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The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

Central to the program is a framework and protocol for routine clinical assessment and response. This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information. PCOC aims to drive improvement in patient outcomes through feedback to individual services and by facilitating service-to-service benchmarking.

Three types of information are presented in this web report: patient-level, episode-level and phase-level.# This web report includes data for the period of 2016, 2017 and 2018. The information reported here includes data from participating services during the stated time periods. The report represents a substantial proportion of palliative care provision within Queensland.

For more information regarding the data included in this report, please contact us at [pcoc@uow.edu.au](mailto:pcoc@uow.edu.au)

#### **Queensland services, patients, episodes of care and phases, 2018#**

	<b>N</b>
<b>Services</b>	<b>33</b>
<b>Patients</b>	<b>8,161</b>
<b>Episodes of care</b>	<b>11,144</b>
<i>Hospital / hospice episodes</i>	<i>7,827</i>
<i>Community episodes</i>	<i>3,317</i>
<b>Phases</b>	<b>22,140</b>
<i>Hospital / hospice phases</i>	<i>15,564</i>
<i>Community phases</i>	<i>6,576</i>

**Number of phases by palliative care phase type and setting, 2018<sup>#</sup>**

Palliative care phase	Hospital / hospice		Community		Total	
	N	%	N	%	N	%
Stable	3,851	24.7	2,682	41	6,533	29.5
Unstable	3,106	20.0	1,024	16	4,130	18.7
Deteriorating	5,577	35.8	2,342	36	7,919	35.8
Terminal	3,030	19.5	528	8	3,558	16.1
<b>Total</b>	<b>15,564</b>	<b>100.0</b>	<b>6,576</b>	<b>100.0</b>	<b>22,140</b>	<b>100.0</b>

<sup>#</sup> PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and / or treatment as evidenced by the existence of a medical record. Family and carers are included in this definition if interventions relating to them are recorded in the patient medical record. An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as a hospital / hospice or community patient. The palliative care phase type describes the stage of the patient’s illness and provides an indication of the level of care a patient requires. Patients may have more than one episode of care and phase.

31,746 people died in Queensland in 2017. Of these, 4,158 deaths (13.2%) were captured in the PCOC data collection. Of all deaths in Queensland, 20,256 (63.8%) could be considered potentially predictable. The PCOC deaths represented 13.2% of all deaths in Queensland, 20.7% of all deaths considered predictable, and 38.3% of deaths from causes typically seen by specialist palliative care. Population-based estimates indicate that in high-income countries, 69%–82% of those who die need palliative care.

**Queensland death data, predictable deaths, proportion of predictable deaths captured in PCOC and specialist palliative care, 2016 & 2017**

<b>Summary</b>	<b>2016</b>	<b>2017</b>
Queensland deaths	29,941	31,746
Potentially predictable	19,082	20,256
Potentially specialist palliative care	10,478	10,916
Deaths in hospital	15,780	16,164
Deaths recorded in PCOC	3,894	4,185
Queensland deaths	100.0%	100.0%
Potentially predictable	63.7%	63.8%
Potentially specialist palliative care	35.0%	34.4%
Deaths in hospital	52.7%	50.9%
Deaths recorded in PCOC as % of total	13.0%	13.2%
Deaths recorded in PCOC as % of potentially predictable	20.4%	20.7%
Deaths recorded in PCOC as % of potentially specialist palliative care	37.2%	38.3%

**Sources:**

Rosenwax, L.K., McNamara, B., Blackmore, A.M. & Holman, C.D.J. 2005, 'Estimating the size of a potential palliative care population', *Palliative Medicine*, vol. 19, no. 7, pp. 556–62.

Murtagh, F.E.M., Bausewein, C., Verne, J., Iris Groeneveld, E., Kaloki, Y.E. & Higginson, I.J. 2014, 'How many people need palliative care? A study developing and comparing methods for population-based estimates', *Palliative Medicine*, vol. 28, no. 1, pp. 49–58.

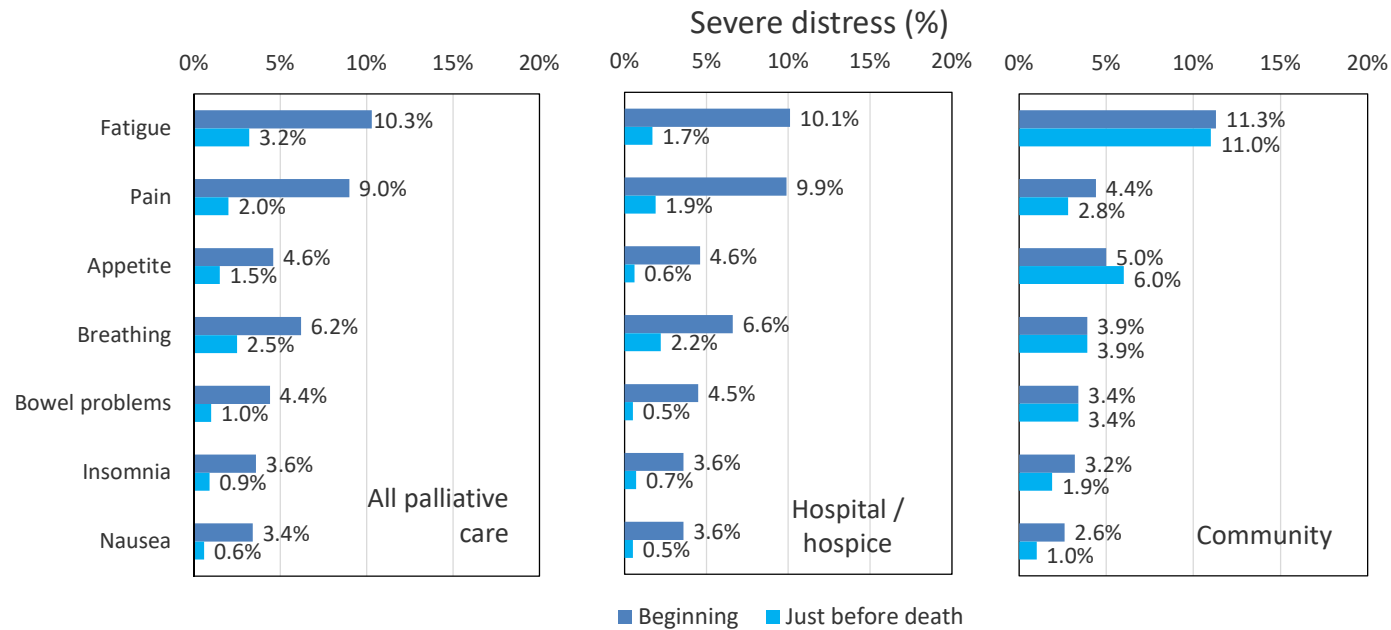
Australian Bureau of Statistics. Causes of Death, Australia, 2017. Cat. No. 3303.0

Australian Bureau of Statistics. Causes of Death, Australia, 2016. Cat. No. 3303.0

**Table 1 Severe symptoms at beginning of episode-of-care and just before death, Queensland, 2018**

	All palliative care			Hospital / hospice			Community		
	N	Beginning	Just before death	N	Beginning	Just before death	N	Beginning	Just before death
Fatigue	2,457	10.3%	3.2%	2,076	10.1%	1.7%	381	11.3%	11.0%
Pain	2,467	9.0%	2.0%	2,081	9.9%	1.9%	386	4.4%	2.8%
Appetite	2,452	4.6%	1.5%	2,071	4.6%	0.6%	381	5.0%	6.0%
Breathing	2,466	6.2%	2.5%	2,082	6.6%	2.2%	384	3.9%	3.9%
Bowel problems	2,452	4.4%	1.0%	2,069	4.5%	0.5%	383	3.4%	3.4%
Insomnia	2,446	3.6%	0.9%	2,070	3.6%	0.7%	376	3.2%	1.9%
Nausea	2,457	3.4%	0.6%	2,074	3.6%	0.5%	383	2.6%	1.0%

The assessment framework incorporates five validated clinical assessment tools: Palliative Care Phase; Palliative Care Problem Severity Score (PCPSS); Symptom Assessment Scale (SAS); Australia-modified Karnofsky Performance Status (AKPS) Scale; and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).



**Table 2 Patient's preferred language, Queensland, 2018**

<b>Language</b>	<b>Palliative care patients</b>	
	<b>N</b>	<b>%</b>
English	7,937	98.0
All other languages	162	2.0
<b>Total</b>	<b>8,099</b>	<b>100.0</b>

**Table 3 Country of birth of palliative care patients, Queensland, 2018**

<b>Country of birth</b>	<b>Palliative care patients</b>	
	<b>N</b>	<b>%</b>
Australia	6,141	75.8
England	528	6.5
New Zealand	324	4.0
Scotland	92	1.1
All other countries	1,025	12.6
<b>Total</b>	<b>8,106</b>	<b>100.0</b>

**Table 4 Cancer and non-cancer diagnosis reported in PCOC, Queensland, 2018**

<b>Diagnosis</b>	<b>Palliative care patients</b>	
	<b>N</b>	<b>%</b>
Cancer	6,266	77.2
Non-cancer	1,854	22.8
<b>Total</b>	<b>8,120</b>	<b>100.0</b>



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**Table 5 Palliative care patients by remoteness, Queensland, 2018**

	Patients receiving care in hospital / hospice		Patients receiving care in the community		Total patients	
	N	%	N	%	N	%
<b>Remoteness</b>						
Major cities	4,347	71.0	1,940	70.4	5,646	69.5
Inner regional	1,032	16.9	583	21.1	1,588	19.5
Outer regional, remote and very remote#	741	12.1	232	8.4	894	11.0
<b>Total</b>	<b>6,120</b>	<b>100.0</b>	<b>2,755</b>	<b>100.0</b>	<b>8,128</b>	<b>100.0</b>

# These cells have been combined due to small numbers in the remote and very remote categories.

Note: If a patient receives care in more than one setting, they are only presented once in the 'Total patients' column.

Remoteness classification reference:

<https://www.abs.gov.au/websitedbs/D3310114.nsf/home/remoteness+structure>

**Table 6 Palliative care patients by Indigenous status, Queensland, 2018**

<b>Indigenous status</b>	<b>N</b>	<b>%</b>
Aboriginal and or Torres Strait Islander	164	2.1
Neither Aboriginal nor Torres Strait Islander	7,669	97.9
<b>Total</b>	<b>7,833</b>	<b>100.0</b>

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**Table 7 Palliative care episodes by socioeconomic status, Queensland, 2018**

<a href="#">IRSD quintile</a>	Hospital / hospice		Community		Total		<a href="#">QLD population#</a>
	N	%	N	%	N	%	%
1 (Lowest)	749	9.6	559	16.9	1,308	11.8	21.4
2	1,155	14.8	337	10.2	1,492	13.4	22.2
3	1,538	19.7	662	20.0	2,200	19.8	21.7
4	3,028	38.9	1,062	32.0	4,090	36.8	20.7
5 (Highest)	1,322	17.0	695	21.0	2,017	18.2	14.0
<b>Total</b>	<b>7,792</b>	<b>100.0</b>	<b>3,315</b>	<b>100.0</b>	<b>11,107</b>	<b>100.0</b>	<b>100.0</b>

# Queensland population information obtained from  
<https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Socio-Economic%20Advantage%20and%20Disadvantage~123>



**Table 8 Palliative care episodes by age group and setting, Queensland, 2018**

	Hospital / hospice		Community		Total Queensland	
	N	%	N	%	N	%
<b>Age group (years)</b>						
< 25	26	0.3	12	0.4	38	0.3
25-64	2,178	27.8	920	27.7	3,098	27.8
65-84	4,168	53.3	1,787	53.9	5,955	53.4
85+	1,454	18.6	598	18.0	2,052	18.4
<b>Total</b>	<b>7,826</b>	<b>100.0</b>	<b>3,317</b>	<b>100.0</b>	<b>11,143</b>	<b>100.0</b>
Average age	71.6	-	71.4	-	71.5	-
Median age	73.0	-	73.0	-	73.0	-

**Table 9 Palliative care episodes by sex and setting, Queensland, 2018**

<b>Sex</b>	<b>Hospital / hospice</b>		<b>Community</b>		<b>Total</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
Male	4,240	54.2	1,805	54.4	6,045	54.3
Female	3,584	45.8	1,511	45.6	5,095	45.7
<b>Total</b>	<b>7,824</b>	<b>100.0</b>	<b>3,316</b>	<b>100.0</b>	<b>11,140</b>	<b>100.0</b>

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**Table 10 Palliative care episodes of care by age group and Indigenous status, Queensland, 2018**

	Aboriginal and or Torres Strait Islander		Neither Aboriginal nor Torres Strait Islander nor Aboriginal and Torres Strait Islander	
	N	%	N	%
<b>Age group (years)</b>				
< 50	47	22.3	687	6.6
50+	164	77.7	9,738	93.4
<b>Total</b>	<b>211</b>	<b>100.0</b>	<b>10,425</b>	<b>100.0</b>
Average age	61.6	-	71.7	-
Median age	63.0	-	73.0	-

**Table 11 Summary of patient outcomes and benchmarks by palliative care setting, Queensland, 2018**

Outcome measure	Benchmark	All Queensland services	Hospital / hospice setting	Community setting	
<b>Timeliness of care</b>					
Patients commencing an episode of palliative care on the day of, or the day following, the date they were ready for care	90%	95.7%	99.5%	85.3%	
<b>Responding to urgent needs</b>					
Patients in the unstable phase for three days or less	90%	78.7%	83.6%	63.9%	
<b>Anticipatory care</b>					
<i>Patients with absent/mild at the beginning of a phase remaining absent/mild when the phase ends</i>					
<b>Clinician-rated</b>	90%	Pain	89.2%	92.0%	81.1%
		Family / carer problems	90.2%	93.6%	79.3%
<b>Patient-rated</b>	90%	Pain	90.2%	92.7%	84.7%
		Fatigue	90.7%	93.6%	82.5%
		Breathing problems	95.2%	96.8%	91.2%
<b>Responsive care</b>					
<i>Patients with moderate/severe at the beginning of a phase becoming absent/mild when the phase ends</i>					
<b>Clinician-rated</b>	60%	Pain	57.6%	63.6%	41.2%
		Family / carer problems	45.7%	54.2%	30.2%
<b>Patient-rated</b>	60%	Pain	53.2%	61.0%	34.7%
		Fatigue	40.7%	50.2%	25.0%
		Breathing problems	45.1%	54.7%	27.0%

**SUGGESTED CITATION:**

Palliative Care Outcomes Collaboration (04 July 2019) *Palliative care at a glance in Queensland, Web Report*. Australian Health Services Research Institute, University of Wollongong.

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