

This service participates in



Palliative Care Outcomes Collaboration

Information for patients and their family and carers

What is PCOC? PCOC is a national palliative care project funded by the Australian Government Department of Health and Aged Care and based at the University of Wollongong.

What is palliative care? Palliative care is person and family-centred treatment, care and support for people living with a life-limiting or terminal illness.

What does PCOC do? PCOC collects information from palliative care services across Australia to measure the impacts of palliative care treatment and care. Sometimes this information includes Patient Reported Outcome Measures, or PROMs. This is information from the patient and/or their family or carer, about symptoms like pain, breathlessness or fatigue. Care teams use this information to plan and provide appropriate and holistic care.

PCOC analyses the information from services and sends out reports every six months. The reports help palliative care services to better understand if the care they provide is effective and appropriate to the needs of patients and their families and carers.

Organisations and researchers can also use PCOC information and reports to study palliative care outcomes. In this situation the researchers and organisations must follow strict criteria, including protecting the privacy of patients.

What about privacy? PCOC respects and protects the privacy of patients and their family and carers. The names and addresses of patients **are not included** in the information that palliative care services send to PCOC, or in PCOC reports or research. All information is stored on a secure database hosted at the University of Wollongong.

You can contact PCOC on (02) 4239 4393 or at pcoc@uow.edu.au if you do not want your information included in PCOC research.

For more information:

About PCOC: Talk to your nurse or doctor or visit the PCOC website at <https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc>

About PROMs: <https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-reported-outcomes/proms-consumers>

Complaints: Contact Population and Health Services Research Ethics Committee (PHSREC) at Email: cinsw-ethics@health.nsw.gov.au Phone: (02) 8374 3610 or (02) 8374 5689 quoting 2024/ETH02363