



6. Koninklijk Besluit van 21 oktober 2018 gepubliceerd op 20 november 2018. Koninklijk besluit tot vaststelling van de criteria om een palliatieve patiënt te definiëren 2018.
7. Leemans K, Cohen J, Werrebrouck B. Kwaliteitsindicatoren voor de palliatieve zorg. Waar staan we en wat is de toekomst? Beleidsrapport. Available from: http://www.endoflifecare.be/sites/default/files/beleidsrapport_qi_06-04-1.pdf

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

13.2.1. Documentation sheet

Description	Cancer patients who started receiving palliative care and died within one week after start of palliative care
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 that died in the studied time period and who received palliative care services
Rationale	The start of palliative care is sometimes postponed until patients are in a terminal phase of the disease. This can denote either problems of accessibility of end of life care, or that the decision on the start of palliative care was made too late.
Data source	Belgian Cancer Registry (BCR), linked with IMA 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 having a poor prognosis and deceased during the study period.</p> <p><u>Inclusion Criteria</u></p> <p>Incidence years: 2006-2015</p> <p>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</p> <p>Patients deceased before January 1st 2017</p> <p>Age at diagnosis ≥ 18 years</p> <p><u>Exclusion Criteria</u></p> <p>Patients with more than one invasive tumour (until 2015)</p> <p>Patients without a Belgian residence</p> <p>Patients without national social security number</p> <p>Patients for whom no IMA data of the year of death were available (=3.9%)</p> <p>Patients with an uncertain date of diagnosis</p>



	<p><u>Maximum 3 years of follow-up</u></p> <p>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 in order to assure that for every diagnosis, the same follow-up period could be taken into account. By applying this definition, a bias induced by varying length of the follow-up period could be avoided.</p> <p><u>Palliative care</u></p> <p>Palliative care as identified in billing data includes patients receiving 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.</p>
Limitation	<p>Real proportion may be underestimated as patient may receive palliative care without nomenclature codes being registered.</p> <p>Cause of death is unknown: it is assumed that patients died from the cancer, and hence required palliative care at the end of their life, but this is probably not the case for 100% of the patients (e.g. patients dying from other causes, patients requesting euthanasia).</p> <p>No information on terminal patients apart from the oncology setting.</p>
International comparability	This is not an international indicator. Some results are available in national reports or in specific scientific articles.
Dimensions	Accessibility
Key-words	End-of-life; palliative care service; timeliness

13.2.2. Results

Analysis by the Belgian Cancer Registry shows that over the period 2008-2015 19.2% of the cancer patients who received palliative care services, died within one week after the start of palliative care (see Table 121). Analysis showed a discrete downward evolution between 2008 and 2015 (20.8% versus 18.9%) (Table 121).

The BCR also performed a sub analysis, differentiating between acute and chronic tumour types (see Table 122). The proportion of patients who died within one week after start of palliative care differed substantially among the different tumour types, ranging from 11.6% in patients with brain cancer to 35.4% in patients with acute lymphatic leukaemia. On average no differences were found between the combined acute and chronic tumour

types (19.1% versus 19.3% respectively). However, the proportion of patients dying within one week after start of palliative care was consistently higher in haematological tumours in comparison to other tumour types (26.8% in acute myeloid leukaemia, 27.3% in multiple myeloma, 35.4% in acute lymphatic leukaemia, 29.4% in chronic myeloid leukaemia).

Evolution over time per tumour type (i.e. acute versus chronic type) showed a more or less stable trend for both categories between 2008 and 2015 (see Table 121).

Some differences were observed between the Regions (see Table 123) in that a lower proportion of patients who died within one week after start of palliative care was noted in the Flemish Region (16.3%) compared to the Brussels-Capital Region (23.0%) and Walloon Region (21.7%).



Table 121 – Proportion of patients who died within one week after start of palliative care, by year of death (2008-2015) (deaths in 2006, 2007 and 2016 excluded, maximum 3 years of follow-up)

	All Tumours			Acute Tumours			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	%
2008	4 603	956	20,8	4 093	837	20,4	510	119	23,3
2009	4 543	889	19,6	4 024	795	19,8	519	94	18,1
2010	4 810	969	20,1	4 321	870	20,1	489	99	20,2
2011	4 982	948	19,0	4 500	863	19,2	482	85	17,6
2012	5 129	1 003	19,6	4 608	889	19,3	521	114	21,9
2013	5 176	973	18,8	4 658	886	19,0	518	87	16,8
2014	5 436	955	17,6	4 930	853	17,3	506	102	20,2
2015	5 257	993	18,9	4 727	891	18,8	530	102	19,2
Total	39 936	7 686	19,2	35 861	6 884	19,2	4 075	802	19,7

Source: BCR linked to IMA data

Table 122 – Proportion of patients who died within one week after start palliative care by tumour type (all patients 2006-2015, maximum 3 years of follow-up)

	Patients with palliative care		Died within one week	
	N		n	%
Acute	43 493		8 324	19,1
• Oesophagus	2 326		450	19,4
• Stomach	3 440		677	19,7
• Liver, primary	1 992		477	24,0
• Gallbladder and biliary Tract	1 214		238	19,6
• Pancreas	6 149		1 179	19,2
• Lung, bronchus and trachea	23 628		4 599	19,5



• Pleura	1 073	168	15,7
• Brain	2 948	342	11,6
• Acute myeloid leukaemia	723	194	26,8
Chronic	4 892	944	19,3
• Head and Neck	2 114	384	18,2
• Small Intestine	304	64	21,1
• Nasal cavities and sinuses	192	36	18,8
• Ovary and uterine adnexa	1 544	251	16,3
• Multiple Myeloma	554	151	27,3
• Acute lymphatic leukaemia	65	23	35,4
• Chronic myeloid leukaemia	119	35	29,4
Total	48 385	9 268	19,2

Source: BCR linked to IMA data

Table 123 – Proportion of patients who died within one week after start of palliative care, by region (year of death=2015, incidence year 2006-2009 excluded)

	All Tumours			Acute Tumours			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-Capital Region	395	91	23,0	336	81	24,1	59	10	16,9
Flemish Region	3 840	626	16,3	3 375	536	15,9	465	90	19,4
Walloon Region	1 842	400	21,7	1 572	348	22,1	270	52	19,3
Total	6 077	1 117	18,4	5 283	965	18,3	794	152	19,1

Source: BCR linked to IMA data



Key points

- **The start of palliative care very close to the time of death is an indicator of both the accessibility of palliative care services and of the appropriateness of timing of palliative care.**
- **In one out of five patients with cancer with poor prognosis who received palliative care, palliative care started in a very late phase (i.e. one week or less before death) (19%). 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 acute lymphatic leukaemia (35.4%) as the extremes. A generally higher percentage of start of palliative care very close to the time of death was observed in haematological tumours.**
- **A lower proportion of patients who started palliative care in a very late stadium was found in Flanders (16.3%) compared to the Brussels-Capital (23.0%) and Walloon Region (21.7%).**

References

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