



Palliative Care Outcomes Collaboration: the challenges of developing a national data collection



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For a Dynamic Future



What is PCOC?

A national initiative funded by the Department of Health & Ageing to introduce routine assessment of palliative care outcomes across Australia.

- ◆ PCOC aims to:
- ◆ Support continuous development of palliative care
- ◆ Introduce a benchmarking service that will improve practice
- ◆ Demonstrate outcomes (service and patient/caregiver)
- ◆ Standardise palliative care assessment
- ◆ Develop a 'common language'

What is PCOC?

- ◆ PCOC is a national network for specialist palliative care services that facilitates the collection of information and the reporting of outcomes.
- ◆ Will assist palliative care services meet the Standards for providing Quality Palliative Care for all Australians and as a by-product of participation will assist services meet accreditation processes

What does PCOC do?

- ◆ Works with services to incorporate the PCOC data collection into routine practice
- ◆ Three levels of routine data – demographic, episode and phase
- ◆ Data collected by services are owned by them
 - services need to give written approval for PCOC to release their data to anyone else
- ◆ PCOC is the owner of aggregate data and a data custodian of individual site data
- ◆ Nationally de-identified aggregated data are reported in the PCOC reports

PCOC is a collaboration

Funded by the Australian Government Department of Health & Ageing, it is a collaboration of 4 organisations:

- ◆ Centre for Health Service Development, UOW (PCOC Central)
 - Professor Kathy Eagar
- ◆ Institute of Health & Biomedical Innovation Queensland University of Technology (PCOC North)
 - Professor Patsy Yates
- ◆ Western Australian Centre for Cancer and Palliative Care, Curtin University of Technology and Edith Cowan University (PCOC West)
 - Professor Linda Kristjanson
- ◆ Department of Palliative and Supportive Services, Flinders University (PCOC South)
 - Professor David Currow

PCOC Staffing

Team at University of Wollongong:

- ◆ Manager
- ◆ Training Manager
- ◆ Data and IT manager
- ◆ Statisticians
- ◆ Administrative support

+ Zone coordinators based in Brisbane, Melbourne, Adelaide, Perth and Wollongong

How PCOC aims are being achieved

- ◆ Work with services to incorporate the PCOC data collection into routine practice
- ◆ Provide ongoing support through training and assistance with IT
- ◆ Analyse the data and provide feedback on the results to individual services
- ◆ Facilitate benchmarking with other services
- ◆ Assist services with practice changes

Overview of Progress (1)

- ◆ 78 specialist palliative care services (of about 147 in Australia) have agreed to join PCOC so far, with approximately 50 submitting data for the third PCOC Report
- ◆ Majority are large metropolitan services
- ◆ These 70 services represent more than 75% of specialist palliative care episodes
- ◆ All other specialist PC services across Australia are at various stages of follow up, with most expected to join

Overview of Progress (2)

- ◆ Version 2 of the PCOC data set released and software adapted
- ◆ Patient and carer surveys currently being conducted for all interested palliative care services
- ◆ 42 training sessions conducted in the ACT, NSW, Queensland, South Australia, Victoria and Western Australia for over 370 staff to end 2007
- ◆ First benchmarking workshop conducted in August 2007

The Challenges!

The challenge to develop a national data set for specialist palliative care services is due in part to:

- ◆ the wide variation in clinical practice,
- ◆ the many ways clinicians use assessment instruments, and/or
- ◆ the multiplicity of software systems used to collect and/or record data.

These challenges have been both technical and cultural

The IT Challenge

- ◆ Large range of data collection methods
- ◆ Data collection/reporting requirements vary around the states and territories
- ◆ Not always full coverage of all agencies and data often incomplete

The IT Challenge (cont'd)

- ◆ Often data at state and territory level is collected to meet system accountability purposes
- ◆ Data reported annually and often not in the year the data was collected
- ◆ Data therefore not useful to assist in clinical decision making at the patient level

PCOCs Response

- ◆ Liaise with State and Territory Health Departments to ensure PCOC data set included in state IT systems
- ◆ Developing a list of PCOC compliant software options
- ◆ Currently PCOC is undertaking data entry for some services
- ◆ Work closely with software developers and IT companies to ensure systems are PCOC compliant
- ◆ Provided SnapShot V3.8 free of charge to 35 services around the country

The Challenge for Consultative and Community Services

- ◆ Often difficult to measure outcomes
- ◆ Service may only see patient once
- ◆ Variety of models of care
- ◆ What is the threshold to collect data?

PCOCs Response

- ◆ Wide consultation with the sector
- ◆ Developed a typology of models of care for consultative and community services
- ◆ Typology incorporated into a survey together with suggested dataset
- ◆ Consultative workshop held to refine typology and dataset

Institutional and Cultural Issues

PCOC commitment = potential change in work practice/culture

- ◆ Possible change in the way a service interacts with a patient/family
- ◆ Possible changes in the data and the way it is collected or recorded
- ◆ Possible lack of administrative support

PCOCs Response

- ◆ Zone coordinators = change agents
- ◆ Building partnerships with local service providers
- ◆ Tailoring the needs of each service
- ◆ Education crucial part of culture change
- ◆ Employment of a National Training Manager

PCOC Education

- ◆ PCOC training programs encourage services to view PCOC data collection as part of routine practice
 - To guide clinical care
- ◆ PCOC assessment tools provide trigger points for staff to initiate appropriate treatment in light of assessment results.
 - Helping services to use evidence in their day to day practices.
- ◆ Tools also help services use a common language to describe the condition of their patients and to also determine the level and kind of resources needed.

Conclusion

- ◆ Participation in PCOC is voluntary
 - leading to good commitment and data quality
 - but participation depends on resources (data entry, IT etc)
- ◆ PCOC collaborates with others to avoid duplication and exploit the potential synergies between the work of different groups
- ◆ Early days but expectation that PCOC data will describe the palliative care services being provided in Australia