Palliative Care and End-of-Life Care: PI 05h-Proportion of palliative care phases with improvement in patient distress from breathing problems, from moderate/severe to absent/mild at the end of the phase (patient-rated), 2021

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Identifying and definitional attributes

Metadata item type:	Indicator
Indicator type:	Indicator
Short name:	PI 05h-Proportion of palliative care phases with improvement in patient distress from breathing problems, from moderate/severe to absent/mild at the end of the phase (patient-rated), 2021
Synonymous names:	Change in symptoms and problems (PCOC)
METEOR identifier:	742786
Registration status:	Health!, Qualified 21/10/2021
Description:	Palliative care phases that started with the patient reporting moderate/severe distress from breathing problems and ended with absent/mild distress from breathing problems as a proportion of all palliative care phases that started with the patient reporting moderate/severe distress from breathing problems, using the patient-rated PCOC Symptom Assessment Scale (SAS).
Rationale:	The National Palliative Care Strategy 2018 (the Strategy; DoH 2019) has stated that quality of care should be routinely monitored in order for care to be assessed and improved across all care settings. In particular, the Strategy emphasises that it is essential that people receive palliative care that matches their needs and preferences. Monitoring for change in key symptoms during palliative care provides an indication of whether the care needs of a patient and their family are being met. Palliative care phases are used to describe the care needs of patients and their families to indicate whether or not the current care plan meets these needs. A positive outcome for patients is to have symptoms and problems in the absent/mild range during their palliative care phase. For patients who experience moderate/severe symptoms and/or problems, the goal is for this to reduce to absent/mild by the end of the phase (PCOC 2021).
Indicator set:	Palliative Care and End-of-Life Care Key Performance Indicators 2021 Health!, Qualified 21/10/2021

Collection and usage attributes

Computation description:

Coverage/scope:

Palliative care services contributing to the Palliative Care Outcomes Collaboration (PCOC).

The PCOC is a national program that aims to systematically drive improvements in patient and carer outcomes, using standardised, validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in the PCOC is voluntary and open to all palliative care service providers across Australia. Contribution to the collection is sought from services in:

- public and private health sectors;
- metropolitan, rural and remote areas; and
- inpatient (hospital or hospice) and community settings.

Methodology:

- This measure is the proportion of phases that start with moderate/severe patient reported distress from breathing problems which end with absent/mild patient reported distress from breathing problems.
- Distress from breathing problems is reported by the patient using the PCOC Symptom Assessment Scale (SAS), at the start and end of each phase. The breathing problems domain of the PCOC SAS is rated on an 11-point scale, ranging from 0=absent to 10=severe.
- Where patient reporting is not possible, proxy reporting may occur.
- Phase records must have a valid start and end PCOC SAS: breathing problems domain score for the patient phase to be included.

Presented as a percentage.

Computation: (Numerator ÷ Denominator) x 100

Numerator: Number of palliative care phases within the reference period where patient distress from breathing problems is moderate/severe at the start of a phase and absent/mild at the end of the phase

Numerator data elements:

Data Element / Data Set

Phase—PCOC Symptom Assessment Scale (SAS) at phase end: breathing, code N[N]

Guide for use

Data source type: Administrative by-product data

Item 3.3.33 in the PCOC Version 3.0 Data set: data dictionary and technical guidelines

Data Element / Data Set

Phase—PCOC Symptom Assessment Scale (SAS) at phase start: breathing, code N[N]

Guide for use

Data source type: Administrative by-product data

Item 3.3.15 in the PCOC Version 3.0 Data set: data dictionary and technical guidelines

Denominator: Number of palliative care phases within the reference period where patient distress from breathing problems is moderate/severe at the start of the phase

Denominator data elements:

Data Element / Data Set

Phase—PCOC Symptom Assessment Scale (SAS) at phase start: breathing, code N[N]

Guide for use

Data source type: Administrative by-product data

Item 3.3.15 in the PCOC Version 3.0 Data set: data dictionary and technical guidelines

Disaggregation:

Service attributes:

- Episode type (inpatient / community)
- Year (2016 - 2020)
- Episode type by Year

Disaggregation data elements:

Data Element / Data Set

Episode—episode type, code NN

Guide for use

Data source type: Administrative by-product data

Item 3.2.10 in the PCOC Version 3.0 Data set: data dictionary and technical guidelines

Episode type categories: inpatient / community

Comments: Reference period for 2021 reporting: 2020.

Representational attributes

Representation class: Percentage

Data type: Real

Unit of measure: Episode

Format: N[NN]{.N[N]}

Indicator conceptual framework

Framework and dimensions: 1. Effectiveness

Accountability attributes

Organisation responsible for providing data: Palliative Care Outcomes Collaboration (PCOC)

Other issues caveats:

Data for this indicator is sourced from [PCOC](#).

PCOC’s national longitudinal database was established in 2005, and in 2021 consists of more than 300,000 patients and greater than 1 million palliative care phases provided within hospitals, patients’ homes and in residential aged care facilities. The number of services reporting palliative care patient outcome data increased from 127 services in 2009 to 188 services in 2019, with most specialist palliative care providers within Australia participating in this voluntary national program.

PCOC has a set of rule checks and flags that ensure consistency of data entry at the point of collection by trained staff from participating services, and also comprehensive data quality checks at the point of data entry, data receipt and prior to data analysis (Woods et al. 2021). Limited missing data values are evident (i.e. <4% per item) (Daveson et al 2021).

Participation in PCOC is voluntary and open to all palliative care service providers across Australia. The data are administrative and embedded into routine clinical practice.

Source and reference attributes

Submitting organisation:

Australian Institute of Health and Welfare on behalf of the Palliative Care and End-of-Life Care Data Development Working Group

Reference documents:

Daveson BA, Allingham SF, Clapham S, Johnson CE, Currow DC, Yates P, et al. 2021. The PCOC Symptom Assessment Scale (SAS): A valid measure for daily use at point of care and in palliative care programs. PLoS ONE 16(3): e0247250. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0247250

DoH (Department of Health) 2019. National Palliative Care Strategy 2018. Canberra: Department of Health. Viewed 9 June 2021, https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018.

PCOC (Palliative Care Outcomes Collaboration) November 2012. PCOC Version 3.0 Dataset: Data Dictionary and Technical Guidelines (version 1.2.0). Viewed 9 June 2021, https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow126175.pdf

PCOC 2021. Patient Outcomes in Palliative Care: National Report July to December 2020. Viewed 9 June 2021, https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow269015.pdf

Woods JA, Johnson CE, Allingham SF, Ngo HT, Katzenellenbogen JM, Thompson SC 2021. Collaborative data familiarisation and quality assessment: Reflections from use of a national dataset to investigate palliative care for Indigenous Australians. Health Inf Manag; 50(1-2):64-75. doi: 10.1177/1833358320908957.