



1.1. Death at usual place of residence (at home or in residential care) (EOL-4)

1.1.1. Documentation sheet

Description	Percentage of cancer patients dying at their usual place of residence (at home or in residential care) (% of cancer patients with poor prognosis who died)
Calculation	Numerator: number of patients who died at home or in residential care Denominator: number of patients diagnosed with cancer who died within the studied time period
Rationale	Studies show that most people prefer to die at home. ¹ In order to meet patients' preferences, palliative care services in Belgium are being oriented towards a more home-focused approach with maximum support for patients and relatives to stay at home, or in a home-replacing environment (e.g. a home for older people).
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 who 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: see EOL-1</p> <p>Patients deceased before July 1st, 2021</p> <p>Age at diagnosis ≥18 years</p> <p><u>Exclusion criteria</u></p> <p>Patients with more than one invasive tumour (until 2020)</p> <p>Patients without a Belgian residence at time of diagnosis</p> <p>Patients without national social security number</p> <p>Patients for whom no IMA data of the year of death were available (=4.1%)</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 to assure that for every diagnosis, a similar follow-up period could be taken into account and to avoid bias by varying length of follow-up period.</p> <p><u>Place of death</u></p> <ul style="list-style-type: none"> Dying at home and in residential care: derived from the reimbursement of (pseudo)nomenclature codes.



- Dying in the hospital: derived from the hospitalisation information as obtained from the IMA-AIM HOSP database. Of note, this database aggregates detailed administrative reimbursement data on hospitalisation level through an internally validated algorithm.⁶ One-day hospitalisations were not taken into account as hospitalisations.

To determine the place where the patient died, the algorithm of the Pallcare project was used. The place of death was determined using the following priority:

- Date of death = end date/date of medical act ^a
 - End date for hospitalisation equals the day of death
 - End date for residential care equals the day of death
 - Home nursing at day of death
- Date of death – 1 = end date/date of medical act
 - End date for residential care one day before day of death
 - Home nursing one day before day of death
 - End date for hospitalisation one day before death
- Date of death – 2 or 3 = end date/date medical act
 - End date for residential care two or three days before death
 - Home nursing two or three days before death
- Home nursing during last week before death

Limitation	There is no data on end-of-life care for terminally ill patients without the diagnosis of cancer.
International comparability	This is not an internationally reported indicator. Some results are available in national reports or in specific scientific articles.
Dimensions	End-of-life care; Quality (patient centeredness); Quality (Effectiveness)
Reviewers	Cindy De Gendt (BCR), Lien Van Walle (BCR)

^a End dates of hospital or residential care and home nursing acts until a week after death (due to administrative errors) are considered as on the date of death.



1.1.2. Results

Over the period 2008-2020 the majority of cancer patients in the analysis died in the hospital (63.4%), 23.0% died at home and 6.0% died in residential care (see Table 1). Over the period 2008-2019, the proportion of cancer patients who died at home was more or less stable. In 2020 however there was an increase to 28.6% (from 22.6% in 2019), likely linked to the COVID-19 pandemic. Furthermore, from 2019 onwards it seems that data on deaths in residential care setting are not complete; we notice both a decrease in deaths in residential care and an increase in deaths in undefined place since that year.

Although 2020 is an atypical year, also in that year a continuation of some trends can be observed. First, the proportion of patients who died at home was lower in patients with chronic tumour types (19.4%) compared to acute tumour types (29.9%) (see Figure 1). Second, analysis of place of death per region showed a discrepancy between Brussels and the two other regions: in Brussels, fewer people died at home (19.1% vs 30.8% in Flanders and 27.1% in Wallonia) and more people were admitted to a hospital at time of death (66.0% vs 54.7% and 57.8% respectively) (see Figure 2).

Remarkably, in the year 2020 nearly no deaths occurred in residential care in Flanders. For 14.4% of deaths however the place of death is undefined (in Flanders).

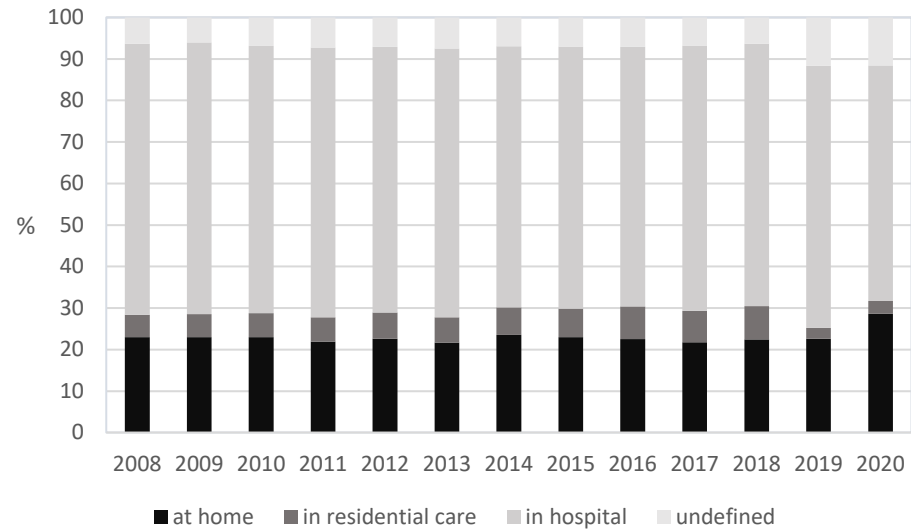
Table 1 – Place of death in cancer patients (2008-2020) by year of death, all tumours (deaths in 2006, 2007 and 2021 excluded, maximum 3 years of follow-up)

	Total	Died at home		Died in residential care		Died in hospital		Place of death undefined	
	N	n	%	n	%	n	%	n	%
2008	9597	2204	23.0	517	5.4	6270	65.3	606	6.3
2009	9455	2175	23.0	522	5.5	6190	65.5	568	6.0
2010	9873	2271	23.0	573	5.8	6351	64.3	678	6.9
2011	9950	2178	21.9	587	5.9	6465	65.0	720	7.2
2012	10059	2271	22.6	638	6.3	6433	64.0	717	7.1
2013	10120	2197	21.7	615	6.1	6554	64.8	754	7.5
2014	10048	2362	23.5	665	6.6	6325	63.0	696	6.9
2015	9876	2273	23.0	672	6.8	6236	63.1	695	7.0
2016	9773	2204	22.6	763	7.8	6112	62.5	694	7.1
2017	9472	2062	21.8	718	7.6	6050	63.9	642	6.8
2018	9409	2110	22.4	757	8.1	5942	63.2	600	6.4
2019	9467	2142	22.6	247	2.6	5975	63.1	1103	11.7
2020	9643	2762	28.6	298	3.1	5464	56.7	1119	11.6
Total	126742	29211	23.0	7572	6.0	80367	63.4	9592	7.6

Source: BCR linked to IMA-AIM data



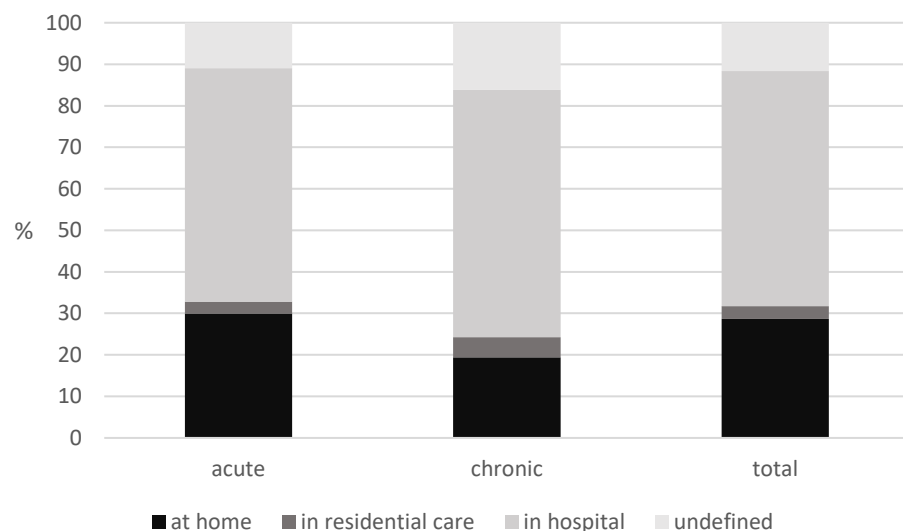
Figure 1 – Place of death in cancer patients (2008-2020) by year of death, all tumours (deaths in 2006, 2007 and 2021 excluded, maximum 3 years of follow-up)



Source: BCR linked to IMA-AIM data



Figure 2 – Place of death of patients diagnosed with an acute versus chronic tumour type (year of death=2020, incidence years 2018-2020 included)



Source: BCR linked to IMA-AIM data

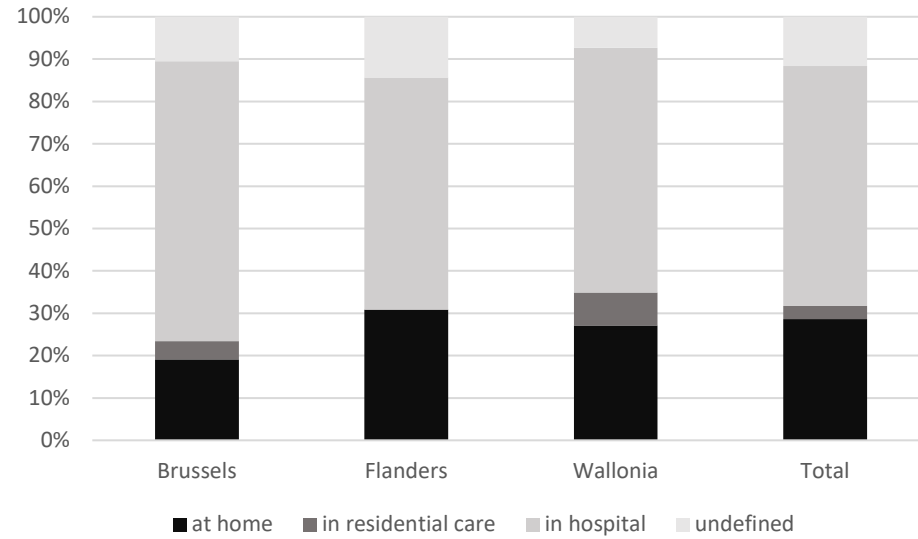
Table 2 – End of life: Place of death, by Region, all tumours (year of death=2020, incidence years 2018-2020 included)

	Total	Died at home		Died in residential care		Died in hospital		Place of death undefined	
		N	%	N	%	N	%	N	%
Brussels	721	138	19.1	31	4.3	476	66.0	76	10.5
Flanders	5537	1707	30.8	3	0.1	3031	54.7	796	14.4
Wallonia	3385	917	27.1	264	7.8	1957	57.8	247	7.3
Total	9643	2762	28.6	298	3.1	5464	56.7	1119	11.6

Source: BCR linked to IMA-AIM data



Figure 3 – Place of death, by region, all tumours (year of death=2020, incidence years 2018-2020 included)



Source: BCR linked to IMA-AIM data



Key points

- **The majority of cancer patients, about two out of every three, dies in the hospital. Around 23% of the patients die at home. Around 7% of the patients die in residential care.**
- **Over the period 2008-2019, there is a more or less stable trend in deaths at home, but in 2020 there is an increase from 23 to 29% of deaths at home. This increase is likely a consequence of the COVID-19 pandemic.**
- **In 2020, in patients with chronic tumour types the proportion of patients who died at home was lower compared to patients with acute tumour types (19.4% versus 29.9%).**
- **There is some regional variation in the place of death. In Flanders generally more people die at home (30.8% in 2020) compared to Wallonia (27.1%) and Brussels (19.1%).**

References

1. Gomes B, Calanzani N, Gysels M, Hall S, Higginson I. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*. 2013;12(7).
2. Gielen B, De Gendt C, De Schutter H, Henin E, Ceuppens A, Peltier A, et al. Hospitalisaties bij het levenseinde van kankerpatiënten. 2013.
3. De Angelis R, Francisci S, Baili P, Marchesi F, Roazzi P, Belot A, et al. The EUROCORE-4 database on cancer survival in Europe: data standardisation, quality control and methods of statistical analysis. *Eur J Cancer*. 2009;45(6):909-30.
4. Sant M, Allemani C, Santaquilani M, Knijn A, Marchesi F, Capocaccia R. EUROCORE-4. Survival of cancer patients diagnosed in 1995-1999. Results and commentary. *Eur J Cancer*. 2009;45(6):931-91.
5. Rossi S, Baili P, Capocaccia R, Caldora M, Carrani E, Minicozzi P, et al. The EUROCORE-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.
6. Camberlin C, Dubois C, Di Zinno T, Préal R, Guillaume J, Van de Reydt R, et al. Coupling of the Permanent Sample with the Hospital Data: Feasibility and data representativeness study. *KCE Reports 208 Brussels: Belgian Healthcare Knowledge Centre (KCE); 2013. Health Services Research (HSR) D/2013/10.273/64*