

1.1. Cancer patients who died within one week after start of palliative care (EOL-2)

1.1.1. Documentation sheet

Description	Cancer patients who died within one week after start of palliative care (% of cancer patients with poor prognosis who received palliative care and died)						
Calculation	Numerator: Number of patients who started palliative care and died within one week after start of palliative care Denominator: Total number of patients diagnosed with cancer with poor prognosis who died in the studied time period and who received palliative care						
Rationale	The start of palliative care is sometimes postponed until patients are in a terminal phase of the disease. This can point out either problems of accessibility of end-of-life-care, and/or that the decision to start palliative care was made too late.						
Data source	Belgian Cancer Registry (BCR), linked with IMA-AIM data						
Technical definitions	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.						
	Inclusion criteria						
	Incidence years: 2006-2020						
	Tumour selection based on the Pallcare project ¹ : combination of topography and morphology according to Eurocare-4 ²⁻³ , and Eurocare-5 ⁴ : see EOL-1						
	Patients deceased before July 1 st , 2020						
	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 or 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 proportion may be underestimated as a patient may receive palliative care without nomenclature codes being registered.
	The cause of death is unknown: it is assumed that patients died from their cancer, and hence could benefit from palliative care at the end of their life. Nevertheless, this is probably not 100% correct (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	
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1.1.2. Results

Analysis by the Belgian Cancer Registry shows that over the period 2008-2020 18.7% of the cancer patients who received palliative care services, died within one week after the start of palliative care (see Table 1). Since 2013 the indicator stays below 19%.

The BCR also performed a sub analysis, differentiating between acute versus chronic tumours and by specific tumour type (see Table 2). On average no large differences were found between the group of acute versus the group of chronic tumour types (18.7% versus 19.3% respectively). However, the proportion of patients who died within one week after the start of palliative care differed substantially according to the specific tumour types, ranging from 11.6% in patients with brain cancer to 32.2% in patients

with chronic myeloid leukaemia. Furthermore, the proportion was consistently higher in haematological tumours in comparison to other tumour types (27.3% in acute myeloid leukaemia, 27.0% in multiple myeloma, 20.0% in acute lymphatic leukaemia, 32.2% in chronic myeloid leukaemia).

Evolution over time (2008-2020) for acute tumours showed a slightly decreasing trend. For chronic tumours the numbers are too low to assess a possible trend (see Table 1).

Some differences were observed between the regions (see Table 3). A lower proportion of patients who died within one week after start of palliative care was noted in Flanders (16.7%) compared to Brussels (22.3%) and Wallonia (21.6%).

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Table 1 –Cancer patients receiving palliative care who died within one week after start of palliative care - by year of death (2008-2020) (deaths in 2006, 2007 and 2021 excluded, maximum 3 years of follow-up)

	All T	umours	Acu	te Tumours	Chron	Chronic Tumours			
	Patients with palliative care			Patients with palliative care	Died within one	Died within one week		Died within one week	
	N	n	%	N	n	%	N	n	%
2008	4604	955	20.7	4098	837	20.4	506	118	23.3
2009	4538	886	19.5	4024	795	19.8	514	91	17.7
2010	4807	969	20.2	4320	868	20.1	487	101	20.7
2011	4982	944	18.9	4505	863	19.2	477	81	17.0
2012	5133	1000	19.5	4620	890	19.3	513	110	21.4
2013	5195	975	18.8	4677	888	19.0	518	87	16.8
2014	5449	957	17.6	4943	856	17.3	506	101	20.0
2015	5267	989	18.8	4741	890	18.8	526	99	18.8
2016	5252	975	18.6	4750	887	18.7	502	88	17.5
2017	5072	877	17.3	4596	788	17.1	476	89	18.7
2018	4934	890	18.0	4496	801	17.8	438	89	20.3
2019	5151	892	17.3	4631	786	17.0	520	106	20.4
2020	5478	1019	18.6	4978	927	18.6	500	92	18.4
Total	65862	12328	18.7	59379	11076	18.7	6483	1252	19.3

Source: BCR linked to IMA-AIM data

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Table 2 – Cancer patients receiving palliative care who died within one week after start palliative care - by tumour type (all patients incidence years 2006-2020, maximum 3 years of follow-up)

	Patients with palliative care	Died within	one week
	N	n	%
Acute	65901	12341	18.7
Oesophagus	3537	670	18.9
• Stomach	4997	963	19.3
Liver, primary	3377	780	23.1
Gallbladder and biliary Tract	1900	380	20.0
Pancreas	10016	1863	18.6
Lung, bronchus and trachea	34662	6601	19.0
Pleura	1637	231	14.1
• Brain	4608	534	11.6
Acute myeloid leukaemia	1167	319	27.3
Chronic	7117	1372	19.3
Head and Neck	3095	574	18.6
Small Intestine	470	100	21.3
Nasal cavities and sinuses	274	46	16.8
Ovary and uterine adnexa	2218	358	16.1
Multiple Myeloma	823	222	27.0
Acute lymphatic leukaemia	35	7	20.0
Chronic myeloid leukaemia	202	65	32.2
Total	73018	13713	18.8

Source: BCR linked to IMA-AIM data

Table 3 –Cancer patients receiving palliative care who died within one week after start of palliative care - by region (year of death=2020, incidence years 2018-2020 included)

	All Tu	mours		Acute Tun	ours	Chronic Tu	Chronic Tumours		
	Patients with palliative care	Died within one week		Patients with palliative care	Died within one week		Patients with palliative care	Died within one week	
	N	n	%	N	n	%	N	n	%
Brussels	350	78	22.3	310	69	22.3	40	9	22.5
Flanders	3423	573	16.7	3117	522	16.7	306	51	16.7
Wallonia	1705	368	21.6	1551	336	21.7	154	32	20.8
Total	5478	1019	18.6	4978	927	18.6	500	92	18.4

Source: BCR linked to IMA-AIM data



Key points

- The start of palliative care very close to the time of death is an indicator of the (in)appropriateness of timing of palliative care.
- In nearly one out of five patients with cancer who received palliative care, palliative care started in a very late phase (i.e. one week or less before death) (18.6% in 2020). The majority of patients received palliative care for more than one week.
- Substantial variation between different tumour types regarding start of palliative care in a very late phase was observed, with brain tumours (11.6%) and chronic myeloid leukaemia (32.2%) as the extremes. A generally higher percentage of start of palliative care very close to the time of death was observed in patients with haematological tumours.
- A lower proportion of patients who died very shortly after the start of palliative care was found in the Flanders (16.7%) compared to Brussels (22.3%) and Wallonia (21.6%).

References

- 1. Gielen B, De Gendt C, De Schutter H, Henin E, Ceuppens A, Peltier A, et al. Hospitalisaties bij het levenseinde van kankerpatiënten. 2013.
- 2. De Angelis R, Francisci S, Baili P, Marchesi F, Roazzi P, Belot A, et al. The EUROCARE-4 database on cancer survival in Europe: data standardisation, quality control and methods of statistical analysis. Eur J Cancer. 2009;45(6):909-30.
- 3. Sant M, Allemani C, Santaquilani M, Knijn A, Marchesi F, Capocaccia R. EUROCARE-4. Survival of cancer patients diagnosed in 1995-1999. Results and commentary. Eur J Cancer. 2009;45(6):931-91.
- 4. Rossi S, Baili P, Capocaccia R, Caldora M, Carrani E, Minicozzi P, et al. The EUROCARE-5 study on cancer survival in Europe 1999-2007: Database, quality checks and statistical analysis methods. Eur J Cancer. 2015;Oct 51(15):2104-19.