



1.1. Cancer patients who received palliative care at the end of their life (EOL-1)

1.1.1. Documentation sheet

Description	Cancer patients who received palliative care at the end of their life (% of cancer patients with poor prognosis who died)
Calculation	Numerator: Number of cancer patients who received palliative care (in usual place of residence or in hospital) (regardless of time period) Denominator: Number of patients diagnosed with cancer with poor prognosis who died within the studied time period
Rationale	<p>The 2002 WHO definition states that “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.</p> <p>In Belgium, many structures and services for palliative patients have been developed over the years. Palliative networks were created in 1997, with the aim to develop palliative care culture, to organize trainings for caregivers, to coordinate actions between organisations and services, and to evaluate the palliative services.</p> <p>In the home setting, palliative home care teams support caregivers and facilitate the care for the palliative patient who wishes to stay at home. A “palliative lump sum” (so called “forfait”) is offered during two months, to cover supplementary costs created by the palliative care. Furthermore, the palliative patient at home does not have to pay any personal contribution when treated by nurses, physiotherapists and general practitioners. Finally, palliative day care centres can offer some relieve to the patients’ supporting families.</p> <p>In the hospital setting, two types of palliative care structures were set up. First, approximately 400 specialised (SP)-palliative beds are clustered in small Palliative Care Units (PCU). Second, the palliative function has been developed in all hospitals in order to provide tailored care for palliative patients not staying in a PCU. A similar palliative function has been created in nursing homes.¹</p>
Data source	Belgian Cancer Registry (BCR), linked with IMA-AIM data
Technical definitions	<p>It is currently not possible to identify all palliative patients in administrative databases or in registries. Therefore, the indicator has been restricted to patients diagnosed with cancer that have a poor prognosis (based on relative survival probability) and deceased during the study period.</p> <p><u>Inclusion criteria</u></p> <p>Incidence years: 2006-2020</p> <p>Tumour selection based on the Pallcare project ² : combination of topography and morphology according to Eurocare-4 ³⁻⁴, and Eurocare-5 ⁵</p> <ul style="list-style-type: none"> • Chronic tumours (5-yr RS <50%) <ul style="list-style-type: none"> ○ Head and neck ○ Nasal cavities and sinuses ○ Small intestine ○ Multiple myeloma ○ Ovary and uterine adnexa ○ Chronic myeloid leukaemia ○ Acute lymphatic leukaemia • Acute tumours (1-yr RS <50%)



- Lung, bronchus and trachea
- Pleura
- Oesophagus
- Stomach
- Gallbladder and biliary tract
- Liver, primary
- Pancreas
- Acute myeloid leukaemia
- Brain

Patients deceased before July 1st, 2021

Age at diagnosis ≥ 18 years

Exclusion criteria

Patients with more than one invasive tumour (until 2020)

Patients without a Belgian residence at time of diagnosis

Patients without national social security number

Patients for whom no IMA data of the year of death were available (=4.1%)

Maximum 3 years of follow-up

Analyses were limited to patients who died before January 1st of the third year following the year of incidence. For example: patients diagnosed in 2006 were included in case they died in 2006, 2007 or 2008; patients diagnosed in 2007 were included in case they died in 2007, 2008 or 2009, etc.

These cohorts were defined to assure that for every diagnosis, a similar follow-up period could be taken into account, and to avoid bias by varying length of the follow-up period.

Palliative care

Palliative care as identified in IMA-AIM data includes: patients receiving the lump sum for palliative care at the usual place of residence, patients reimbursed for visits of the general practitioner or nurse within a palliative setting, patients hospitalized in palliative units, or hospitalized patients reimbursed for visits of multidisciplinary palliative care teams (the latter only if it concerns visits from the palliative home care team; visits from palliative support teams from within the hospital cannot be defined in the IMA-AIM data).

Limitation

The true proportions may be underestimated as patients may receive palliative care without nomenclature codes being registered.

Cause of death is unknown: it is assumed that the patients died from their cancer, and hence can benefit from palliative care at the end of their life. Nevertheless, this is probably not 100% accurate (patients dying from other causes).

No information on terminally ill patients apart from the oncology setting.

International comparability

This is not an international indicator. Some results are available in national reports or in specific scientific articles.

Dimensions

End-of-life care; Accessibility

Related indicators



Reviewers Cindy De Gendt (BCR), Lien Van Walle (BCR)

1.1.2. Results

Analysis of national data revealed that in the year 2020 on average 56.8% of the cancer patients who died in this year (and were diagnosed during 2018-2020) received palliative care. A slight increase in the use of palliative care services was seen since 2008 (48.0%) (see Table 1). A subanalysis by tumour type (acute versus chronic tumour) showed a higher proportion receiving palliative care in patients with acute tumours compared to patients with chronic tumours (58.9% vs 41.9% of patients who died in 2020 respectively, see Table 1). The increase in palliative care over time was mostly seen in the acute tumour group; in the chronic tumour group, no evolution over time is observed.

Results by specific tumour type showed substantial differences in the use of palliative care within the two broad categories. For example, within the group of patients with acute tumours, the proportion of patients receiving palliative care ranged from 31.7% for acute myeloid leukaemia to 67.5% for brain cancer (see Table 2). Also, the proportion of patients receiving palliative care is generally lower in haematological tumours, both in acute and chronic types.

A higher proportion of cancer patients receiving palliative care was seen in Flanders (61.8%) compared to the two other regions (48.5% in Brussels and 50.4% in Wallonia) (see Table 3).

Table 1 –Cancer patients who received palliative care at the end of their life, by year of death (2008-2020) (maximum 3 years of follow-up)

	All Tumours			Acute Tumours			Chronic Tumours		
	Total	Receiving palliative care		Total	Receiving palliative care		Total	Receiving palliative care	
	N	n	%	N	n	%	N	n	%
2008	9597	4604	48.0	8385	4098	48.9	1212	506	41.7
2009	9455	4538	48.0	8243	4024	48.8	1212	514	42.4
2010	9873	4807	48.7	8614	4320	50.2	1259	487	38.7
2011	9950	4982	50.1	8770	4505	51.4	1180	477	40.4
2012	10059	5133	51.0	8813	4620	52.4	1246	513	41.2
2013	10120	5195	51.3	8906	4677	52.5	1214	518	42.7
2014	10048	5449	54.2	8882	4943	55.7	1166	506	43.4
2015	9876	5267	53.3	8677	4741	54.6	1199	526	43.9
2016	9773	5252	53.7	8614	4750	55.1	1159	502	43.3
2017	9472	5072	53.5	8326	4596	55.2	1146	476	41.5
2018	9409	4934	52.4	8299	4496	54.2	1110	438	39.5



	All Tumours			Acute Tumours			Chronic Tumours		
2019	9467	5151	54.4	8335	4631	55.6	1132	520	45.9
2020	9643	5478	56.8	8449	4978	58.9	1194	500	41.9
Total	126742	65862	52.0	111313	59379	53.3	15429	6483	42.0

Note: To assure a similar follow-up period for every included patient, deaths occurring in 2006 and 2007 were excluded. Deaths occurring in 2021 were also excluded, as no diagnoses were studied for that year.

Source: BCR linked to IMA-AIM data

Table 2 –Cancer patients receiving palliative care at the end of their life – by tumour type (all patients, maximum 3 years of follow-up) (2006-Jun2021)

	Total	Receiving palliative care	
	N	n	%
Acute			
• Oesophagus	7435	3537	47.6
• Stomach	9875	4997	50.6
• Liver, primary	6657	3377	50.7
• Gallbladder and biliary Tract	3567	1900	53.3
• Pancreas	16271	10016	61.6
• Lung, bronchus and trachea	68069	34662	50.9
• Pleura	2523	1637	64.9
• Brain	6826	4608	67.5
• Acute myeloid leukaemia	3677	1167	31.7
Chronic			
• Head and Neck	7238	3095	42.8
• Small Intestine	1011	470	46.5
• Nasal cavities and sinuses	535	274	51.2
• Ovary and uterine adnexa	4269	2218	52.0
• Multiple Myeloma	3056	823	26.9



• Acute lymphatic leukaemia	138	35	25.4
• Chronic myeloid leukaemia	894	202	22.6
Total	142041	73018	51.4

Source: BCR linked to IMA-AIM data

Table 3 –Cancer patients who received palliative care at the end of their life by region (year of death=2020, incidence years 2018-2020 included)

	All Tumours			Acute Tumours			Chronic Tumours		
	Total	Receiving palliative care		Total	Receiving palliative care		Total	Receiving palliative care	
	N	n	%	N	n	%	N	n	%
Brussels	721	350	48.5	623	310	49.8	98	40	40.8
Flanders	5537	3423	61.8	4896	3117	63.7	641	306	47.7
Wallonia	3385	1705	50.4	2930	1551	52.9	455	154	33.8
Total	9643	5478	56.8	8449	4978	58.9	1194	500	41.9

Source: BCR linked to IMA-AIM data. Note that the region corresponds to the region of the residence of the patient at time of diagnosis.

In the financing of palliative care, patients are recognized as palliative patient when they have a life expectancy between 24 hours and three months. With this definition, patients are often recognized too late as palliative patient. Since the second half of 2018, a new definition was published in the law to identify a palliative patient at an earlier stage, based on fragility. This new definition is based on the Palliative Care Indicator Tool (PICT) scale, in which the first question is “Would you be surprised if your patient would decrease in the coming 6 to 12 months?”.⁶ This new definition, however, is not yet used in the financing of palliative care. One exception: from November 2022 a new nomenclature fee was introduced, notably for advance care planning discussions with palliative care patients. Identification of eligible patients for these discussions is based on the PICT scale.

Key points

- **Analysis of national data shows that 57% of the cancer patients who died in 2020 received palliative care. This percentage has increased over the years.**
- **There is variation in palliative care according to the tumour type. Patients with haematological tumours appear to receive less palliative care compared to other cancer patients.**
- **A higher proportion of cancer patients received palliative care in Flanders (62%) compared to Wallonia (50%) and Brussels (49%).**
- **Data from abroad is lacking for international comparison.**



References

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