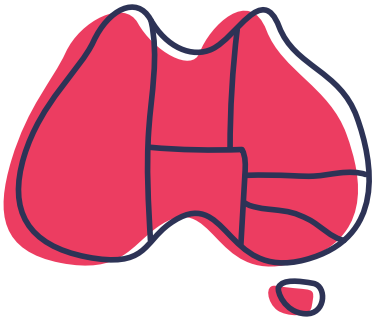
PCOC

palliative care
outcomes collaboration



PCOC 2017 Annual Report

Evidence based improvement of patient, family and carer outcomes

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PCOC is funded by the Australian Government Department of Health

MESSAGE FROM
THE EXECUTIVE DIRECTOR

Professor Kathy Eagar



As Executive Director of the Palliative Care Outcomes Collaboration (PCOC), I am pleased to present the 2017 annual report. This year was one of high activity for PCOC - you will find the accomplishments and achievements of both the team and palliative care services are comprehensively described throughout this report.

I'm pleased to announce that in July 2017 PCOC achieved their funding goal as the program was extended through to 2020. I would like to thank the Australian Government Department of Health for their support. This achievement will allow for exploration of new oppportunities, partnerships and directions. As we look to the future of palliative care in Australia, PCOC will continue to work to improve outcomes for patients, families and carers and proudly operate as a key contributor to the national conversation surrounding palliative care.

My thanks go to the entire PCOC team for their excellent work in 2017. I would also like to acknowledge the Chief Investigators for their ongoing leadership and support. We also thank those service providers, consumers and industry partners who collaborate in our projects, use our research outputs, provide us with constructive feedback and help us to improve.

PROFESSOR KATHY EAGAR

Director, Australian Health Services Research Institute
Executive Director, Palliative Care Outcomes Collaboration

PCOC program overview

As the national evidence hub on patients' daily pain and symptom outcomes in Australia, PCOC is recognised as a worldwide, leading authority in palliative care outcomes. PCOC is a national palliative care program funded by the Australian Government Department of Health and is a collaboration between the University of Wollongong, University of Western Australia, Flinders University and Queensland University of Technology. In July 2017, continued funding of the program through to June 2020 saw a change in collaboration partners – from Flinders University to the University of Technology Sydney.

PCOC holds information on pain and symptom control for more than 250,000 people who have received palliative care over the last decade. Fundamental to the program is patient reported outcome measures (PROMs) and driving systematic improvement in patient, family and carer outcomes through benchmarking.

This report aims to highlight key achievements of the program and to recognise the work of participating palliative care services throughout 2017.



How the program works

- Palliative care services working with the program agree to use a data set established by PCOC
- Services are educated in the PCOC assessment framework, which uses five validated tools to measure patient function and performance, palliative care phase and symptoms and problems for patients, carers and their family
- Services measure outcomes that were developed in collaboration with the specialist palliative care sector and include the PCOC assessment framework tools
- Services submit their data twice a year. This data is obtained from their assessments and includes other descriptive information
- Feedback is provided to services about their reports by PCOC Quality Improvement Facilitators through advanced workshops, service visits or via phone
- Clinicians use the information PCOC produces to measure the effectiveness of the care they provide and to continually improve the palliative care provided to patients and their families

Case Study #1: **Service model affirmation**

A large metropolitan service managed by a new medical director and team. The director chose to implement a model which was seen as optimally successful in multiple other services managed by this team. The initial PCOC Patient Outcomes Report proved the efficacy of this decision with an extremely high percentage of benchmarks met. The two subsequent reports have also further demonstrated the success of the externally introduced model. The reports presented to Executive Hospital Management were received well.

Since 2008 the number of palliative care services participating in

national benchmarking

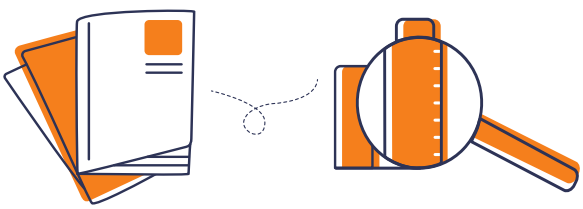
has increased from 54 to 120



In the media & website

The euthanasia debate sparked an interest in the data generated by PCOC; however, this data was misrepresented. In response, an article was published in the academic media outlet, *The Conversation*. This article dispelled the myth that people are in severe pain when they die, "No, most people aren't in severe pain when they die" (Eagar, Clapham, Allingham 2017). The evidence from PCOC data about palliative care is that pain and other symptoms, such as fatigue, insomnia and breathing issues, actually improve as people move closer to death. More than 85% of palliative care patients have no severe symptoms by the time they die. Radio interviews were also conducted along the same theme.

The PCOC website has been revised to allow better access to relevant information for target audiences on the outcomes achieved by palliative care in Australia. An evidence hub page was created which provides a platform to engage with more contemporary conversations about end of life care.



Evidence for palliative care

There is a significant body of evidence from PCOC that Australian palliative care has achieved statistically significant improvements over the last decade in pain and other end of life symptoms. This is due to several factors linked to more effective palliative care, including thorough and regular assessments of patient and family / carer needs.

The evidence shows palliative care is highly effective. Fatigue is the most common symptom that causes patients distress – in 2016, 13.3% of patients reported feeling severe distress due to fatigue at the start of their palliative care episode. This was followed by pain (7.4%) and appetite (7.1%) problems. Distress from fatigue and appetite is not surprising as a loss of energy and appetite is common as death approaches. For the vast majority of people, pain can be effectively managed.

How many people receive palliative care?

Each year in Australia, about 160,000 people die and around 100,000 of these deaths are predictable. Of those, 40,000 patients receive specialist palliative care and 60,000 do not. Patients may receive palliative care for years, months, weeks or days before death. Palliative care is highly effective for those patients who receive it.

Common symptoms and problems

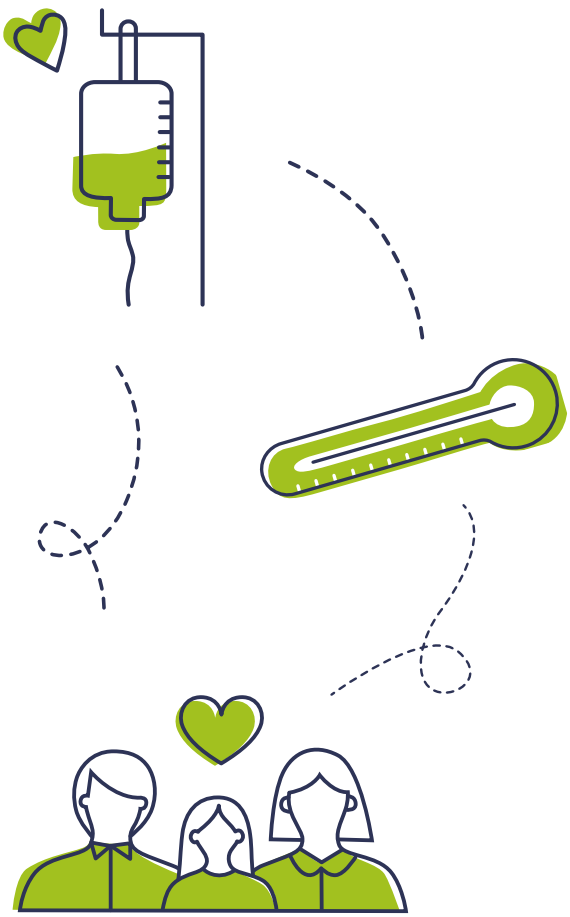
Palliative care clinicians use standardised patient and family / carer assessment tools to assess and respond to each patient's needs. PCOC measures outcomes for pain, physical symptoms, psychological and spiritual needs, as well as family and carer outcomes. We also measure outcomes for patients as they move between home and hospital. Fatigue is the most common symptom.

The most common reason for going to hospital for palliative care is when symptoms and problems develop that can't be managed at home.

What are the experiences of patients in their last few days of life?

Over 80% of patients receiving palliative care do not have severe symptoms at the time of death. Only a small proportion experience severe symptoms and evidence shows these symptoms either become absent or mild as death approaches.

When patients are referred to palliative care about 9% experience severe pain but this reduces to approximately 2% prior to death. Patients in their final days and hours receiving palliative care experience less pain, symptoms and problems than earlier in their illness. See Figure 1 on following page.



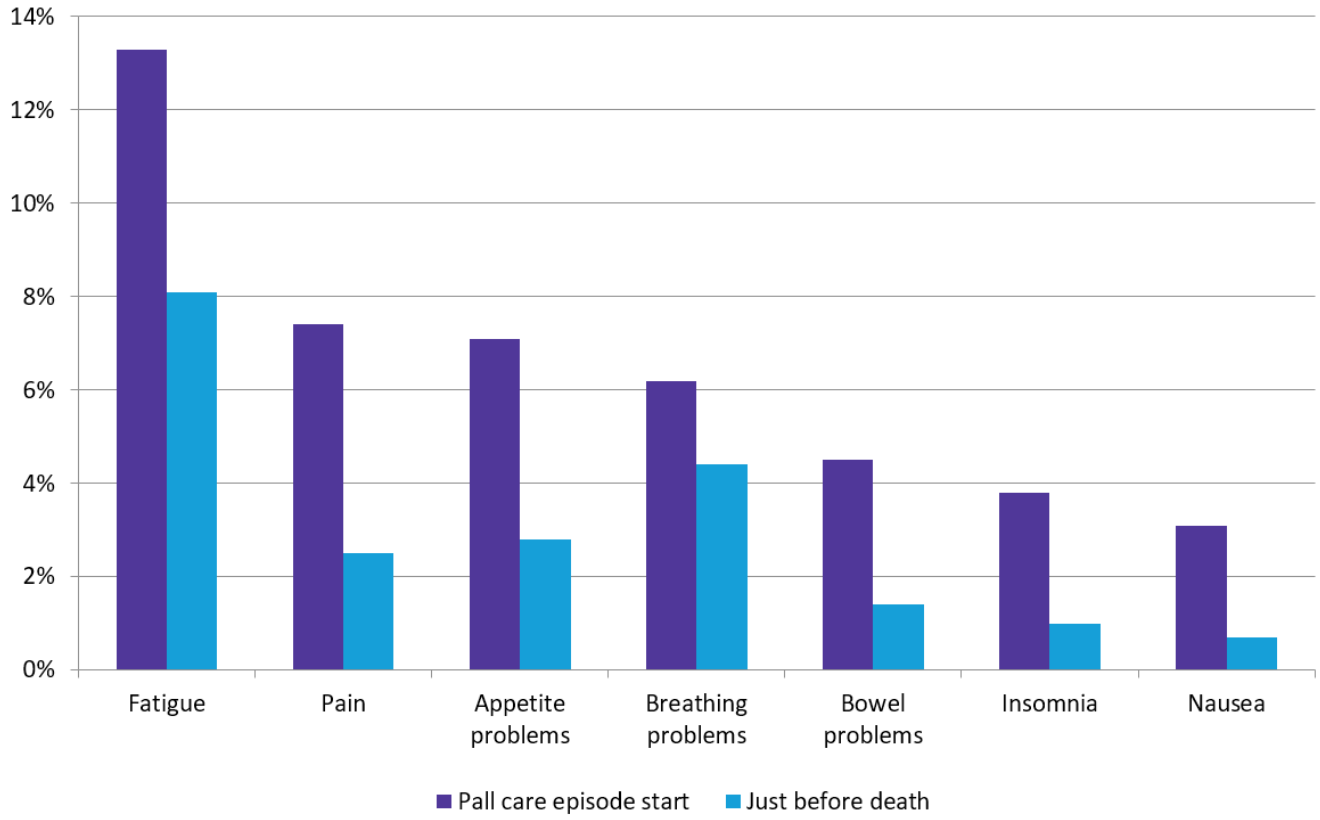


Figure 1: Proportion of patients (%) reporting side-effects at start of palliative care, and at end of life

Note: PCOC commonly reports outcomes at the phase level, and so you may have seen similar graphs in other reports. However, the results shown in Figure 1 take a different perspective, looking at changes between the start and end of episodes in which the patient died. Results for hospital/hospice and community settings have been combined. The dark purple bars show the percentage of severe symptoms at the beginning of the episode, whilst the light blue bars show the percentage of severe symptoms just prior to death.

Case Study #2: **Service amalgamation**

A regional health authority made the decision to change focus of their palliative care unit to also include a slow stream rehabilitation / early terminal patient cohort. The clinicians who came from the rehabilitation unit to work in the conjoined palliative care unit had very little specialist palliative care knowledge or expertise.

Mentorship programs and specifically tailored education were established and provided for staff. Ongoing audits and evaluations were conducted. The PCOC daily assessments were monitored closely to ensure patient care remained at usual high levels. Following this integration, the PCOC Patient Outcome Report showed no difference or reduction of the usual, long term consistently high results achieved by this service.

Research & project highlights

The following is a summary of PCOC's research, project and educational initiatives for 2017.

- PCOC presented a paper at the 2017 Australian Palliative Care Conference in Adelaide titled, *Predicting bowel problems at the very end of life.*



Pippa Blackburn & Clare Christiansen at the PCOC booth.

- A research study was commenced investigating the prevalence of patient reported symptoms and relationship between preferred language and functional status.

- A study on perceptions of the care received from Australian palliative care services was published, using survey data from PCOC.

- Other research topics using PCOC data included studies on palliative care in adolescents and young adults, delirium, and outcomes for patients with neurological diagnoses.

- In 2017, PCOC embarked on a national project relating to one of the assessment tools – the Symptom Assessment Scale (SAS). The SAS measures the distress of the patient in relation to their symptoms (e.g. pain, fatigue, etc). The aim of Stage 1 of the project is to estimate the percentage of SAS assessments that are completed by proxy (a family member or clinician rather than the patient) and explore the factors associated with proxy assessment.

PCOC invites services to partner with us to undertake research. If you have a research question or are working on an activity that you would like to progress to publication please contact us.

Education

Two new educational initiatives were introduced:

- The *Advanced workshop*, an interactive, face-to-face program designed for participants to utilise their PCOC reports to identify and undertake quality improvement activities. This style of workshop targets clinicians and managers who are already familiar with the PCOC tools.

- Development of *PCOC Essentials*, on-line learning modules for managers and clinicians to support an interdisciplinary approach to consistent and effective use of the PCOC tools. The modules enable learning about the benefits of PCOC, and how to implement, embed and sustain the program in their services. Due for release and implementation in May 2018.



System development

A new data entry and reporting platform called epiCentre (Electronic Patient Information Centre) has been developed. It is a custom-built software for entering and managing PCOC data. A range of new, on-site reporting functions, including patient and assessment summary reports, will assist in the interpretation of data. The platform promotes consistent terminology, processes and protocols among services participating in PCOC.

epiCentre features include:

- a user-friendly interface for entering patient and assessment information
- printable reports to track the patient journey
- a streamlined process of data extraction and submission to the Secured Online Submission platform
- the ability to review patients currently under the care of the service
- accessible user guides and FAQs for installation and data entry

Due for release in May 2018, epiCentre is available free of charge for any palliative care service, both hospital and community based.

Collaborations & benchmarking events

Collaboration is intrinsic to PCOC's work.

- PCOC welcomed a team of clinical allied health service managers from the Hong Kong Hospital Authority. The team attended a Fundamentals workshop and visited palliative care services in Sydney and Adelaide.
- In collaboration with palliative care services, conference presentations and posters were developed.
- Three benchmarking workshops for inpatient, community and consultation services were held, investigating ways to improve patient outcomes in palliative care by bringing services with similar models and characteristics together to share practices and lessons.



Attendees at the 2017 Benchmarking Workshop for community palliative care services.

International snippets

Portugal: The Portugese Oncology Institute sought permission to use the Palliative Care Phase assessment for the systematic evaluation of their palliative patients.

Spain: The Hospital Clinic of Barcelona sought permission to use the Palliative Care Problem Severity Score for a study.

India: Physicians in Mumbai, India requested use of the PCOC assessment tools for developing palliative care guidelines for rural populations as part of their comprehensive primary health care services. The guidelines are for rural communities where the backbone of service delivery is training village health workers and nurse-midwives, making for an 'exciting and challenging project'.

Singapore: St Andrew's Community Hospital requested use of the PCOC tools for benchmarking and quality improvement purposes.

Recognising achievements

Sydney Adventist Hospital receives award

Congratulations go to the team led by Julie Edwards and Dawn Hooper, Nurse Practitioners at the Sydney Adventist Hospital (SAN) for receiving the 2017 annual Adventist Healthcare Clinical Care Quality Award. Their project was titled 'Supporting patients' death in place of choice and measuring patient outcomes in community palliative care'.

The SAN Palliative Care Service used PCOC data to demonstrate improvements in patient outcomes. The SAN uses the PCOC Assessment Framework, which comprises a suite of validated clinical assessment tools specifically meaningful to palliative care patients, their carers and family.

Contribution from Dr Alison White - St John of God Murdoch Hospice WA

The PCOC standardised clinical assessment tools have become an invaluable part of our care plan at St John of God Murdoch community hospice. We have utilised the PCOC feedback to identify areas in need of improvement in our assessment and management of patients' symptoms and distress along with families and carers in need of increased support. We have increased the frequency of assessment using the PCOC tools and focused on the early identification of psychological and spiritual distress among our patients and families.

As a consequence of our increased attention to assessment of patient and family needs, we have greatly improved upon our outcome measures and we are meeting almost all of our benchmarks. We are particularly proud of our 2017 results. They indicate that our patients are spending very little time in the unstable phase which likely reflects our early identification of increased pain and/or other symptoms, patient distress and family/carer concern. This allows us to adjust our care plan accordingly in a timely fashion to meet the needs of patients and their families and carers.

Contribution from Eileen Harris CNS - St John of God Bunbury Hospital WA

Participating in PCOC enables our unit to assess patient outcomes, highlighting any areas of need. One of our most successful quality improvement initiatives came about from our voluntary participation in PCOC. Palliative care and PCOC acknowledge the key role that family/carers have and that this role can be challenging at times. PCOC measures this as family/carer problem severity scores (PCPSS). Recognising that family/carer distress negatively affects both the patient and the family, careful consideration is given to family/carer needs.

Over a two-year period, PCOC reports for our palliative care unit illustrated that family/carers were experiencing high levels of carer distress – consistently higher than the national average. With this information, we were able to examine why this may be occurring and what actions we could take to improve the family/carer scores. Over a 12-month period, changes including education regarding the importance of family/carer scores and recognition of the key role social work and pastoral practitioners play have resulted in significant improvements in the PCPSS scores for family/carers. With sustainable changes, the unit has now met this benchmark, evidenced within our PCOC reports.

Case Study #3:

Service relationship with external accreditation bodies

PCOC provided support to a large specialist rural community service with the Australian Council on Healthcare Standards (ACHS) on-site accreditation. Feedback to surveyors demonstrated the links to patient, family and carer outcomes and demographics within the PCOC reports. Continual improvement was strongly evidenced and supported by outcomes. The service achieved excellent ACHS results.

New additions to the PCOC team

Samuel Burns and Nesa Mossamet joined the team in 2017. We have also welcomed back Alanna and Anna from maternity leave.



New recruits: Sam & Nesa.



Alanna & baby Natasha overlooking the beautiful Wollongong coast line.



Anna & baby Summer at home in sunny Queensland.

PCOC Team

Chief Investigators

Kathy Eagar – University of Wollongong

Patsy Yates – Queensland University of Technology

Claire Johnson – University of Western Australia

David Currow – University of Technology Sydney

Management Advisory Board

Noel Hicks – Independent Chair

Amanda Bolleter – State Palliative Care Representative

Katy Clark – Clinical Director

Chief Investigators (as above)

Staff

Karen Quinsey – Director

Sabina Clapham – Quality & Education Manager

Fiorina Mastroianni – Quality & Education Manager

Sam Allingham – Statistician & Data Manager

Alanna Connolly – Statistician

Nesa Mossamet – Statistician

Sam Burns – Data Analyst

Linda Foskett – Administrative Officer

Lucie Thompson – Administrative Support

Gaye Bishop – Quality Improvement Facilitator

Pippa Blackburn – Quality Improvement Facilitator

Clare Christiansen – Quality Improvement Facilitator

Jane Connolly – Quality Improvement Facilitator

Anna McPherson – Quality Improvement Facilitator

Tanya Pidgeon – Quality Improvement Facilitator



PATIENT REPORTED OUTCOME MEASURES



OUTCOME MEASUREMENT REPORTING



SYMPTOM MANAGEMENT TOOLS



NATIONAL BENCHMARKING WORKSHOPS

Strategic directions for 2018

Funding for PCOC through to June 2020 will allow exploration of new opportunities, partnerships and directions in order to be responsive in the following contexts:

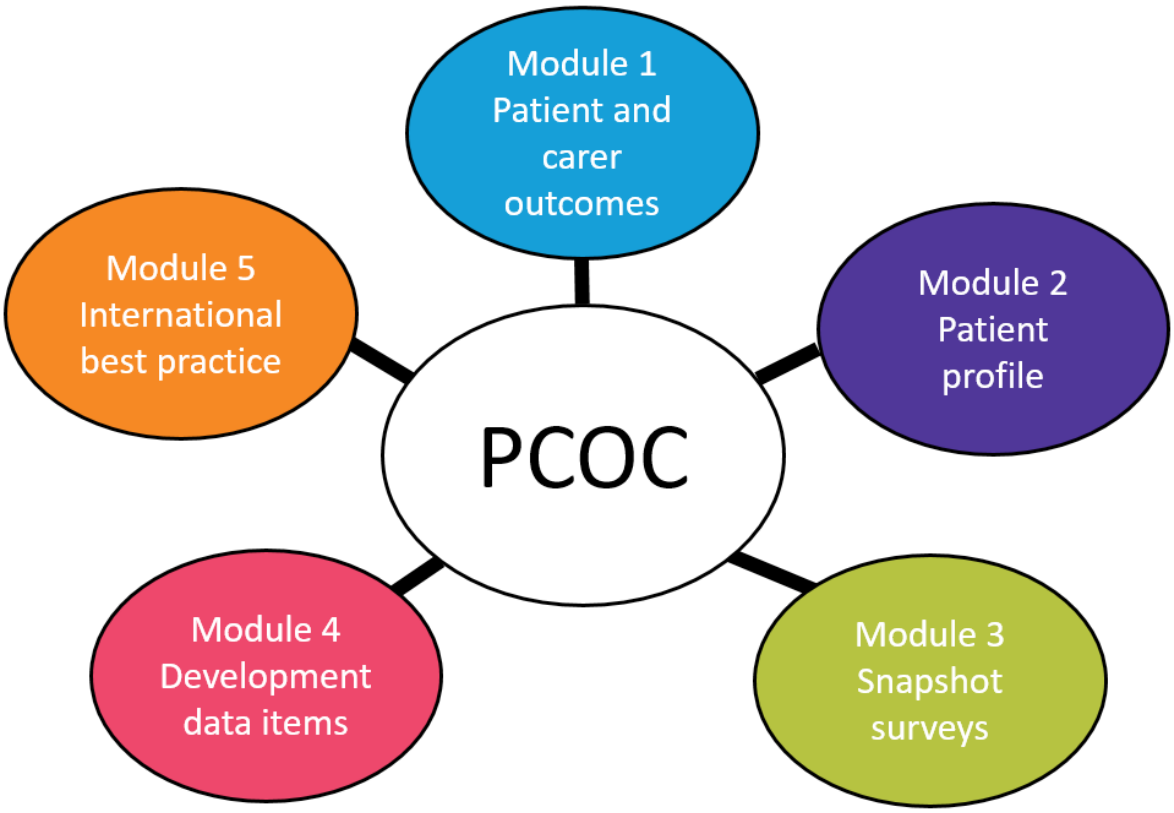
- The palliative care sector has undergone significant change over the last decade
- The national conversation about euthanasia has turned new focus onto palliative care
- PCOC has been in place for over a decade, and continued funding provides a strategic opportunity to refresh our overall approach and our role in the palliative care sector

In response, PCOC has reviewed its model and, over the next few years, aims to broaden its scope in collecting information on patients receiving palliative and end of life care in settings other than specialist palliative care and within different subgroups, such as;

- Acute care settings, such as intensive care units or general medical wards
- Primary care sector
- Aged care
- Paediatrics

By expanding the existing PCOC data set to enable participation from different sectors, the program will explore linking data with other clinical registries. PCOC will also introduce a new range of information targeted at the general public and patient and carers.

PCOC model 2018 - 2020: PCOC aims to broaden its scope through collecting information on palliative care patients in other settings and within different subgroups. The following modules will enable PCOC to provide a bespoke package tailored to the individual needs of services and respective sectors.



Publications 2008 - 2017

Journal Articles

1. Eagar K, Clapham S and Allingham S (2017) No, most people aren't in severe pain when they die. The Conversation 11 December 2017, 1-4.
2. Pidgeon T M, Johnson CE, Lester L, Currow D, Yates P, Allingham S, Bird S and Eagar K (2017) Perceptions of the care received from Australian palliative care services: A caregiver perspective. Palliative and Supportive Care, 1-11 online ahead of print, doi:10.1017/S1478951517000177.
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16. Rawlings D, Hendry K, Mylne S, Banfield M and Yates P (2011) Using Palliative Care Assessment Tools to Influence and Enhance Clinical Practice. Home Healthcare Nurse, 29 (3): 139-145.
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Conference Papers

20. Eagar K (2017) Palliative Care Outcome Measurement in Australia – Experiences and Lessons. Hospice New Zealand Palliative Care Outcomes Symposium, Wellington, NZ, 17 February 2017.
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