempt to provide informed awareness of specialist palliative care.

There is early work happening in terms of planning for the State Conference 2018. Please stay tuned for announcements regarding dates.

The issue of RACFs and the partnership and collaboration with specialist palliative care continues to be a topical issue across the state. We will keep you informed of any developments or opportunities that may arise in this sector within NSW.

We continue to provide “NSW” feedback to Palliative Care Australia on documents that they are developing.

We are looking forward to hosting the 2017 Palliative Care annual Professional Education Forum at Campbelltown hospital this year on Friday 26 May.

For registration details please visit: www.palliativecarensw.org.au/Prof_Education_Forum17

For those that are able to host an activity for National Palliative Care week I wish you well and on that note “Happy National Palliative Care Week” to all.

*Therese Smeal*
President, Palliative Care NSW

Conference – what next?
It’s a real challenge to pick oneself up from one amazing conference and get started on the next one, but we like to be well organised and we have already started planning for Conference 2018.

I’m pleased to announce that the team hosting the next conference are the Illawarra Shoalhaven LHD team and the venue will be Kiama! Following the enormous success of Broken Hill, we are heading to another small-ish town but one that has trains hurtling towards it at regular intervals and the most amazing blowhole this side of the equator!

More importantly – it is home to a wonderful team of palliative care professionals who have come away from Broken Hill invigorated, inspired and dare I say – transformed. They are jumping out of their skin to work with us in putting together another amazing experience for you – our members.

We will have dates finalised very soon, but keep November 2018 clear for now.

2017 Budget Submission
We have made a number of suggestions to government about where palliative care funding should go and I am in regular contact with the Ministry and with the new Minister’s office to keep talking about priorities for palliative care in NSW. I am also fortunate to be speaking with a number of other parliamentarians and their staff and I am energised by the support and encouragement they are providing. I shall keep at it.

As you will know, the new Minister for Health, The Hon Brad Hazzard, has instigated round table conversations around NSW about palliative care. The first one was held in Sydney on Wednesday 26 April and was a terrific opportunity for those present to meet the Minister and have their say on the future of palliative care in this state.

We welcome the Minister’s initiative and obvious interest in palliative care, along with his colleague Leslie Williams, Rural Health Minister who has a special interest in palliative care. It was great to see the opposition spokesperson on health Walt Secord there in the morning too. Leslie will be running the rural and remote roundtables and is keen to hear from everyone, so don’t be shy!

Website
I’m sorry to report a delay in finalising the new website. I know that some of you have been frustrated with the slow and inconsistent current site but rest assured, we’re all working hard to finish this work and it will be up and running by National Palliative Care Week at the very latest.

National Palliative Care Week 2017
Speaking of NPCW – I have started to receive promotional items from PCA and will post them out to anyone who has ordered them as soon as I have everything. Hopefully it will be this week. I have no control over the delivery date unfortunately and neither does PCA, but we will all do our best.

Pallium
The next issue will be out by the end of June 2017. Please feel free to submit anything you think would be of interest to members – events, research, ideas for research – just contact the office for more information.

Membership
It’s time to think about renewing your membership for 2017–18. You can do this online. I will send individual reminder letters with an invoice just to make it easier for you.

Thank you as always for your support.

Linda Hansen
Executive Officer, Palliative Care NSW
PCOC Report

The Palliative Care Outcomes Collaboration
The Palliative Care Outcomes Collaboration (PCOC) is a nationally funded program designed to embed clinical assessment tools into routine clinical practice.

PCOC captures clinically meaningful information across a patient’s disease trajectory to facilitate improved patient outcomes. This is achieved by:

Clinical assessment tools
Five standardised and validated tools.

Education
Suite of education programs.

National dataset for palliative care
Point of care assessments collected and submitted every six-months.

Outcome measurement and benchmarking
Sector formed patient outcome measures and associated benchmarks for palliative care services.

Patient outcome reporting
Reports provided every six-months for participating services, states and nationally.

National benchmark workshops
Benchmarking groups by service type brought together annually to reflect upon and share patient outcomes.

Quality improvement
Improvement facilitated through a range of activities.

Research
Research activities undertaken and assistance provided with data requests and data analysis.

Advanced QI Workshops
Are you ready to expand your skills in applying PCOC to quality improvement? Workshops are scheduled based on interest. Check out Upcoming Workshops on the PCOC website to see when future workshops are available.

To find more information and to register your interest, go to www.ahsri.uow.edu.au/pcoc/workshops/index.html

Audit Tools
Have you looked at the audit tools on the PCOC website yet? There are some excellent audit tools available to services under the section ‘Quality Improvement Audit Package’. The PCOC audit tools assist services to identify areas for improvement in the documentation of the five clinical assessments and with consistency in assessments between clinicians. The following audit tools are available from the website:

- Response to PCOC Assessments
- PCPSS
- Phase Assessment
- Phase Change
- Phase Definition
- SAS

There is also a template for services to summarise the plan and outcome of quality improvement activities.

Toolkit for services: NSQHS Mapping Tool
Some services undergoing accreditation have found the Mapping to National Standards tool really helpful. If you haven’t already done so, visit our website and download this tool.

Another useful tool is key strategies and enabling factors, which enables services to identify areas for improvement and support needs. The tool assists you to identify factors at organisational, governance and practice levels that help to embed PCOC in routine policy, practice and quality improvement.

PCOC support with APC Abstracts
Are you considering submitting an abstract for the conference? PCOC is offering support and assistance to use PCOC data as evidence for project or quality improvement activities you’ve undertaken. Abstracts close on 18 April 2017. Please contact the PCOC team.

Patient Outcome report and Quality Improvement Visits
The patient outcome reports for the July to December period are now being distributed. The team will once again be visiting services in NSW to present the reports and facilitate discussions on ways to improve patient and family outcomes. We are looking forward to working with you on quality improvement plans.

We are very interested in working with services to share information and link services on their quality improvement activities. If you are currently undertaking or are interested in collaborating with other services on quality improvement activities, please contact us.

Benchmarking workshops
One of the highlights for the PCOC year is benchmarking workshops where services have the opportunity to share ideas for improving patient outcomes. Recent workshops held for inpatient and consult services were a success.

If you want any information from these, please contact us. We will be holding benchmarking workshop for community services in Sydney on Thursday 25 May 2017 and will be sending out invitations soon.
PEPA Update

Memories of the fantastic NSW Palliative Care Biennial Conference in Broken Hill linger in the back of my mind as we move to the end of the current iteration of funding. There is still opportunity for Specialist Palliative Care Service to work in conjunction with PEPA NSW to deliver education sessions targeting a Palliative Approach in Aged Care and Palliative and a Palliative Approach Yarn-up for Aboriginal Health Professionals. If this is a group you would like to engage further with please let me know.

PEPA NSW observational placements are available to all non-palliative care specialist providers across the State. The short (3–5 days) observational placement is available to Nurses (CNC, CNS, CNE, RNs, EENs, ENs), Doctors (interns, residents, registrars, GPs, non-palliative medicine Specialists), Allied Health and Aboriginal Health Professionals. An application kit can be downloaded via the PEPA NSW webpage or by contacting PEPA NSW. Currently, all placements and education sessions need to be completed by 30 June 2017 so get your applications in ASAP!

Email: janeen.foffani@sswahs.nsw.gov.au
PEPA NSW: www.slhd.nsw.gov.au/services/pepa
PEPA National: www.pepaeducation.com

Janeen Foffani
PEPA NSW Project Manager

palliAGED is coming soon!

palliAGED is a new website being developed by the Palliative Care Aged Care Evidence (PCACE) project. The project is funded by the Department of Health.

Australia produced the first evidence-based guidelines relating to palliative care in residential aged care (APRAC Guidelines 2006) and for older people living in the community (COMPAC Guidelines 2011). They showed how a palliative approach can help improve care for older Australians at the end of their life.

The new palliAGED site will be released in May 2017. It will provide palliative care and end-of-life guidance within an aged care context. You can also register for a launch pack on the CareSearch website.
It was very pleasing to hear that the vast majority of you are either very or extremely satisfied with what we are doing in providing information to you, our members, as the highest level of satisfaction and the provision of education/information to both the public and health professionals as being an area we could improve in.

In terms of relevant activities, my regular email updates won hands down, followed by Pallium and state and national conferences.

The major issues facing us over the next 12 months were workforce and euthanasia/assisted dying and the lack of information about palliative care relating to those two issues.

In terms of the next three years, workforce and funding were indicated as the two key issues facing palliative care.

An electronic Pallium was given an overwhelming support so we will make that happen with this issue. You will be receiving this as an attachment to a member email but will also be able to download it from the website.

Finally – the messages for the Management Committee ranged from ¼ of respondents heaping praise on us to wanting better and broader engagement with you and more education generally.

For a more detailed report, please read the following data summary and analysis.

The vast majority of you are either very or extremely satisfied with what we are doing in providing information to you, our members.
Q3. How satisfied are you with how Palliative Care NSW carries out the following activities:

Overall, respondents are very satisfied with PCNSW activities. When asked what other areas of activity they would like to see PCNSW involved with:

- 56% of respondents cited the need for more information or education. Of these, 56% want this directed to the public, 33% want this directed to health professionals and 22% want this directed to the government.
- 1 respondent suggested PCNSW work with health funds to increase understanding about how elderly people would benefit from a palliative care team providing a holistic support system rather than a narrow focus on only their physical rehabilitation needs.
- 19% mentioned the need for more coverage and support in rural areas.
- 19% want PCNSW to put more pressure on the government, lobbying for better funding and support for palliative care.

Q4. How relevant is each of the following activities of PCNSW to you?

Email updates are the most relevant activity for members with 83% of respondents answering very or extremely relevant to them. This is higher than the Pallium for which only 70% of respondents thought was very or extremely relevant to them.

The Biennial State Conference and the National Conference also rate very well as the second and third most relevant activities to members. Respectively, 80% and 75% of respondents rate them as very or extremely relevant to them.

36% of respondents say National Palliative Care Week is only slightly, somewhat or not at all relevant to them.
Q6. What do you think are the major issues facing palliative care in NSW in the short term (12 months)?

49% of responses mentioned a shortage of resources as an issue.

“Shortage of beds in hospitals for palliative care patients”
“Chronic shortage of specially trained doctors”

Of these, 22 answered that the deficit of trained staff was an issue, 15 respondents were worried about a lack of funding.

“Ongoing funding of services especially in rural and remote areas”
“Heavy workloads, and no funding for more staff or resources”

Euthanasia and/or assisted dying was mentioned by 33% of people.

“The public need to be more aware of palliative care so they know the difference between assisted dying and palliative care”
“I work in a palliative care ward I have heard several people say they would like it to end it so their suffering would stop”
“EOL issues being drowned out by superficial emoting about voluntary euthanasia”

16% of respondents mentioned better education as a major issue. 7 of these wanted better education for the public and 6 of these wanted better education about palliative care for those working in the aged care sector, especially RACFs.

“Community education on End of Life issues”
“Helping... nurses understand palliative care is not death and dying... but symptom management in all chronic diseases”

12% of respondents called for better palliative care in aged care, especially RACFs.

“Referrals from aged care to palliative care doesn’t happen enough”
“Models of care that support palliative care in RACF’s... PCNSW can advocate for this”
Q7. What do you think are the major issues facing palliative care in NSW in the medium term (3-5 years)?

The biggest concern was with funding and resources with 31% of respondents mentioning this as a concern.
“Government commitment to funding palliative care in the public sector”
“Funding for the regional sector as well”

The next biggest concern at 27% respondents was for a deficit in the workforce. Staffing shortages are attributed to stretched resources, experienced staff retiring, the need for more specialist staff especially in rural/regional areas, and a lack of engagement with younger health professionals and trainees.

“How do we engage younger health professionals to pursue the speciality of Palliative Care? Universities not providing comprehensive in Palliative Care mandatory units in undergraduate Allied Health, medicine, nursing and Social Sciences”

“Specialist staff shortage and training needed in Palliative care, doctors, nurses and volunteers.”

“Lack of adequate staff in terms of academic qualifications, experience and numbers.”

There was recognition that with the population ageing there would be an increased demand for services. 26% of responses were concerned with improving palliative care services for the frail aged.

“Increase in the number of frail aged needing palliative care demands from the baby boomer tsunami”
“Growing need in aged care for palliative care approaches”
“Sustaining the workforce in light of increasing demand and expectations on an already under-resourced service”

40% of respondents raised the issue of more training needed, within palliative care but more so across multi-disciplinary fields, care sectors and for a broader range of health care professionals.

“Skilling all health professionals so it is a shared responsibility not just presumed it is a palliative care responsibility”
“Changing the opinion that ‘professionally’ palliative care is not my responsibility”

Q8. The debate about Euthanasia and Physician Assisted Dying continues in Australia with recent debates and bills notably in South Australia, Victoria and Tasmania. Please rate the following statements:

58 respondents disagree/completely disagree with supporting Euthanasia compared to 32 respondents who agree/completely agree.

56 respondents disagree/completely disagree with supporting Physician Assisted Suicide compared to 30 respondents who agree/completely agree.

More people agree/completely agree that PCNSW should oppose the introduction of any legalising Euthanasia or Physician Assisted suicide than disagree/completely disagree.

Although the responses are clearly weighted generally against supporting Euthanasia/PAD, there is more contention about whether PCNSW should be active in opposing any legislative changes.

“If we are asking primary, aged and acute care staff to deliver palliative care to a ‘palliative approach’ model we should be planning, training and resourcing those sectors to enable them to do it. This process needs to be more formalised and structured.”

“Medical training of ALL doctors in PC at degree level”

“Supporting a palliative approach within the generalist and informal care sectors”
REPORTS

Q9. Pallium is currently provided only to members and only in printed form. There is a significant financial and environmental cost: Money saved could be spent on other member services eg bursaries. Please rate the following alternatives:

The results are overwhelmingly in support of an electronic only version of Pallium.

Q10. Finally, if there was one message that you would like the Management Committee of PCNSW to hear as they develop their strategic plan for the next 3 years, what would it be?

A quarter of respondents were filled with praise for PCNSW telling us to keep up the good work.

"Keep up the good work and get the word out there"

16% wanted better support and/or broader engagement with members as well as the broader health community.

"Staffing ratios in NSW need to be improved and we need your support"

"Support for those of us at the coalface"

"Increase engagement with stakeholders"

"I would love to see PCNSW take on the role of developing strengthening networks in the palliative care community"

13% of respondents thought education should be a focus.

"Continue education opportunities and conferences"

"Provide training at all levels from students to teaching hospitals and aged care"

The major issues facing us over the next 12 months were workforce and euthanasia/assisted dying and the lack of information about palliative care relating to those two issues.

CareSearch releases new pages on Aboriginal and Torres Strait Islander Care

A new set of pages supporting Aboriginal and Torres Strait Islander Care have been developed by the CareSearch Project Team with the support of the Aboriginal and Torres Strait Islander Reference Group for the Palliative Care Education and Training Collaboration (QUT). The pages bring together a range of resources and information to help the health care workforce and carers in providing palliative care to Aboriginal and Torres Strait Islander people. Culturally Safe and Responsive Care is the responsibility of all health professionals and The Care Journey reminds us that the person sits at the heart of the care. We should all find out more.
The NSW Minister for Health, the Hon Brad Hazzard announced earlier in April that the Ministry would be organising a series of round table discussions on palliative care.

The first of these was held in Sydney on 26 April and around 80 people accepted an invitation to attend.

The Ministry invited three people to sit on a pane to open proceedings. Carolyn Walsh (consumer), Linda Ora (CNC Palliative Care) and Professor Meera Agar (Professor of Palliative Medicine) all provided important insights into specialist palliative care from their experiences.

Dr Norman Swann was the facilitator for the day and did a great job of bringing out more from the panel and moving things along to get the most out of the day.

Following the panel presentations and ensuing conversations we moved on to sorting out the three top priorities for palliative care for each table and a comprehensive set of notes were taken by the Ministry representatives at each table and incorporated into slides that will form the basis of future work once all round tables have been held.

As might be expected, several areas of overlap occurred including in no particular order – palliative care needs to be core business for RACFs, IT infrastructure to improve communication between services, GPs to be supported to provide primary palliative care and the specialist workforce needs to increased.

Thank you to the Ministry staff for working hard to get this organised in a very short time. It was all hands to the pump on the day and I think the room was impressed with how quickly and professionally the day was organised and run.

Some comments from participants during the day:

“Carers tell me that they want to help their loved ones to die at home but its hard graft”.

“A lot of Palliative Care occurs in the home but we don’t have the (GP) resources for that...it’s not in the GP business model, especially for younger GPs”.

“GP are effectively the medical case managers in community care”.

“There is really two Palliative Cares – generalist and specialist”.

“Doctors don’t know how to say no, or are too scared to say no, to (futile) treatment. Our specialists and doctors don’t need to (but should) learn about end of life care”.

“Many clinicians don’t want to have THE discussion (about end of life)...there is futile care everywhere. Sometimes we just need to get back to basics and talk about futility because this is not something that we can expect the community to understand.”

“Advance care planning and coordination is something that would save the health services a lot of money, a LOT of money. It needs to be resourced though and there needs to be triggers to have the ACP conversation like age anniversary or entry to RACF”.

Closing comments by Minister Hazard:

“(I think) mostly we are doing reasonably, but there is so much more we can do, and I think that is probably what we will see as we tailor across each of the next 8 forums. It will be really important to get the regional perspective. When we are in this (Metro) area we have amazing resources with our various community outreach plus our hospitals (but) it can be a lot more difficult in some of the remote areas, Broken Hill for example, it will be quite fascinating to hear (their feedback).

“The fact of the matter is there are different issues within each of the different components of our system. For specialist, whether you’re a renal specialist or coronary specialist or whatever specialist you are, the challenge is ‘at what point do we integrate (palliative care)’? One of the lessons that has come out for me is that it’s got to be much earlier on.

“From our earlier discussions it seemed to me that it was either community nursing or palliative nursing and yet I know that community nurses (are given) absolute trust to walk through the door, so it seems to be that perhaps there are opportunities there to train up more community nurses in palliative skills. All these things are yet to unfold, but I’m quite excited about it.

“I’ve really enjoyed listening to the experts, the consumers – the consumers who are experts – the nursing staff, the medical staff and all of the advocacy bodies who are here.”
Silence

Ashen faced and owl-eyed, she sat by the window staring vacantly. Mrs S (a pseudonym) was a woman who was much younger than first appearances would suggest, but you would not know it by her gaunt frame, the numerous worried lines on her brow that had become more pronounced over recent weeks, her sunken sallow cheeks. I could tell from quite early on that this was a woman who was dying, and indeed suffering terribly. Acutely aware of my limited life experiences, my own fears about death and not really knowing how I could help this woman, I gather the courage to introduce myself nonetheless. “I’m Lawson, I’m a palliative care volunteer” I began, before being cut off. “Please have a seat,” she replied with a weak smile. Taken aback, I drew a seat by her bed and sat next to her. Silence is something I had never befriended – acquainted of course – but never comfortable enough to sit down with. I sat there anxiously, not knowing what to say but hoping that somehow the words would come and fill the void, to perhaps in a small way heal some of her anguish. Where there’s emptiness, it seems to me at least that our instinct is to fill it because surely – surely, something is better than nothing.

Thankfully after some time, Mrs S opened her eyes and told me her story. The relief.

Our conversation took hours but it seemed like mere moments. She told me about her children, her grandchildren, her hobbies, her home... and then her deepest fears and insecurities, all the things she had wished she had done but did not – things that, given the understanding offered by the fullness of time that she could have done differently. And what if she’d be forgotten? What about her garden, surely there’d be weeds all over by now. And good grief, what about the children who needed their mother? What about her neighbours who didn’t know she had been readmitted to the palliative care ward?

I didn’t have any answers as she poured her heart to me, and not knowing any better, I offered to pen a number of letters that she could send to her friends. The effect was stunning – Mrs S sat up energetically, this time with a grin, wanting to know when we could get started. “Today?” she asked. “Now,” I responded sheepishly, baffled at how a simple offer could mean so much.

I sat down writing her words verbatim, and seeing her joy, we posted the letter with the hope her friend would be able to see her in the coming days. It was then that I realised, then and there, that this was something I was meant to do, something that was perhaps just meant to be. And then the silence came once again as Mrs S drifted off to much needed sleep. But this time the silence was different. It was easy.

Lawson Ung
Palliative Care Volunteer,
South West Sydney Local Health District,
Liverpool Hospital

Note from Palliative Care NSW:
If you have a story or reflection you’d like published on VolunteerHub please email Ros Bradley at stories@palliativecarensw.org.au. We’d love to hear from you!
Exploring cultural and linguistic diversity, palliative care and volunteers

How do palliative care volunteer services respond to the needs of culturally and linguistically diverse groups?

In late 2016 Megan Burke, PCNSW Policy Officer, interviewed managers in several Sydney Metropolitan services (health and aged care) involved with volunteers to gain an insight into: how different services provide palliative care to CALD patients and their families; how they utilise CALD volunteers; and explore attitudes on how culturally and linguistically diverse needs are addressed within palliative care in the context of death and dying.

The telephone survey helped us to understand CALD related concerns by exploring the comments of respondents about how need is assessed and met. One of the challenges was how to identify that a person was CALD and if that implied a differentiated approach to care.

“For me it’s about recognising a surname sometimes”

“We’re not really focused on meeting the CALD needs, we do respite and companionship, the nurses need to do that not the volunteers... for me I meet all their needs individually, I don’t give anymore to that [CALD] group than any other”

There is general consensus in the literature that many health services are underutilised by those from ethnic minorities and this applies to palliative care as well. This was reflected in the survey findings, noting that 50% of services did not believe their local demographic was accurately represented by the patients accessing their services and similarly by those volunteering.

The study also illuminated some interesting examples of the unique companionship needs of CALD patients and their families, and some creative responses by volunteers in order to meet the needs of CALD patients, where language and communication are a challenge:

“There was one case, where a patient, a gentleman who only spoke Italian had an Australian/Lithuanian volunteer, they couldn’t communicate with the same language, but the gentleman understood that he [the volunteer] was there for him. Then one day, the volunteer brought in his neighbour, who was Italian to come and talk with the patient in his own language – Where there’s a will there’s a way”

The above quote also illustrates that different understandings of formal care within different groups is one of the challenges for volunteer managers and volunteers. Some respondents talked about their efforts to respond to specific needs:

“Just recently colleagues and I met with three women from the Muslim community here locally, who are very active – and talked to them about palliative care volunteering... we have asked them to look at the application, training and suggested they attend training next March.”

Megan closes by adding “With further community education that seeks to demystify the role of palliative care there will be more equitable access for all. For CALD communities that have additional hurdles to overcome, including language barriers, isolation, racism or religious discrimination this task will be more challenging but not impossible. Palliative care services will need to develop policies and programmes that work with emerging and ever changing societal trends such as ageing and increasing cultural diversity by embracing the uniqueness of Australian society.”

Megan’s report will be available soon on the Volunteer Support Services Programme website: www.volunteerhub.com.au.

In the two years since we published our first resource on VolunteerHub we have recorded some 1800 downloads.

The most popular download has been the Sample Policy Manual for NGOs published in 2015 (545 downloads) with Palliare: A Handbook for Palliative Care Volunteers also published in 2015 (220 downloads) and our very first resource A Snapshot of Palliative Care Volunteering in NSW 2014 (177 downloads) also popular.

Our Palliative Care Volunteer Quiz series was published early in 2017 and has so far attracted 160 downloads.

Our research reports have also attracted some 200 downloads across: Paediatric hospice volunteering; the views of Service Development Officers of volunteers; the experience of other non-palliative care volunteers working with people at or near end of life; the life and death of a palliative care volunteer service in the bush; our reviews of volunteer-led community Hospice; and aged care, palliative care and volunteering.

Since 2014 the Volunteer Support Services Programme has studied, reported on, blogged about and developed resources to address the experiences and challenges of the 1600 or so palliative care volunteers in NSW on VolunteerHub and our followers include people in the UK, USA, Canada, Germany, Denmark, Netherlands, South Africa, Qatar, Jordan, Malaysia, Indonesia, China and Australia.

In the two years since we published our first resource on VolunteerHub we have recorded some 1800 downloads.
I recently had the opportunity to meet with Rosalind (Ros) Bradley, author of *A Matter of Life and Death: 60 voices share their wisdom*. The book is presented as a compilation of reflections and narratives by people from various countries and backgrounds sharing their wisdom and perspectives on death ... yet as the title suggests, the reflections are as much about life, as death.

Meeting in a Sydney café for a cup of tea, I found Ros to be a petite, friendly and gentle lady. Born in the UK but resident in Sydney for over 30 years and with a work-life centered around people and volunteering, Ros found herself pondering the existential aspects of life and death after her mother died suddenly during a visit to Sydney. For Ros those few days, coming just after ‘September 11’, were profound: “One day we were walking past the Opera House, and the next day she had a cardiac arrest and died”.

With emotion gently cushioning her words, Ros spoke about her anxious time in the Emergency Department waiting room as staff tried to revive her mother, and then being taken to a room the size of a broom cupboard to view her mother after she had died. Her mother was the first deceased person she had seen. For three years after her mother’s death, Ros experienced physical symptoms that she now relates to her grief. The death of two friends a few years later fuelled her need to further explore and question the meaning of life and death.

As the author of two previous books, this search for answers led Ros to invite sixty people to share their experiences and views about death to include in this, her most recent publication. With a forward penned by Archbishop Desmond Tutu, the book is in five parts: Personal Encounters with Death; Death Brings us Wisdom; Working Closely with Death; Death and the Circle of Life; and finally, Death is Sacred. This final chapter presents views from a multi-faith and multi-cultural perspective.

The contributors range from diverse backgrounds, and as Ros suggests, “All have their own take on death,” but all share the common experience of death as part of their life’s canvas. Lay people, artists, coroners, funeral directors, intensivists, palliative care workers, counsellors, spiritual leaders, a midwife, a soldier, a Holocaust survivor and a death row inmate to name a few, have all provided their insights on the mystery but inevitability of death.

In a creative and rather comforting approach, Ros invited each person to contribute a passage or image that was significant about what death means to them, and then provide a reflection on that piece from their own experience or from their spiritual base. The reflections are insightful, sensitive and thought-provoking. A short bio follows each contribution.

Olga, a Holocaust survivor whose mother died moments after they were registered as survivors from a war camp, speaks of her despair at witnessing so much death and then her guilt at surviving, but how she now teaches others to care for Holocaust survivors in nursing homes. Sydney’s very own Dr Frank Brennan, Palliative Care Physician, narrates a poignant story of a young man facing his own death a few months after his father died, and the family’s struggle with compounded grief. A French Trappist monk captured and murdered in 1996 during the Algerian Civil War recorded his final testament before his untimely death, and his views about life and his prophesized death are included.

Ros hopes that these reflections might “… help dispel some of the fears that surround death and dying and … encourage us to speak out more about this often avoided and delicate subject”.

As a Palliative Care health professional for over 30 years I believe there is obvious relevance and timeliness of this book as our society slowly but increasingly engages in conversations about dying. And as an avid reader with a love of prose, I found Ros’ use of verse and narrative non-threatening, easy to read and comforting despite the ‘traditionally’ taboo subject matter.

“I am not afraid of death. I know so many people there”. (Amy, eight year old Norwegian girl)

In offering different perspectives on death the narratives will resonate with most audiences and allow the reader to further explore their own beliefs at a time and pace that suits them. More broadly the text has enormous potential as a teaching tool; for professionals (health and non-health sector), volunteers, students and those providing counsel to the dying or bereaved. Its value may be in its use as a prompt for individual or group discussion, or through use as a template for a similar approach to creative writing about death.
With a little bit of help: Meeting the challenges of grief and bereavement in Western Sydney

As time grew short and our cups empty I asked Ros if she found the answers for which she was searching? What messages did she find in the writings of her contributors? Without hesitation she replied “Death is part of life”; don’t live with regrets; be more authentic in our lives and relationships; say ‘I love you’ more often; and live in the present”.

Not surprisingly, Ros’ messages have more to do with life than death. Maybe that is what matters?

“For life and death are one, even as the river and the sea are one”
Kahlil Gibran, The Prophet

Melissa Cumming
Palliative Care NSW Management Committee

A Matter of Life and Death: 60 voices share their wisdom can be purchased from most leading bookstores or at www.footprint.com.au

All royalties from the book go to Ashgate Hospicecare in the UK where Ros’ dear friend Deborah died in 2008.

Author: Rosalind Bradley
Jessica Kingsley Publishers, UK.
1st Edition 2016, 232 Pages
ISBN 978 1 84905 601 4

In an average year Kristin Bindley oversees five memorial services across two sites in Western Sydney Local Health District involving some 820 invitations to recently bereaved families.

Although the scale of Kristin’s task has been made a little easier with the recent introduction of a palliative care volunteer service, this is just one part of Kristin’s role as Bereavement Counsellor for the sprawling Western Sydney catchment.

Importantly her day job is to be actively involved in individual counselling for grief and bereavement.

“There are about 800-900 deaths known to our service across the area in a year.”

Western Sydney is one of the largest, fastest growing, and most multicultural local health districts in NSW with a population of about a million people. In Blacktown less than half the residents speak only English at home.

These statistics bring enormous challenges for the health and wellbeing of the community, and Kristin is a keen advocate for community awareness-raising about grief.

“Grief can have profound implications for the public health of the community, and part of the challenge is getting people to understand how grief can impact health.”

Amongst other things she is keen to develop collaborations within the community as a means of spreading the word.

Kristin is also involved in a longitudinal study under a team of researchers that considers the effects of grief after expected and unexpected death.

Public health and palliative care volunteering

Alex Huntir and Linda Hansen from Palliative Care NSW have recently been accepted to speak about volunteering and public health at the Public Health and Palliative Care International (PHPCI) Conference in Ottawa, September 2017.

With a mere three months left to run in the Volunteer Support Services Programme one of our final tasks is to draft the Statewide Framework for Palliative Care Volunteering in NSW. The Statewide Framework will feature in the PHPCI presentation, as outlined below. Maybe we will see you in Ottawa?
International calendar of events

May 2017
19 May
2017 NSW Palliative Care Volunteer Conference
Maitland, New South Wales
www.expressionsofcare2017.com.au

10–12 May
Australian and New Zealand Society for Geriatric Medicine ASM 2017
Rotorua, NZ
www.anzsgmconference.org/registration-2017

18–20 May
European Association of Palliative Care EAPC 2017
Madrid, Spain
www.eapc-2017.org

26 May
PCNSW Professional Education Forum
Campbelltown Hospital, Sydney
www.palliativecarensw.org.au/Prof_Education_Forum17

June
2 June
28th Annual Supportive and Palliative Care Conference
Penrith, New South Wales
www.bit.ly/2pzSO07

5–7 June
International Death, Grief and Bereavement Conference
La Crosse, USA
www.uwlax.edu/conted/dgb

15–17 June
Cancer Nurses Society of Australia 20th Annual Congress
Adelaide, South Australia
www.cnsacongress.com.au

28–29 June
ICELC 2017: 19th International Conference on End of Life Care
Dubai, UAE
www.waset.org/conference/2017/06/dubai/ICELC/home

11–13 June
International Conference on Opioids Call for Presentations
Boston, USA
www.bit.ly/2qneVJW

July
26–29 July
Asia Pacific Hospice Conference
Singapore
www.aphn.org/asia-pacific-hospice-conference

September
6–8 September
2017 Palliative Care Australia Conference
Adelaide, South Australia
www.pca2017.org.au

6–9 September
Advance Care Planning and End of Life Conference ACPEL 2017
Banff, Canada
www.acpel2017.org

13–15 September
2nd International Conference on End of Life Law, Ethics, Policy and Practice
Halifax, Canada
www.icel2halifax.ca

17–20 September
Public Health and Palliative Care International Conference
Ottawa, Canada
www.iphpc2017.com

October
6 October
The Annual Marie Curie Palliative Care Research Conference 2017
London, UK
www.mariecurie.org.uk/research/annual-research-conference

9–10 October
Palliative Care Nurses New Zealand Conference 2017
Wellington, NZ
www.eenz.com/pcnnz17

Advertise in Pallium
Quarter page (internal): $300 +gst
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Half page (back cover): $650 +gst
Full page (internal): $850 +gst

To discuss or secure advertising space please contact Linda Hansen:
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Treasurer: Michael Edgar

Committee Members: Colleen Carter, Janelle Chruszcz, Melissa Cumming, Gerry Dixon, Peta McVey, Deborah Parker, Joan Ryan.

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