PCOC 2018 Annual Report

Evidence based improvement of patient, family and carer outcomes
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As Executive Director of the Palliative Care Outcomes Collaboration (PCOC), I am proud to present our 2018 annual report. This was a fantastic year full of exciting new developments for PCOC. I would like to commend both the team and the palliative care services for the achievements that are highlighted in this report.

PCOC has become a very successful, mature research program, with the University of Wollongong leading the collaboration in partnership with the University of Western Australia, the Queensland University of Technology, and the University of Technology Sydney. We now hold patient outcome data on about 25% of all predictable deaths in Australia each year. At the unit record level, we hold data on 250,000 deaths and one million palliative care phases.

A steady stream of peer-reviewed publications are produced each year, as well as twice-yearly patient outcome reports for more than 100 palliative care services. In relation to research translation, we have evidence that pain and symptom control has improved across Australia by more than 10% since we introduced systematic patient outcome measurement and benchmarking.

I would like to thank the service providers, consumers and industry partners who collaborate in our projects, support our research outputs, and help us to improve. We’re all looking forward to another great year of achievements for palliative care.

SENIOR PROFESSOR KATHY EAGAR

*Director, Australian Health Services Research Institute*  
*Executive Director, PCOC*
Strategic directions for 2018 – 2020

PCOC is a national palliative care outcomes and benchmarking program. PCOC’s primary objective is to systematically improve patient outcomes.

The changing face of PCOC

2018 marked a new direction for PCOC with the scope of participation broadening to include acute, primary and aged care. This expansion was aided by PCOC’s move to a modular approach in 2017 (see figure below). The PCOC 2018 – 2020 model aims to continue to measure and drive improvements in patient and carer outcomes. At the same time, PCOC aims to capture profile data on other patients at end-of-life. This will help the sector gain a better understanding of both met and unmet need.

We will be working closely with sector partners at a national and jurisdictional level to embed the PCOC tools into any health setting where palliative and end-of-life care occurs.

PCOC Model 2018 – 2020
Cross-sectoral engagement

Engaging with the primary, aged and acute sectors

Development of the Profile Collection

An advisory panel was set up to develop, consult and test a new data collection to profile palliative and end-of-life care in Australia. The profile collection is purpose built to be used in any setting of care by a variety of health care professionals. It complements (but can be used independently of) the current PCOC outcome collection. Our advisory panel consisted of a broad range of clinical and policy experts from aged, primary and acute sectors.

The pilot phase for this collection is scheduled for 2019.

Primary care

PCOC and the Greater Choice for At Home Palliative Care Measure

Executive Director, Senior Professor Kathy Eagar and Sabina Clapham were invited to present to the Greater Choice working group in August 2018. Primary Health Networks (PHNs) were invited to collaborate with PCOC to implement the new profile collection. Four PHNs indicated their interest and two have engaged in using PCOC to support evaluation of the Greater Choice for At Home Palliative Care Measure.

More information on PHNs and the Greater Choice Measure collaboration can be found on the PCOC website.
**Aged care**

**Improving Choices through the Palliative Care Collective – Wicking Trust Project Partnership**

As part of the widening scope of PCOC into aged care we submitted a proposal to The Wicking Trust in August 2018. The proposal was to pilot the implementation of the PCOC program throughout multiple residential aged care facilities across Illawarra Retirement Trust (IRT) in the Illawarra Shoalhaven Local Health District (ISLHD). The application was successful with the project to commence in early 2019 and conclude at the end of 2020.

The project is a new collaboration between IRT and the two Australian Health Services Research Institute (AHSRI) research centres, PCOC and the Centre for Health Research Illawarra Shoalhaven Population (CHRISP). The objectives are to:

- Improve the outcomes and quality of life for those receiving palliative and/or end-of-life care
- Gain insights into IRT customer’s journeys while transitioning across settings
- Improve care provision and service delivery
- Improve customer choice and/or quality of life
- Build relationships, by growing communities of practice with aged care providers, GPs, the Ambulance Service of NSW, hospitals, and palliative care specialist services

**Online engagement**

**Engagement through our website**

In May 2018, PCOC launched a re-designed website, with the aim of streamlining access to relevant information about PCOC. This was done through audience segmentation into three identified groups: patients, families and carers; clinicians and service managers; and researchers and policy makers. Each of these groups now enters the website through a unique landing page which contains relevant information and resources. Graphic design resources were developed and incorporated to help establish a recognisable identity for PCOC’s online presence.

We also established a new ‘Log a Question’ function available on the website. This function enables anyone who has a question that cannot be answered by our online material to log a query, which is promptly replied to by a member of the PCOC team.

In addition, two email subscription services were created which notify subscribers of updates to PCOC reports or resources.

**National engagement**

**National Palliative Care Program (NPCP) Grant Recipients’ Forum, Canberra, February**

Sabina Clapham and Jane Connolly attended the NPCP Grant Recipients’ Forum, and presented on PCOC’s strategic directions. The Forum aimed to share details about each project’s anticipated plan of work for the next three years. The outcome was to identify actions to support collaboration and networking amongst grant recipients.
Research & development highlights

Revision of the Symptom Assessment Scale (SAS) tool

Thank you to the 16 services who participated in the revision of the Symptom Assessment Scale (SAS) tool. The tool incorporates Visual Analogue, Verbal Rating and Categorical Response Scales. These operate alongside the Numeric Rating Scale, which is the primary measurement for the tool. The tool has also been colour-coded to assist in interpretation; red indicates severe distress, yellow indicates moderate distress and green indicates absent to mild distress. The majority of staff (85%) were confident that patient-reported scores were accurate. Staff confidence improved with experience and seniority of clinical designation.

Palliative care encounter for hospital consult teams

Fifteen consultative services participated in the acceptability testing of the encounter collection, with 104 patient assessments completed and analysed. The findings resulted in:

1. Modifications to the items ‘Referral source’ and ‘Reason for referral’
2. Addition of two developmental items ‘Issues at time of assessment’ and ‘Action arising from assessment’
3. Optional assessments ‘RUG-ADL’, ‘SAS’

Capability Framework for provision of palliative, end-of-life care

Palliative Care Australia and PCOC have come together to work with the Australian Government Department of Health, the state and territory representatives, and leaders in the palliative care sector, to develop National Service Levels. The goal is to define a capability to meet population needs, set a standard for levels of service delivery and articulate linkages. The newly developed National Service Levels extend to six levels and cover a diverse range of clinical services across the public, private and non-governmental services.

The National Service Levels provide a common, nationally consistent language to describe capability and a framework for service commissioning and policy provision. Additionally, the levels provide a framework for improving patient outcomes through quality initiatives.

A sector roundtable was held in November to determine face validity with policy, clinical and service-provider experts. The greatest level of agreement was the identification of the linkages between levels. The roundtable also provided an opportunity for deliberation of the terminology with the National Service Levels.
Helicopter report update

The PCOC Helicopter Report was updated to reflect changes in trends over time. This report provides a high-level summary of key patient outcomes, and highlights the improvements achieved by participating palliative care services from 2009 to 2017.

(ABOVE: The new PCOC helicopter report)

palCentre

palCentre is a new data entry software, customised for use by PCOC services. palCentre allows services to enter data for analysis and reporting and promotes consistent terminology, processes and protocols among services participating in PCOC. The new user-friendly interface will replace SNAPshot software, which will be phased out by December 2019.

Research Article

BMJ Supportive and Palliative Care: Patient outcomes in hospital & home

Building on the research conducted for the 2017 article in The Conversation, Kathy Eagar, Sabina Clapham and Samuel Allingham published an article in BMJ Supportive and Palliative Care entitled ‘Palliative care is effective: but hospital symptom outcomes superior’. The research investigates symptom outcomes at the end-of-life, and demonstrates that care provided in a hospital or hospice setting achieves better outcomes than care provided at home. This is important information for policy makers and the palliative care sector, where the focus has traditionally been on people dying at home, rather than dying in their place of choice or where their symptoms are best managed.

Map of all services participating in PCOC 2006 - 2018
Recognising PCOC service achievements

Services participating in PCOC are committed to improving patient and family outcomes. Below are some examples of the achievements of services participating in PCOC and their staff.

Clare Holland House receives top ACT Quality Health Care Award

In February 2018, Clare Holland House Hospice was awarded ACT’s top award at the 2017 Quality in Healthcare ACT Awards. Clare Holland House was honoured for their work on implementing proactive models of palliative care and improving the delivery of safe, quality health services to the ACT community. This is an inspiring achievement and Clare Holland House is to be congratulated for their great work in improving care for patients.

WA Regional Achievement and Community Awards – Kimika Lee

Ms Kimika Lee, Aboriginal Health Worker in the Kimberley Palliative Care Consult service, was nominated by PCOC and won the 2018 Regional Achievement and Community Horizon Power, Leadership and Innovation Award. This is a fantastic achievement for Kimika and palliative care more broadly!

Yorke Peninsula & Lower North Region receives SA Premier’s Excellence Award

The Yorke & Lower North Region Community Nursing and Palliative Care Team was awarded the South Australian Premier’s Excellence Team Award. The award, presented by Premier Steven Marshall, was accepted on behalf of the service by Tim Garfield, Sue Kain and Shelley Tregilgas. The service was commended for their great work:

“In the absence of specialist palliative resources, this client-focused, generalist nursing team uses palliative care assessment tools to improve the identification of, and response to, deteriorating client symptoms. This approach has facilitated significant improvements in symptom management and reduced hospital admissions over the past decade. This successful collaboration is driving the assessment tool provider’s [PCOC] plans to expand this model of care to other rural communities nationally.” Quote from the CHSA CEO Bulletin.

Congratulations to the team at Yorke & Lower North for this fantastic achievement!
Recognition from the Health Minister for the services that met all PCOC benchmarks

Dr Annie Dullow (Director of Palliative Care, Department of Health), on behalf of Minister Hunt, corresponded in July commending the services that met all of the PCOC benchmarks for the period July to December 2017:

“This achievement is a testament to the dedication to quality improvement of staff in these services. I would like to acknowledge the exceptional contribution of the PCOC team in improving outcomes at the end-of-life for Australians.”

Minister for Health Greg Hunt expressed his support of PCOC:

“I am pleased to read of the continued success of PCOC. It is clear that the work of PCOC is making a significant contribution to the development of the palliative care sector and improving the outcomes at the end-of-life for Australians receiving palliative care. The international recognition bestowed upon PCOC is further testament to these accomplishments. I appreciate you bringing PCOC’s successes to my attention.”

Megan Jeon receives COGNO18 Conference award for best poster

Megan Jeon received the award from the Cooperative Trials Group for Neuro-Oncology (COGNO) 2018 conference in October for best supportive care poster in honour of Lynette Williams. Megan’s poster ‘Prevalence and severity of difficulty sleeping in patients with CNS cancer receiving palliative care in Australia’ used PCOC data, exploring sleep difficulties in people with brain tumours.

Leanne Hills, CNC at Albury Wodonga Health on achieving improved patient outcomes using PCOC

Leanne Hills is a Clinical Nurse Coordinator in palliative care at Albury Wodonga Health, VIC. Leanne has provided a summary of her service’s achievements in improving patient outcomes and has identified the following factors, which have contributed to their improved use of the PCOC tools:

- Mentor visits from the PCOC team have significantly strengthened the palliative care team’s understanding of the PCOC assessments and quality improvement strategies
- PCOC’s benchmarking workshops have provided the opportunity to network with other similar services, which has encouraged the trialling and implementation of several new practices that have helped the team utilise the assessment tools for better patient care, including:
  - Using PCOC language (scores, phases, RUG-ADL, AKPS) to discuss patient acuity and need for attention
  - Development of the morning huddle to discuss and plan for our day -
allocating which staff are to follow up on patients

- The use of a white board at our morning huddle to clearly show which patients are in the unstable, deteriorating and terminal phases and document who requires daily/weekly action and review of their care plan
- Administration staff now enter PCOC data to give consistency of data input
- Use of the new PCOC assessment form for new assessment packs and for ongoing use throughout patient admission to the program
- Accessing PCOC staff to answer questions about PCOC assessment parameters, or to solve problems which need trouble-shooting. The team feel very supported by PCOC and have received assistance with our Quality Improvement projects and how to use the PCOC tools to identify areas of potential improvement

A whole-of-health district approach to implementing PCOC in acute care: Western New South Wales Local Health District (WNSWLHD)

As part of PCOC’s continuing expansion into acute generalist settings we ventured into Western NSW in 2016 and began the process of implementing the PCOC program across the whole district. As this was the first time we had undertaken a project like this there were some major challenges and obstacles along the journey. With the vision and determination of a few key PCOC champions (special mention to James Daly at Bathurst) in collaboration with the PCOC team, we finally began to see the implementation and embedding of the program in six sites across the district. The use of the guide to implement, embed and sustain PCOC to focus the plan was essential. PCOC onsite investigative visits, relationship building, executive meetings, ongoing education and data quality checking were also vital to this project succeeding. A clinician’s hub for ongoing communication and collaboration was instrumental in creating a space for open discussions and planning. At the end of December 2018 all six sites were using PCOC assessments routinely and using these to identify patient/family needs. We are looking forward to receiving data from all six sites in January 2019 and working continuously to see improvement in palliative care outcomes in rural Western NSW. Key success factors for this work include:

- Leadership engagement
- Establish a vision
- Local facilitators or champions
- Multidisciplinary approach
- Use data to identify gaps

(ABOVE: Leanne Hills, Melina Villani, Samantha Reeves, Michael Dobson, Jennifer Sutter and Cheryl Lundin from Albury Wodonga PC Team)
International collaborations

PCOC Ireland (PCOCI)

PCOC was first introduced to Dr Mike Lucey, a palliative medicine consultant in Ireland, in 2017. Dr Lucey is leading the national program in Ireland (PCOCI) and was keen to visit Australia to pick the brains of the team and services around PCOC implementation.

Dr Lucey and his colleague, Dr Brian Creedon, had a whirlwind stay in Australia in February 2018, visiting PCOC and taking in the sights of Wollongong. They also travelled to Robina Hospital on the Gold Coast and St Vincent’s Melbourne to learn from staff about implementing PCOC at the service level.

(ABOVE: Mike & Brian with the PCOC team)

PCOCI held a workshop in July that discussed a six-month preparation lead-in for the PCOC dataset to be introduced to services, with a go-live date scheduled for early 2019. The Ireland team is trialling PCOC’s reporting software palCentre with a submission of data from Milford Hospice to PCOC to identify any issues prior to going live.

It has been fantastic collaborating with the Irish representatives in launching PCOC internationally and we thank them for their commitment to improving outcomes in palliative care.

International collaboration and use of tools & measures

PCOC received several international contacts throughout 2018, including requests for permission to use various PCOC assessment tools, offers of translation of the tools, and site visits. Countries that contacted PCOC in 2018 included:

- Brazil
- Germany
- Hong Kong
- India
- Israel
- Italy
- Turkey
- England
- South Korea

PCOC hosted a visit for the Hospice & Palliative Care team at the National Cancer Centre (NCC) of South Korea at the University of Wollongong on 16 March. The NCC organisation would like to participate in one of our new modules (Module 5: International Benchmarking).
Conferences & events

Palliative Care Nurses Australia (PCNA) Conference, Brisbane May

The 2018 PCNA conference in Brisbane was attended by three PCOC staff. Two abstracts were accepted for presentations on symptom outcomes, which Sabina Clapham delivered. The presentations were titled ‘A comparison of symptom outcomes between hospital and home’ and ‘The majority of palliative care patients are not in pain at end-of-life’. There was a panel debate about voluntary assisted dying where the final remarks were on the importance of standardised patient assessment and assessment data to evidence outcomes.

The decorated PCOC booth drew significant interest from attendees, especially about the new materials and education opportunities. The booth provided a platform to highlight the new website design and receive feedback from nurses about the implementation of the revised SAS form. Staff noted a high level of engagement and an overall emphasis on research at the event.

Palliative Care NSW Conference, Kiama November

Kathy Eagar delivered a thought-provoking keynote address ‘Choice at end-of-life: palliative care, euthanasia and other end-of-life decisions’. This address generated many discussions during the conference and at the booth. There was considerable interest in the new directions for PCOC including the profile collection and the palCentre system.

The new SAS Visual Aid rulers were in popular demand at the PCOC booth. PCOC was also highlighted in three poster presentations: Sydney District Nursing Service - ‘Paddling the waves of change’, Western NSW LHD – ‘Embedding PCOC assessment tools in multiple non-specialist palliative care inpatient settings’, and Calvary Health Care Kogarah – ‘On The Same Page: How one specialist palliative care service met their PCOC benchmark’.

(ABOVE: Poster presenters Kate Holdsworth & Mei Lau from Calvary Health Care Kogarah)

(ABOVE: Sabina & Clare at the PCOC Booth at the PCNA Conference in Brisbane)
Palliative Care Queensland’s (PCQ) End-of-Life Expo & Summit, December

Palliative Care Queensland invited PCOC to present on palliative care outcomes in Queensland. Sabina Clapham presented PCOC findings. The response to these events was very positive with many people commenting that these events brought the Queensland palliative care sector together, as well as providing an opportunity to have input into the future of palliative care in Queensland.

At the Good Life, Good Death Expo, National Palliative Care projects, including PCOC, were invited to exhibit and provide an update on project activities to interested members of the public and clinicians.

**Presentation from Central Adelaide Palliative Care Services (CAPCS) at the Australian Nursing and Midwifery Federation SA Conference, Adelaide**

Karen Jacquier, Sue McArdle and Kathy Pearce, from Central Adelaide Palliative Care Services, were invited to deliver a 20-minute presentation based upon the quality improvement work the team had completed using their PCOC data. Their presentation was entitled ‘Improving patient outcomes in palliative care’, and approximately 200 conference participants attended the session.
Education & resources

The aim of the PCOC education program is to sustain the use of clinical tools in practice by implementing the following strategies:

- Empowering organisations to undertake their own internal education and training by having local processes in place. For example, PCOC is included in orientation and ongoing education for allied, nursing and medical staff
- Encouraging a culture of a multidisciplinary approach to PCOC (assessment and use of data)

During 2018, the following training and resources were developed and implemented.

**PCOC Essentials Online course**

The team launched the Essentials Online course in June 2018. Essentials Online provides an overview of the assessment tools and PCOC reports via two modules which are targeted at: (1) clinicians who need to understand how to use the assessment tools, and, (2) managers who are implementing PCOC and using data to drive change.

As of December 2018, 530 people have completed the Essentials Online course. Thirty-five participants provided feedback upon completion of the course, the overwhelming majority of which was positive, with participants stating that the course helped to improve their existing knowledge of the PCOC assessment tools and program.

**Self-directed education package**

This package is a set of resources and guide to support organisations to embed local education and training for participation in routine assessment and outcome measurement. The self-directed education package is created specifically for the local delivery of orientation and ongoing training for health care professionals. This is in line with the five key strategies for implementing, embedding and sustaining PCOC, particularly Key Strategy Two: Local processes are in place to support routine assessment, and Key Strategy Four: PCOC is incorporated into orientation and education for medical, nursing and allied health staff.

**Workshops for clinical leaders**

There are two workshops that PCOC offers regularly in each jurisdiction for clinical leaders from our participating services. One workshop aims to build capacity of palliative care staff to use patient outcome data to drive change. The other workshop aims to embed and sustain the assessment and response framework and improve consistency in use of the clinical language.

**New SAS form & Visual Aid ruler – feedback from services**

Following the development of the new graphic design materials, we revised the Symptom Assessment Scale. It now includes a set of faces to enable improved visual interpretation of the different scores and their meanings. We also developed a new visual aid ruler (see on following page) – a rectangular card that displays a numeric scale, coloured faces, and descriptive information on symptoms. The ruler is designed so that clinicians can show it to patients or refer to it when making assessments. This has been launched in January 2019.
Colour-coded PCOC resources

At the start of the year, PCOC collaborated with graphic design company Rooland, to create a suite of new materials, including website icons, report covers and certificate designs. These materials are colour-coded by target audience and subject matter; e.g. blue documents are usually educational resources targeted at clinicians and service managers. This new colour scheme contributes to greater consistency across our resources and online profile.

Sharing of service-developed resources

A Communities of Practice Resource Bank

The purpose of the Communities of Practice is to support participating services in their continuous improvement. One of the ways we do this is through hosting a resource bank. This bank is a record of resources developed by services who have given PCOC permission to share their documents. If you are interested in accessing any of these resources or have some to share, we encourage you to contact us.

We would like to thank the following services for contributing their resources:

- Bethesda Hospital, WA
- Cabrini Palliative Care, VIC
- Concord Hospital, NSW
- Metropolitan Palliative Care Consultancy Service (MPaCCS), WA
- Mt Isa & Surrounds, QLD
- Palliative Care South East, VIC
- Robina Palliative Care, QLD
- Sir Charles Gairdner Hospital, WA
- Palliative Care South East, VIC
- St John of God Bunbury, WA
- St Vincent’s Hospital, NSW
- Sydney Adventist Hospital, NSW
Collaborations & benchmarking events

The benchmarking workshops help to re-focus service representatives on the purpose of participating in PCOC and feel inspired with new ideas to drive local continuous improvement.

**Benchmarking Workshops, November**

At the national benchmarking workshops, Kathy Eagar presented the national patient outcome results for January – June 2018, and a talk on death and dying in Australia. Sabina Clapham presented on the Capability Framework National Service Levels and profile collection. Samuel Allingham presented on data development and national surveys. It was an opportunity to consult with and receive feedback from services regarding the new strategic directions. 75% of attendees who provided feedback stated they will make service changes as a result of attending the workshops.

**ELDAC Launch, June**

Professor Patsy Yates presented at the End-of-Life Direction for Aged Care (ELDAC) launch about the project and resources available for services. The Hon. Ken Wyatt spoke of the importance of providing quality palliative and aged care and congratulated ELDAC on their work. Representatives from BaptistCare Orana Centre and Palliative and Aged Care Consultancy Services presented on their models and discussed residential aged care facilities being the new hospices.

(ABOVE: Linda Foskett and the PCOC resources)

(ABOVE: Kathy Eagar presenting at the November benchmarking workshops)

(ABOVE: Professor Jen Tieman, CareSearch Director & Gaye Bishop at the ELDAC Launch)
Team

New Additions
PCOC welcomed two new team members in 2018. Carmel Smith took on a casual role as workshop facilitator in Victoria and Tasmania, in addition to liaising with services. Natalie Joseph joined the team as a second Improvement Facilitator covering WA, NT and SA working at our Western Australian base at UWA.

Departures
We farewelled some great members of the team this year; Karen Quinsey (Director), Nesa Mossamet (Statistician) and Dr Pippa Blackburn (Improvement Facilitator). We thank them for their valued contribution to PCOC over the years and wish them all the best for the future.

Team Achievements
Sam Burns, our Data Analyst, graduated in 2018 with a Bachelor of Medical Health Sciences – congratulations Sam!

(ABOVE: Sam receiving his Bachelor’s degree)

Chief Investigators
Kathy Eagar – UOW, Wollongong
Patsy Yates – QUT, Brisbane
Claire Johnson – UWA, Perth
David Currow – UTS, Sydney

Management Advisory Board Members
Noel Hicks – Independent Chair
Amanda Bolleter – PC Interjurisdictional Group
Katy Clark – Clinical Director
Chief Investigators (as above)

Staff
Karen Quinsey – Director
Sabina Clapham – Quality & Education Manager
Samuel Allingham – Statistician & Data Manager
Alanna Connolly – Statistician
Sam Burns – Data Analyst
Nesa Mossamet – Statistician
Linda Foskett – Administrative Officer
Lucie Thompson – Administrative Support
Gaye Bishop – Improvement Facilitator
Pippa Blackburn – Improvement Facilitator
Clare Christiansen – Improvement Facilitator
Jane Connolly – Improvement Facilitator
Natalie Joseph – Improvement Facilitator
Anna McPherson – Improvement Facilitator
Tanya Pidgeon – Improvement Facilitator
Publications 2008 – 2018

Journal Articles


Conference Papers


60. Taylor J and Connolly J (2013). Palliative Care Outcomes Collaboration (PCOC) informing quality improvement in Australian palliative care services. 12th Australian Palliative Care Conference, Canberra, 3 - 6 September 2013.


Reports


PCOC
palliative care outcomes collaboration