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

Prue Watters and Dave Fildes
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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