

International advances in outcome measurement in palliative care: One step closer to cross-national comparisons of routinely collected outcome data in palliative care



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Background

The Palliative Care Outcomes Collaboration (PCOC), Australia, and the Outcome Assessment and Complexity Collaborative (OACC), UK, are initiatives that support the routine use of outcome measures in specialist palliative care. Both initiatives follow a sophisticated implementation approach, facilitating routine clinical assessment tools that can be used to measure and benchmark patient outcomes. Both projects also provide feedback to participating services and encourage the use of outcomes data for service development.

Aim and design

The suites of outcome measures used by PCOC and OACC were selected after careful consideration and consultation among experts in palliative care and research. The searches focused on valid, reliable and robust measures, that capture the key domains important to patients and staff in palliative care. We compare the two suites of measures, as well as the recommended assessment points, in order to enable cross-national analysis.



Commencing in 2005, PCOC is a well-established evidence based programme, which benchmarks routine clinical outcome measures in specialist palliative care across Australia. PCOC is funded by the Australian Government and is a collaboration between four university research centres located across Australia. Currently, there are 115 sites voluntarily submitting data to PCOC. Data are routinely analysed and benchmarking results are reported back to the participating palliative care services and used to drive improvements in patient outcomes. They receive comprehensive benchmark reports every six months and attend annual benchmarking workshops.

OACC commenced in 2014 and has built on PCOC's work. The OACC project aims to implement a suite of outcome measures into palliative care services in the UK. The project team offer resources, training, implementation support, as well as data analysis and feedback sessions. Each service receives feedback on their own data at least quarterly, with aggregate level reports being published on a six-monthly basis. The project started with six palliative care sites in south London and is now being rolled out to a wider group of services.



The table below lists the measures included in the PCOC and OACC suites of measures

Key Domain	PCOC Measures		OACC Measures	
Stage of illness	Palliative Care Phase	Palliative Care Phase is a single item measure that assesses patients' stage in their illness trajectory	Palliative Care Phase	Palliative Care Phase is a single item measure that assesses patients' stage in their illness trajectory
Physical	Australia-modified Karnofsky Performance Status (AKPS)	The AKPS is a single item measure and gives an indication of overall performance	Australia-modified Karnofsky Performance Status (AKPS)	The AKPS is a single item measure and gives an indication of overall performance
	Resource Utilisation Groups - Activities of Daily Living (RUG-ADL)	The RUG-ADL measures four levels of motor function with activities of daily living	10 item Barthel Index	The Barthel Index (10 item version) measures assesses patients' ability to perform 10 activities of daily living
	Palliative Care Problem Severity Score (PCPSS)	The PCPSS includes two items on physical symptoms, assessing "pain" and "other symptoms"	Integrated Palliative care Outcome Scale (IPOS)	The IPOS is patient- or staff-completed and includes 10 items on common physical symptoms, plus questions about any "other" symptoms
	Symptom Assessment Scale (SAS)	The SAS is patient-completed and assesses patients' level of distress relating to seven individual physical symptoms, plus "other" symptoms		
Psychological / Emotional	PCPSS	The PCPSS includes one item on psychological problems, this is combined with spiritual problems	IPOS	The IPOS includes three items on psychological issues, incl. anxiety, depression and ability to share feelings
Spiritual	PCPSS	The PCPSS includes one item on spiritual problems, this is combined with psychological problems	IPOS	The IPOS includes one item on spirituality, asking whether someone is at peace
Family/Carer	PCPSS	The PCPSS includes one item on family/carers problems	IPOS	The IPOS includes one item on family/carers worry/anxiousness
			6-item Zarit carer Interview	The Zarit Carer measure is carer-completed and includes six items focused on carer strain/burden
Other	-	-	Additional carer questions	These two questions are carer-completed and include one item on help and support received and one on the difference made
			Views on Care	This measure is patient-completed and assesses the impact of a service on quality of life

Results

There are many similarities between the two suites of measures. Both include measures to explore the key domains of palliative care, and both include a patient-reported measure (SAS and IPOS) to examine patients' symptoms and concerns. There are some differences, notably in the measures used to assess symptom severity (PCPSS and SAS versus IPOS) and daily functioning (RUG-ADL versus Barthel). In terms of measurement frequency, both initiatives recommend using measures at first assessment, phase change and discharge; however, while PCOC requires regular or daily clinical assessments, OACC currently only requires measurement at two time points, although ongoing assessment is encouraged.

Conclusions

While PCOC and OACC share a common aim and many similarities, some measures used by these initiatives differ. Additionally, the required measurement frequencies are not yet completely aligned. However, the ultimate goal of both initiatives is to achieve a national clinical outcomes set, collected and submitted by the majority of specialist palliative care services. Availability of such data brings us one step closer to cross-national comparisons of routinely collected outcome data in palliative care.



PCOC is a national palliative care project funded by the Australian Government Department of Health



More information can be found at: www.pcoc.edu.au

For more info about PCOC



The Outcome Assessment and Complexity Collaborative is funded by the Guy's and St Thomas' Charity.

The OACC team is also working in collaboration with the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Palliative and End of Life Care Theme. The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London is part of the National Institute for Health Research (NIHR), and is a partnership between King's Health Partners, St. George's, University London, and St George's Healthcare NHS Trust.

For more info about OACC



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