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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 information#. This web report includes data for the period of 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 NSW and ACT.

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

### NSW and ACT services, patients, episodes of care, and phases, 2018#

	<b>N</b>
<b>Services</b>	<b>45</b>
<b>Patients</b>	<b>10,246</b>
<b>Episodes of care#</b>	<b>13,528</b>
<i>Hospital / hospice episodes</i>	<i>7,952</i>
<i>Community episodes</i>	<i>5,576</i>
<b>Phases</b>	<b>37,142</b>
<i>Hospital / hospice phases</i>	<i>22,595</i>
<i>Community phases</i>	<i>14,547</i>

### Number of phases by palliative care phase type and setting, 2018#

Palliative care phase	Hospital / hospice		Community		Total	
	N	%	N	%	N	%
Stable	5,622	38.6	7,772	38.8	11,736	31.6
Unstable	2,422	16.6	842	4.2	8,228	22.2
Deteriorating	5,591	38.4	9,694	48.4	11,749	31.6
Terminal	912	6.3	1,720	8.6	5,429	14.6
<b>Total</b>	<b>22,595</b>	<b>100</b>	<b>14,547</b>	<b>100</b>	<b>37,142</b>	<b>100</b>

# 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 a clinical indication of the level of care a patient requires. Patients may have more than one episode of care, and phase.

55,475 people died in NSW and ACT in 2017. Of these, 5,774 deaths (10.4%) were captured in the PCOC data collection. Of all deaths in NSW and ACT, 34,497 (62.2%) could be considered potentially predictable. The PCOC deaths represented 10.4% of all deaths in NSW and ACT, 16.7% of all deaths considered predictable, and 33.3% 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.

**NSW and ACT death data, predictable deaths, proportion of predictable deaths captured in PCOC and specialist palliative care, 2017**

<b>Summary</b>	<b>2017</b>
NSW and ACT deaths	55,475
Potentially predictable	34,497
Potentially specialist palliative care	18,493
Deaths in hospital#	27,105
Deaths recorded in PCOC	5,774
NSW and ACT deaths	100.0
	%
Potentially predictable	62.2%
Potentially specialist palliative care	33.3%
Deaths in hospital	48.9%
Deaths recorded in PCOC as % of total	10.4%
Deaths recorded in PCOC as % of potentially predictable	16.7%
Deaths recorded in PCOC as % of potentially specialist palliative care	31.2%

**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

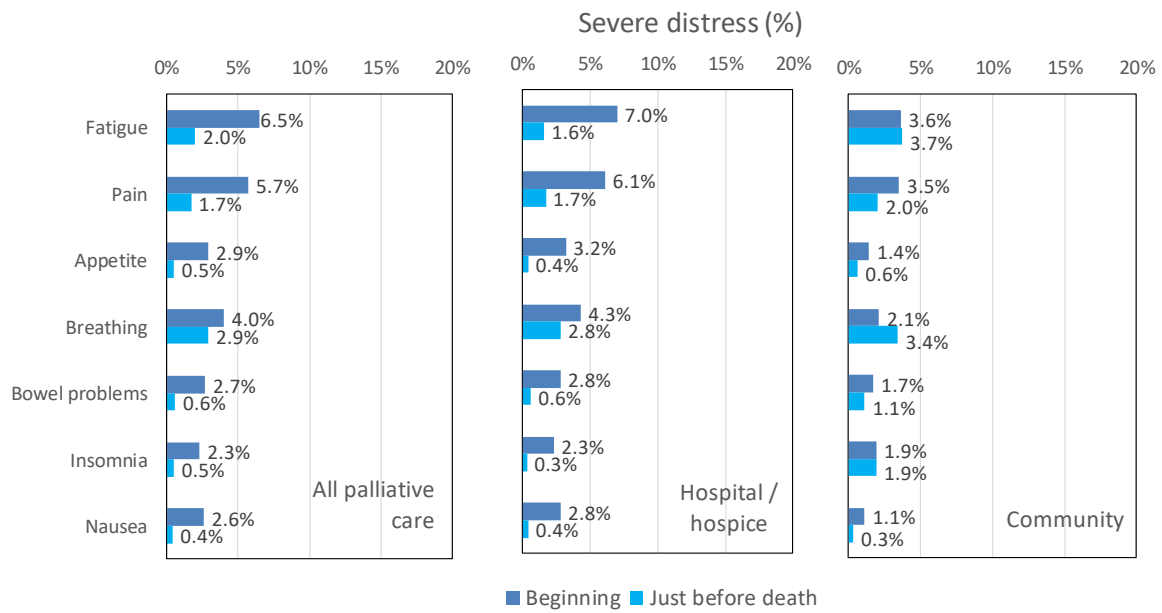
Australian Institute of Health and Welfare 2018. Admitted patient care 2016–17: Australian hospital statistics. Health services series no. 84. Cat. no. HSE 201. Canberra: AIHW.

*# PLEASE NOTE: Deaths in hospital corresponds to the 2016-17 financial year and does not include patients who died in a private hospital in the ACT*

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

	All palliative care			Hospital / hospice			Community		
	N	Beginning	Just before death	N	Beginning	Just before death	N	Beginning	Just before death
Fatigue	4,224	6.5%	2.0%	3,583	7.0%	1.6%	641	3.6%	3.7%
Pain	4,242	5.7%	1.7%	3,584	6.1%	1.7%	658	3.5%	2.0%
Appetite	4,217	2.9%	0.5%	3,581	3.2%	0.4%	636	1.4%	0.6%
Breathing	4,236	4.0%	2.9%	3,581	4.3%	2.8%	655	2.1%	3.4%
Bowel problems	4,231	2.7%	0.6%	3,580	2.8%	0.6%	651	1.7%	1.1%
Insomnia	4,216	2.3%	0.5%	3,580	2.3%	0.3%	636	1.9%	1.9%
Nausea	4,229	2.6%	0.4%	3,580	2.8%	0.4%	649	1.1%	0.3%

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, NSW and ACT, 2018**

Language	Palliative care patients	
	N	%
English	8,594	84.1
All other languages	1,625	15.9
<b>Total</b>	<b>10,219</b>	<b>100.0</b>

**Table 3 Country of birth of palliative care patients, NSW and ACT, 2018**

Country of birth	Palliative care patients	
	N	%
Australia	6,100	60.7
England	490	4.9
Italy	351	3.5
China	264	2.6
All other countries	2,852	28.3
<b>Total</b>	<b>10,057</b>	<b>100.0</b>

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

Diagnosis	Palliative care patients	
	N	%
Cancer	8,037	79.1
Non-cancer	2,126	20.9
<b>Total</b>	<b>10,163</b>	<b>100.0</b>



**Table 5 Palliative care patients by remoteness, NSW and ACT, 2018**

	Patients receiving care in hospital / hospice		Patients receiving care in the community		Total patients	
	N	%	N	%	N	%
<b>Remoteness</b>						
Major cities	5,252	77.7	3,148	78.3	7,809	77.3
Inner regional	1,358	20.1	821	20.4	2,093	20.7
Outer regional, remote and very remote#	147	2.2	50	1.2	196	1.9
<b>Total</b>	<b>6,757</b>	<b>100.0</b>	<b>4,019</b>	<b>100.0</b>	<b>10,098</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, NSW and ACT, 2018**

<b>Indigenous status</b>	<b>N</b>	<b>%</b>
Aboriginal and or Torres Strait Islander	161	1.6
Neither Aboriginal nor Torres Strait Islander	9,831	98.4
<b>Total</b>	<b>9,992</b>	<b>100.0</b>

**Table 7 Palliative care episodes by socioeconomic status, NSW and ACT, 2018**

<a href="#">IRSD quintile</a>	Hospital / hospice		Community		Total		<a href="#">NSW and ACT population#</a>
	N	%	N	%	N	%	%
1 (Lowest)	1,475	18.6	670	12.5	2,145	16.1	<i>18.2</i>
2	1,430	18.0	666	12.4	2,096	15.7	<i>18.0</i>
3	1,079	13.6	749	13.9	1,828	13.7	<i>16.8</i>
4	1,180	14.8	875	16.3	2,055	15.4	<i>18.0</i>
5 (Highest)	2,785	35.0	2,420	45.0	5,205	39.1	<i>29.0</i>
<b>Total</b>	<b>7,949</b>	<b>100.0</b>	<b>5,380</b>	<b>100.0</b>	<b>13,329</b>	<b>100.0</b>	<b><i>100.0</i></b>

# NSW and ACT 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, NSW and ACT, 2018**

	<u>Hospital / hospice</u>		<u>Community</u>		<u>Total NSW and ACT</u>	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
<b>Age group (years)</b>						
< 25	8	0.1	19	0.4	27	0.2
25-64	1,875	23.6	1,283	23.8	3,158	23.7
65-84	4,364	54.9	2,841	52.8	7,205	54.0
85+	1,705	21.4	1,242	23.1	2,947	22.1
<b>Total</b>	<b>7,952</b>	<b>100.0</b>	<b>5,385</b>	<b>100.0</b>	<b>13,337</b>	<b>100.0</b>
Average age	73.5	-	73.3	-	73.4	-
Median age	75.0	-	75.0	-	75.0	-

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

Sex	Hospital / hospice		Community		Total	
	N	%	N	%	N	%
Male	4,279	53.8	2,983	53.5	7,262	53.7
Female	3,670	46.2	2,589	46.5	6,259	46.3
<b>Total</b>	<b>7,949</b>	<b>100.0</b>	<b>5,572</b>	<b>100.0</b>	<b>13,521</b>	<b>100.0</b>

**Table 10 Palliative care episodes by age group and Indigenous status, NSW and ACT, 2018**

	<b>Aboriginal and or Torres Strait Islander</b>		<b>Neither Aboriginal nor Torres Strait Islander nor Aboriginal and Torres Strait Islander</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Age group (years)</b>				
< 50	31	13.8	627	4.9
50 +	194	86.2	12,133	95.1
<b>Total</b>	<b>225</b>	<b>100.0</b>	<b>12,760</b>	<b>100.0</b>
Average age	63.4	-	73.6	-
Median age	62.0	-	75.0	-

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

Outcome measure	Benchmark	All NSW and ACT 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%	94.6%	97.9%	88.8%	
<b>Responding to urgent needs</b>					
Patients in the unstable phase for three days or less	90%	88.6%	92.1%	80.0%	
<b>Anticipatory care</b>					
<i>Patients with absent/mild at the beginning of a phase remaining absent/mild when the phase ends</i>					
Clinician rated	90%	Pain	89.6%	92.9%	85.0%
		Family / carer problems	90.1%	93.7%	84.3%
Patient rated	90%	Pain	87.9%	91.2%	83.5%
		Fatigue	87.9%	91.5%	82.4%
		Breathing problems	94.0%	95.6%	92.0%
<b>Responsive care</b>					
<i>Patients with moderate/severe at the beginning of a phase becoming absent/mild when the phase ends</i>					
Clinician rated	60%	Pain	59.2%	62.7%	54.5%
		Family / carer problems	48.1%	52.2%	44.5%
Patient rated	60%	Pain	50.9%	56.5%	43.9%
		Fatigue	43.7%	54.5%	32.8%
		Breathing problems	42.3%	50.2%	33.1%

SUGGESTED CITATION:

Palliative Care Outcomes Collaboration (20 September 2019) *Palliative care services at a glance in NSW and ACT, Web Report*. Australian Health Services Research Institute, University of Wollongong

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