

Using linked administrative and disease-specific databases to study end-of-life care on a population level

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Project goals

Identify, monitor and evaluate End-of-life Care on a full population level, across different trajectories of dying (COPD, cancer, Alzheimer's disease)

1. Mapping direct costs and resource use near the end of life
2. Monitoring quality of end-of-life care on a population level

Value big data and challenge of linking and using administrative data

VALUE

- Include subgroups or difficult-to-reach populations
- Continuously collected and inexpensive compared to original data collection

CHALLENGE

- Not specifically designed for research purposes
- Collect, link, integrate, store and process administrative data for EOLC research

Administrative population-level data providing a unique opportunity

Fiscal data

Net taxable income

Cancer Registry

Cancer diagnoses

Death certificate

Causes of death

Census data

socio-economic position



Population database

socio-demographics

Hospital database

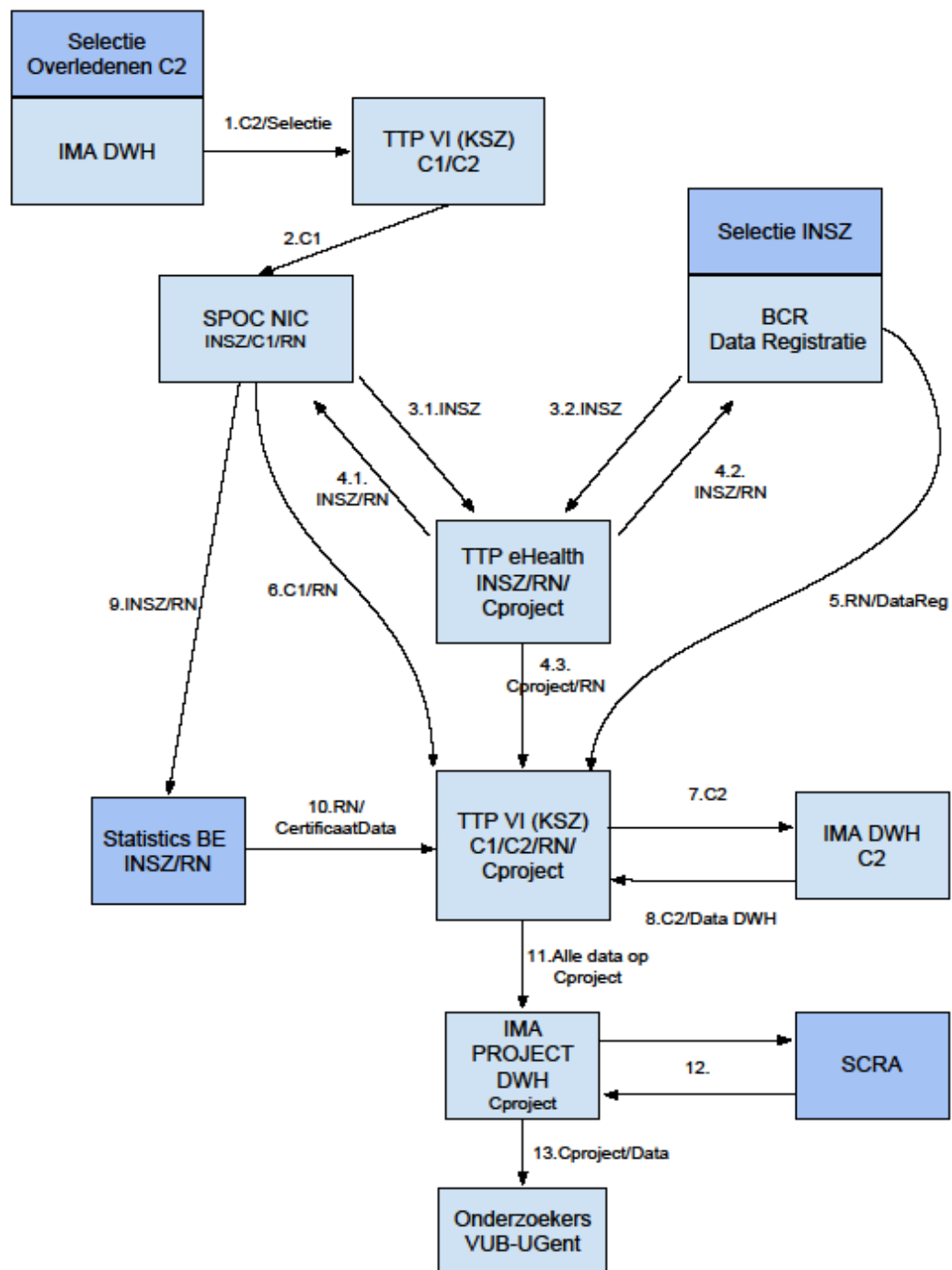
All hospital treatment

Pharma database

All prescribed medication

Health claims database

All reimbursed treatment





Population level evaluation of the quality of end-of-life care



Increasing appropriateness of end-of-life care is a public health concern

- Appropriate care is not an individual patient's concern
- The health care system should support appropriate rather than inappropriate care
- Increasing the appropriateness of care requires population level monitoring

We developed quality indicators to evaluate appropriateness of end-of-life care using such data

Cancer, COPD, Alzheimer's disease (3 * 26)

- Aggressiveness of care
- Pain and symptom treatment
- Palliative care
- Place of treatment and place of death
- Coordination and continuity of care

Administrative Data

Quality indicators



Measurement of quality of care

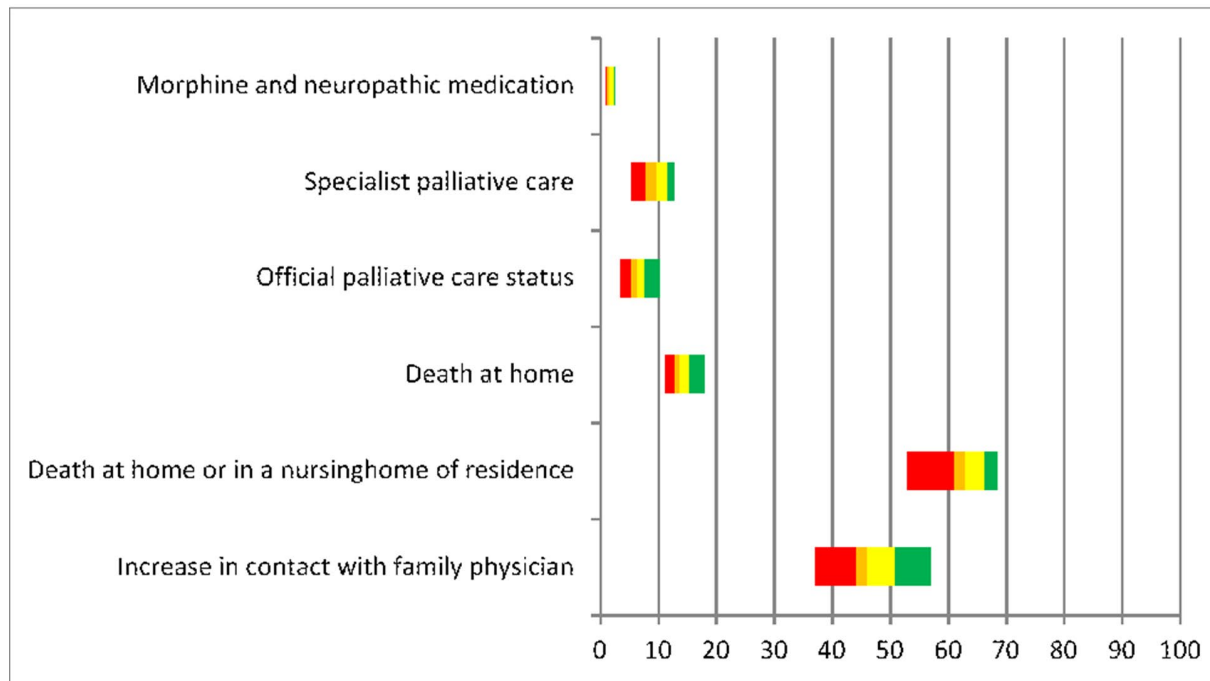
Example

“When X% of people who died from Alzheimer’s disease has an emergency room visit, 2 weeks before death or later, that is an indication of possibly inappropriate end of life care”

- X%?
- Clearly defined population
- Specific treatment or medication
- In a specific time frame

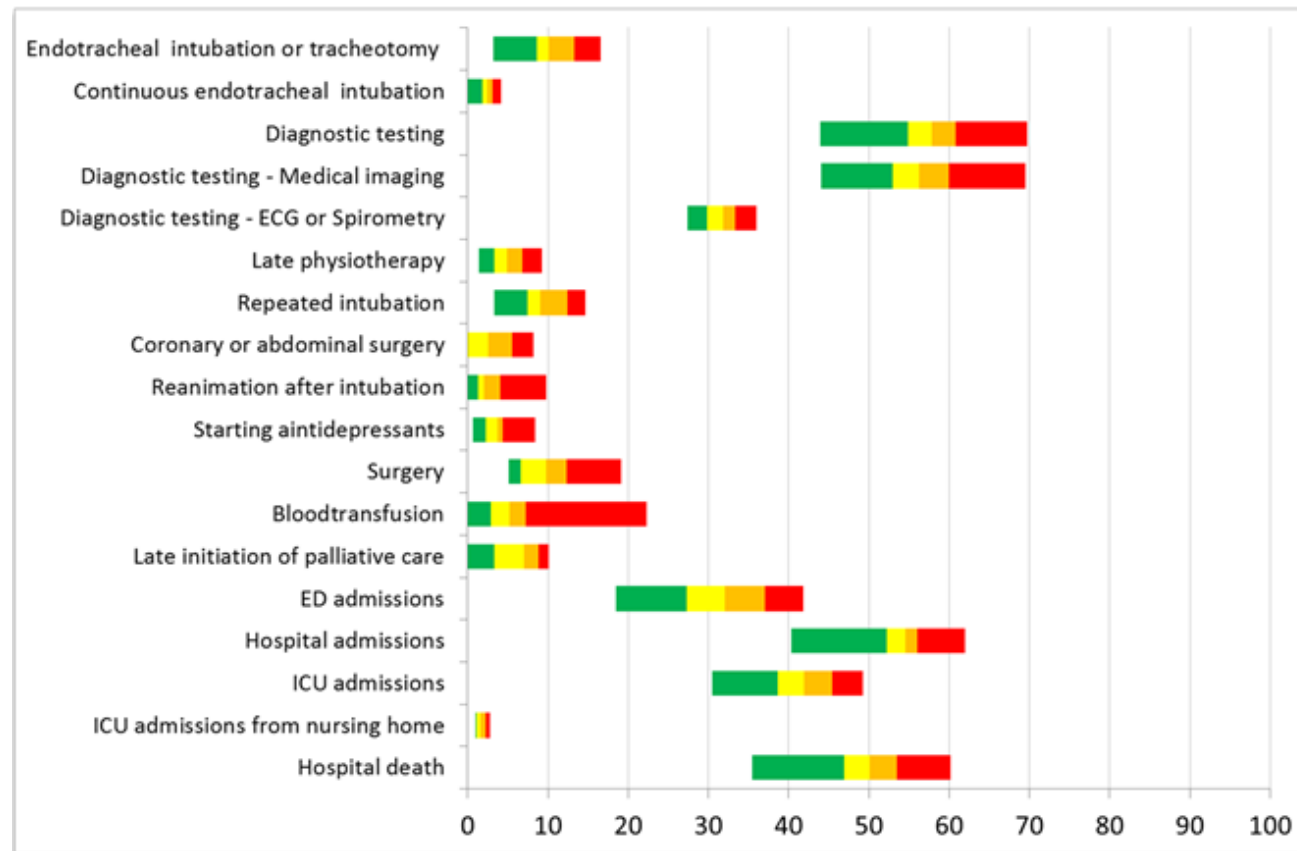
Results

Figure 1: Risk adjusted comparison between all health care regions in Flanders on indicators indicating appropriate end-of-life care, within the total population dying from dementia (N=11,410), Belgium, 2012



We used the period of 30 days before death for all indicators, or closer to death if the indicator was validated only for a shorter period before death.

Figure 2: Risk adjusted comparison between all health care regions in Flanders on indicators indicating inappropriate end-of-life care, within the total population dying from COPD (N=4,231), Belgium, 2012



We used the period of 30 days before death for all indicators, or closer to death if the indicator was validated only for a shorter period before death.

Resource use and costs of End-Of-Life Care
For Non-Cancer Patients In Belgium:
a health resource and economic analysis.



- 10-25% of all healthcare expenditures can be related to the last year of life
- Main factors: hospitalization, use of SNF, number of inpatient procedures
- Most evidence based on cancer or small samples non-cancer

Challenge

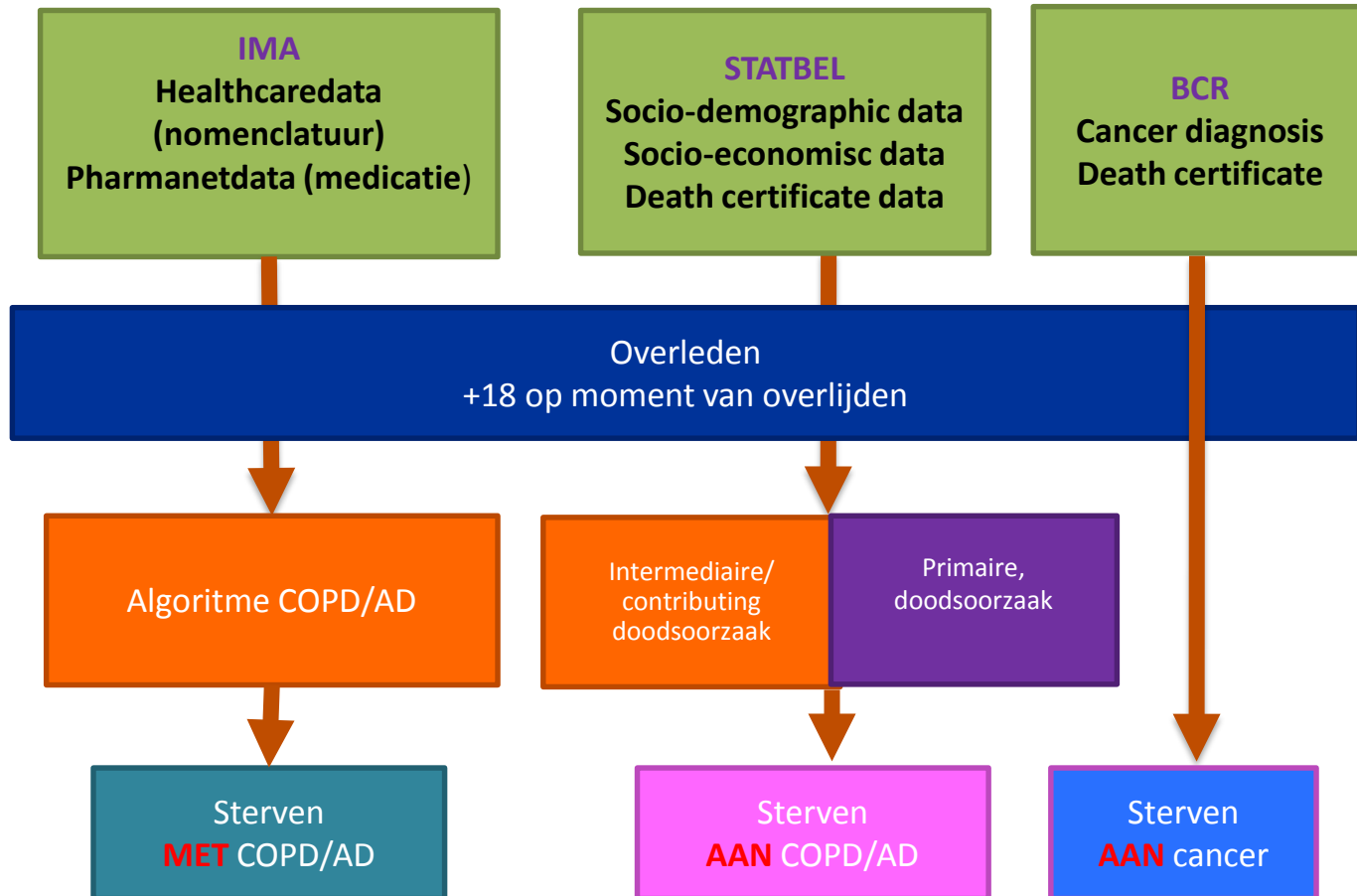
What influences the intensity and costs of end of life care for non-cancer diseases in Belgium?

Research Questions

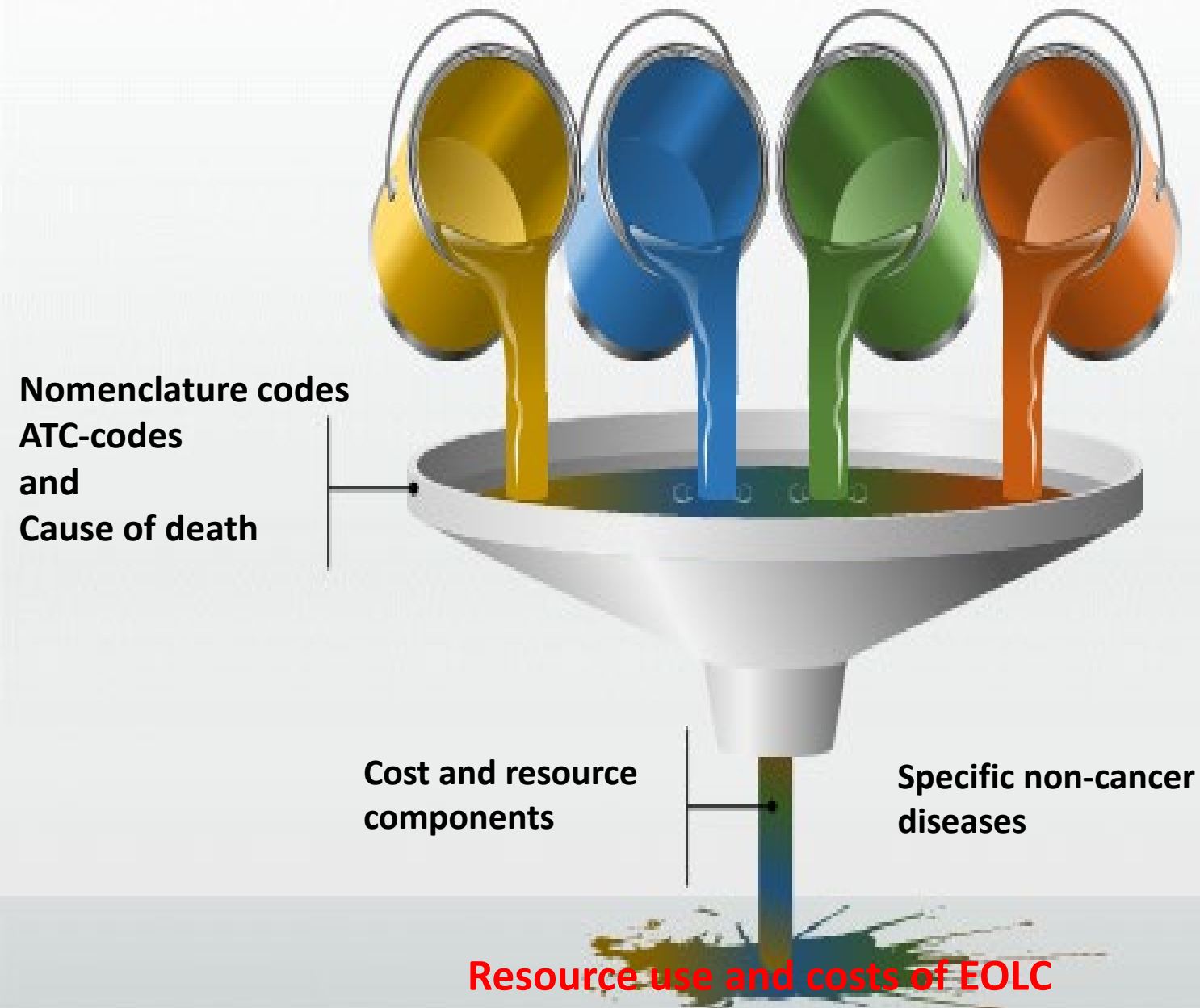
1. Do Lung cancer and cardiovascular disease influence resource use in COPD patients at life's end?
2. Is dying with Alzheimer's disease influenced by related morbidities?
3. What specific cost-components influence end-of-life care costs during the last year of life between cancer, COPD and Alzheimer's disease?

Can we evaluate end-of-life resource use and costs on a full population basis with administrative data?

Identification of non-cancer diseases: COPD and Alzheimer's disease (AD)



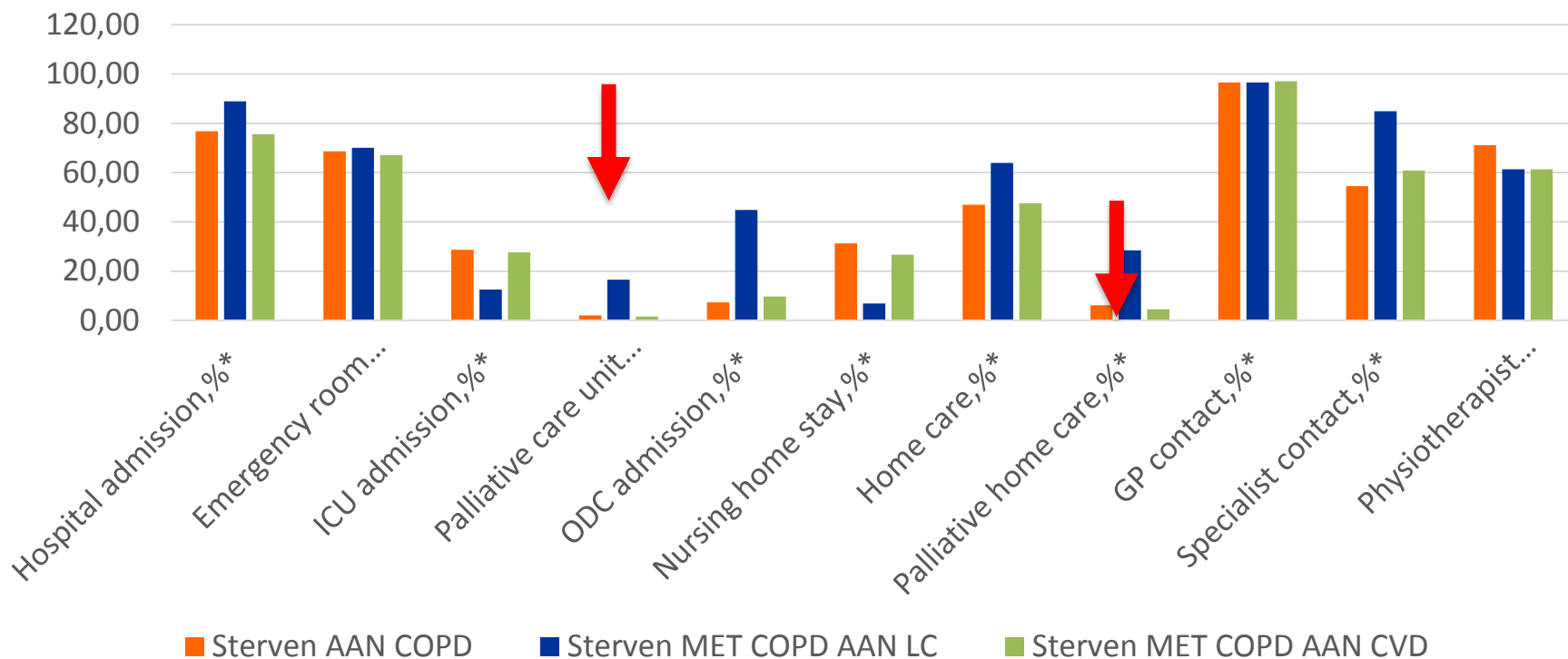
Statbel, IMA and BCR data



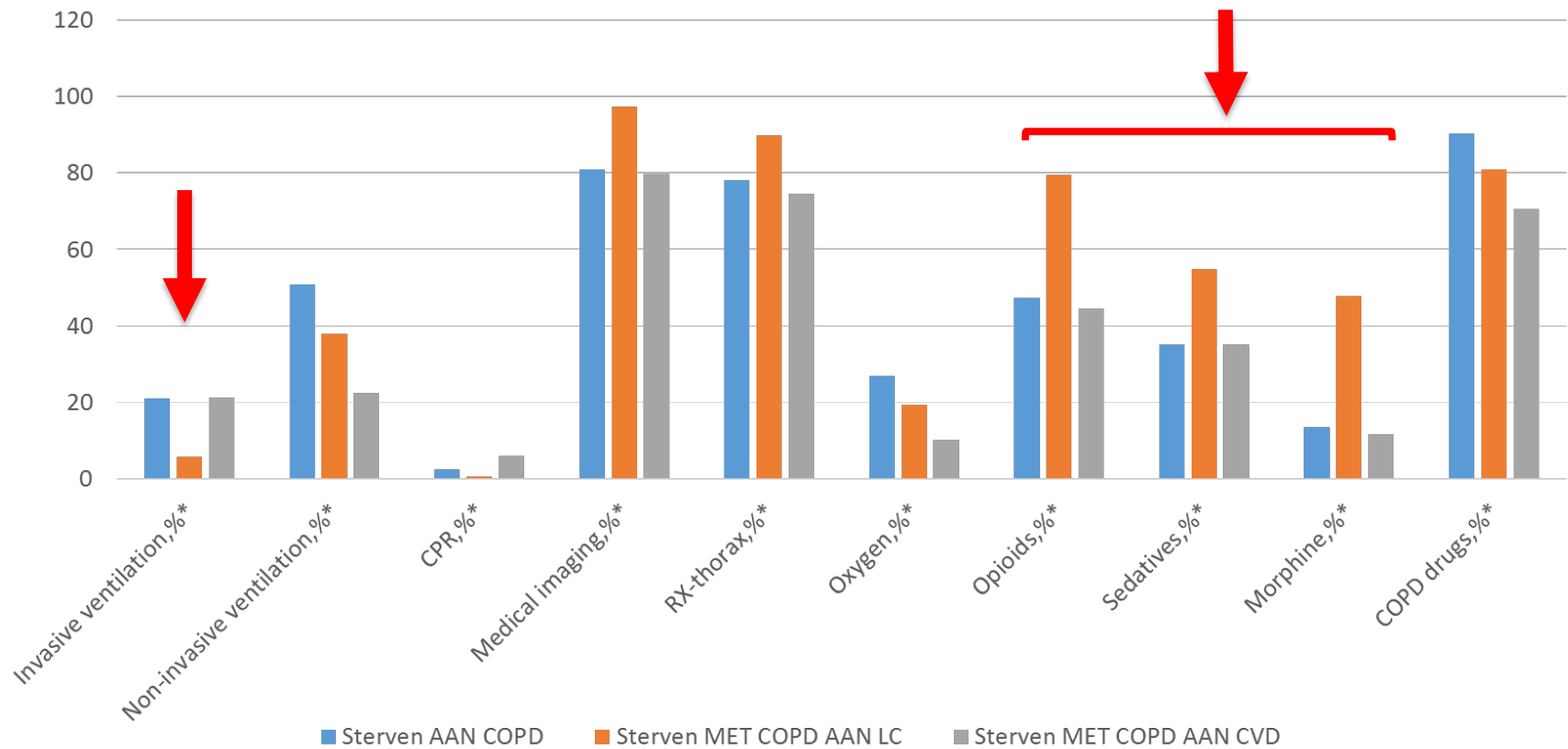
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Zorggebruik laatste 6 maanden sterven aan COPD, met COPD aan LC of CVD



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Table 2. Resource Use During the Last 180, 90, and 30 Days of Life of Individuals Dying with and of Alzheimer's Disease

Resource	With, n=8,804			Of, n=2,606			Relative Risk (95% Confidence Interval)		
	180 days	90 days	30 days	180 days	90 days	30 days	180 days	90 days	30 days
Hospital admission, %	61.1	53.1	36.5	40.5	32.9	17.7	1.5 (1.4–1.6)	1.6 (1.5–1.7)	2.1 (1.9–2.3)
Hospital days, mean (95% CI)	16.5 (16.1–16.9)	15.1 (14.7–15.4)	10.0 (9.7–10.2)	17.1 (16.2–18.0)	16.0 (15.1–16.7)	10.7 (10.1–11.4)			
ICU admission, %	8.8	7.5	5.9	2.0	1.7	1.2	4.5 (3.4–5.9)	4.6 (3.4–6.2)	4.8 (3.4–6.7)
ICU LOS, mean (95% CI)	3.4 (3.1–3.6)	3.4 (3.1–3.7)	3.4 (3.1–3.7)	2.8 (2.0–3.7)	2.8 (1.8–3.8)	3.2 (1.9–4.6)			
PCU admission, %	2.2	2.1	2.0	1.2	1.2	1.2	1.8 (1.2–2.6)	1.8 (1.2–2.6)	1.8 (1.2–2.6)
PCU LOS, mean (95% CI)	8.2 (7.2–9.3)	8.1 (7.1–9.1)	7.4 (6.4–8.4)	6.3 (4.1–8.6)	6.3 (4.1–8.6)	6.0 (3.6–8.4)			
One-day care admission, %	4.6	2.3	1.2	1.9	1.1	0.4	2.5 (1.8–3.3)	2.5 (1.7–3.6)	3.2 (1.7–6.2)
Nursing home stay, %	70.1	69.7	68.2	80.0	79.8	78.5	0.9 (0.9–0.9)	0.9 (0.9–0.9)	0.9 (0.8–0.9)
Home care, %	32.4	27.5	20.1	25.4	21.7	16.7	1.3 (1.2–1.4)	1.3 (1.2–1.4)	1.2 (1.1–1.3)
Palliative home care, %	5.5	5.3	5.1	6.8	6.8	6.7	0.8 (0.7–1.0)	0.8 (0.7–0.9)	0.8 (0.6–0.9)
Number of palliative home care days, mean (95% CI)	63.2 (57.2–69.2)	40.5 (37.4–43.6)	18.8 (17.8–19.9)	83.5 (72.6–94.4)	50.7 (45.3–56.1)	22.1 (20.4–23.7)			
General practitioner contact, %	97.1	95.1	85.9	96.5	94.6	88.7	1.0 (1.0–1.0)	1.0 (1.0–1.0)	1.0 (1.0–1.0)
Number of general practitioner contacts, mean (95% CI)	12.4 (12.2–12.5)	7.9 (7.8–8.0)	4.6 (4.5–4.7)	12.3 (12.1–12.6)	8.2 (8.0–8.4)	4.9 (4.8–5.0)			
Specialist contact, %	40.8	24.2	8.5	27.9	15.7	5.5	1.5 (1.4–1.6)	1.5 (1.4–1.7)	1.6 (1.3–1.9)
Number of specialist contacts, mean (95% CI)	2.2 (2.1–2.3)	1.6 (1.6–1.7)	1.2 (1.2–1.3)	1.8 (1.7–1.9)	1.5 (1.4–1.5)	1.2 (1.1–1.2)			
Physiotherapist contact, %	47.9	41.5	32.8	37.8	31.8	24.0	1.3 (1.2–1.3)	1.3 (1.2–1.4)	1.4 (1.3–1.5)
Number of physiotherapist contacts, mean (95% CI)	26.4 (25.5–27.2)	17.6 (17.0–18.1)	9.1 (8.9–9.4)	27.3 (25.5–29.2)	18.3 (17.3–19.4)	9.2 (8.7–9.7)			

CI=confidence interval; ICU=intensive care unit; LOS=length of stay; PCU=palliative care unit.



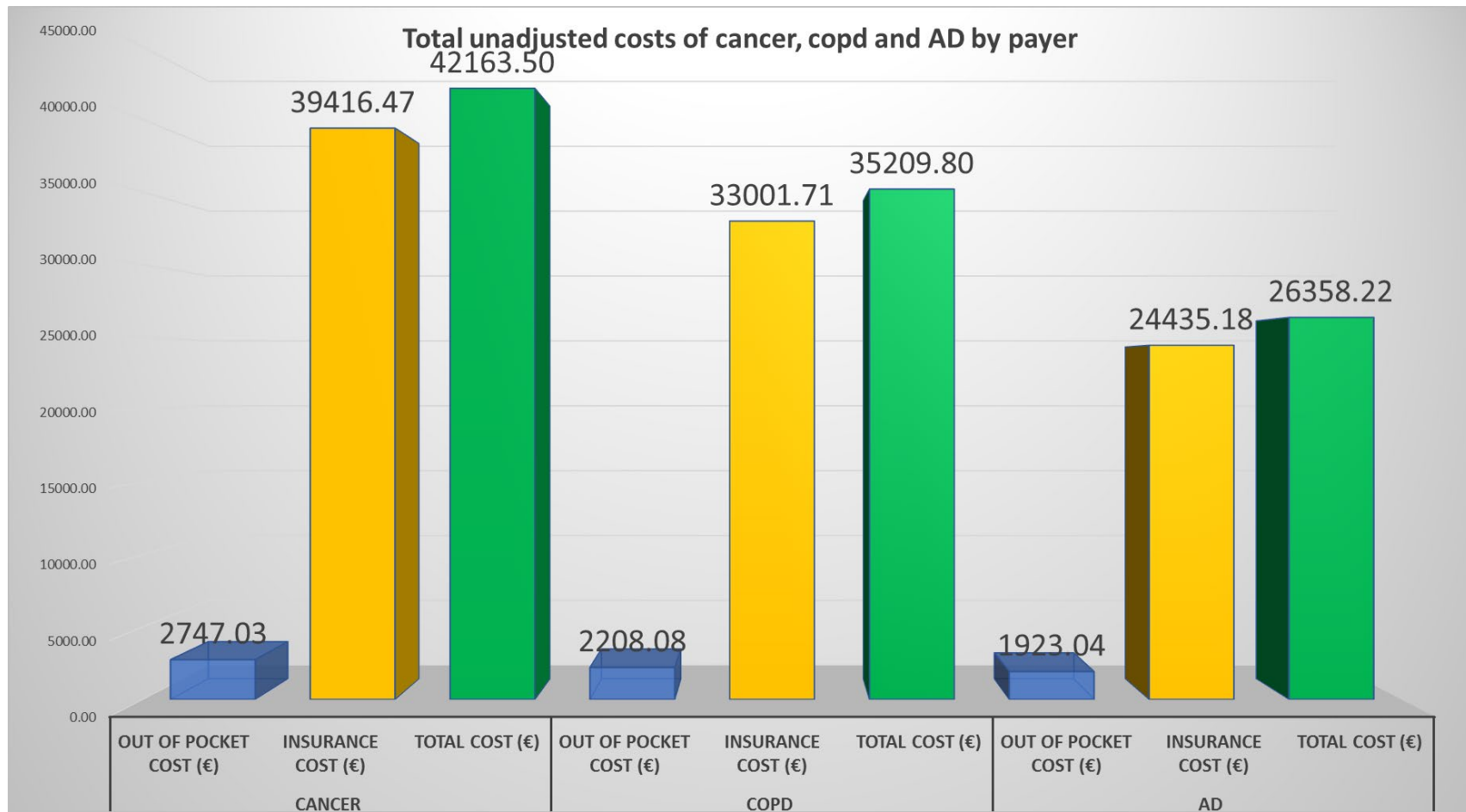
Table 3. Procedures and Medication Use During Last 180, 90, and 30 Days of Life of Individuals Dying with and of Alzheimer's Disease

Procedure	With, n=8,804			Of, n=2,606			Relative Risk (95% CI)		
	180 days	90 days	30 days	180 days	90 days	30 days	180 days	90 days	30 days
Invasive ventilation, %	5.4	4.9	4.4	0.9	0.9	0.8	6.1 (4.0-9.2)	5.6 (3.7-8.5)	5.4 (3.5-8.4)
Days of invasive ventilation, mean (95% CI)	2.0 (1.0-6.0)	2.0 (1.0-6.0)	2.0 (1.0-5.0)	2.0 (1.0-4.0)	2.0 (1.0-4.0)	2.0 (1.0-4.0)			
Noninvasive ventilation, %	10.2	9.5	8.6	10.1	9.7	8.5	1.0 (0.9-1.1)	1.0 (0.9-1.1)	1.0 (0.9-1.2)
Days of noninvasive ventilation, mean (95% CI)	7.0 (4.0-13.0)	6.0 (4.0-9.0)	4.0 (3.0-6.0)	5.0 (4.0-9.0)	5.0 (4.0-7.0)	4.0 (4.0-6.0)			
Gastric tube, %	1.0	0.9	0.5	1.0	1.0	0.5	1.0 (0.6-1.5)	1.0 (0.6-1.5)	1.0 (0.6-2.1)
Cardiopulmonary resuscitation, %	0.8	0.8	0.7	0.1	0.1	0.1	6.8 (2.1-21.6)	6.5 (2.0-20.7)	5.8 (1.8-18.6)
Medical imaging, %	66.0	57.7	44.1	47.0	38.1	23.3	1.4 (1.3-1.5)	1.5 (1.4-1.6)	1.9 (1.8-2.0)
Medication, %									
Oxygen	4.0	3.3	2.6	4.8	4.5	3.7	0.8 (0.7-1.0)	0.7 (0.6-0.9)	0.7 (0.6-0.9)
Opioids	42.7	38.8	34.5	44.9	42.1	37.2	1.0 (0.9-1.0)	1.0 (0.9-1.0)	1.0 (0.9-1.0)
Sedatives	23.2	19.8	15.2	12.2	9.9	6.3	1.9 (1.7-2.1)	2.0 (1.8-2.3)	2.4 (2.1-2.8)
Morphine	9.3	8.5	7.2	6.6	6.4	5.5	1.4 (1.2-1.6)	1.3 (1.1-1.6)	1.3 (1.1-1.6)
Dementia drugs	52.4	43.0	24.5	28.7	21.6	11.0	1.8 (1.7-1.9)	2.0 (1.8-2.1)	2.2 (2.0-2.5)

CI=confidence interval.

Research Questions

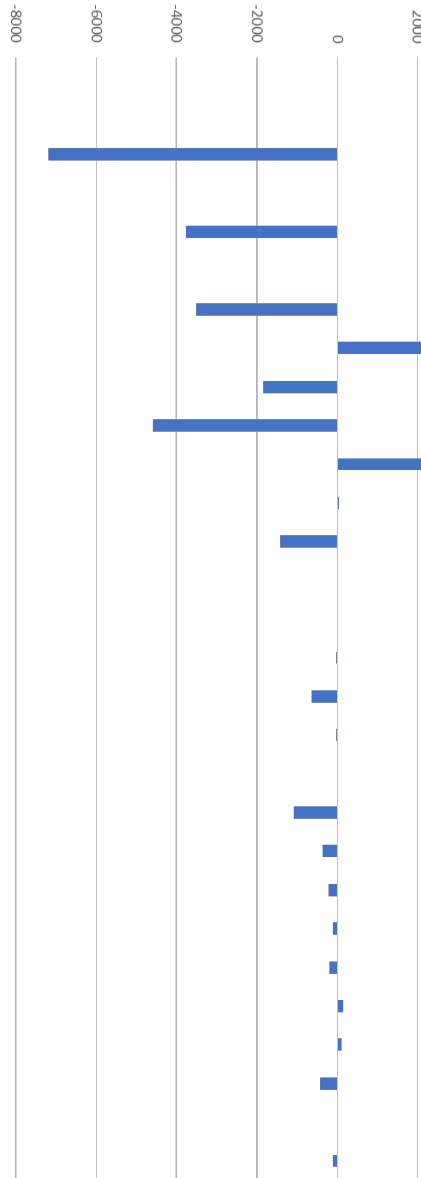
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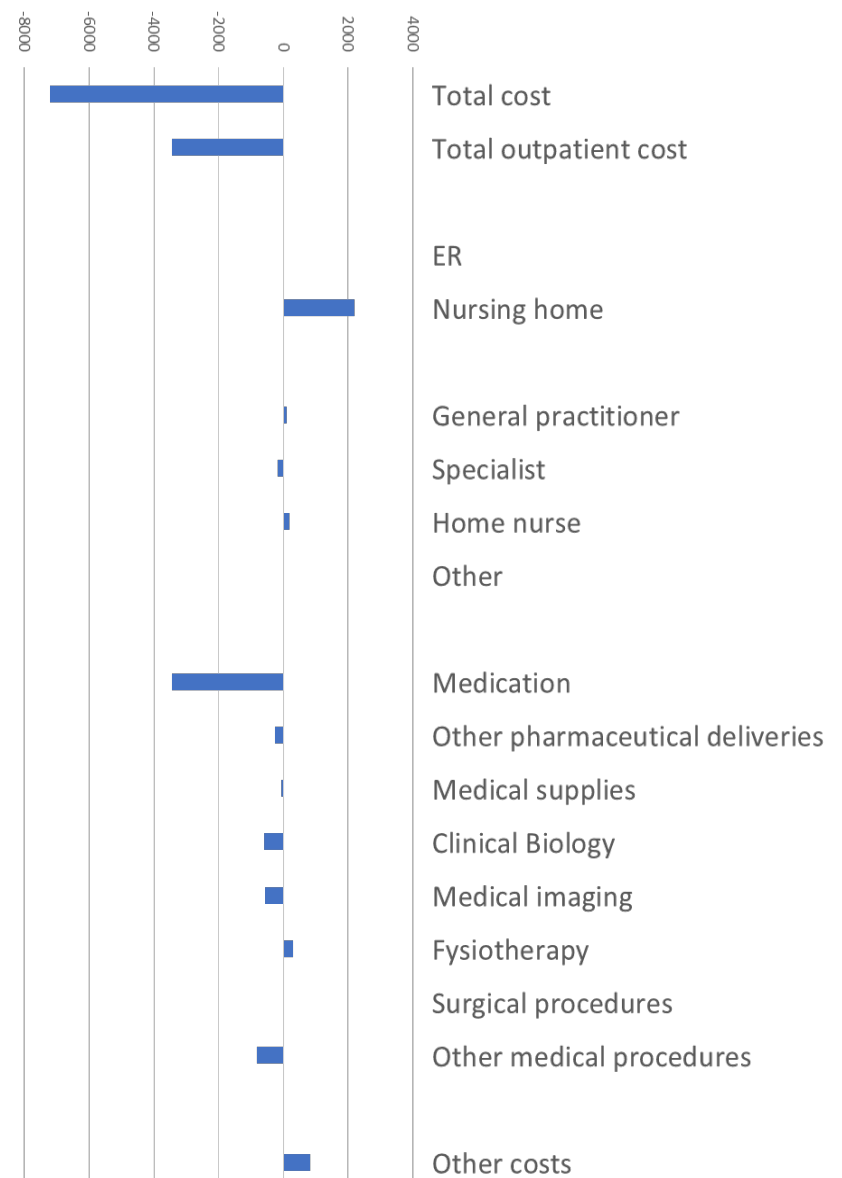


COPD v Cancer

INPATIENT



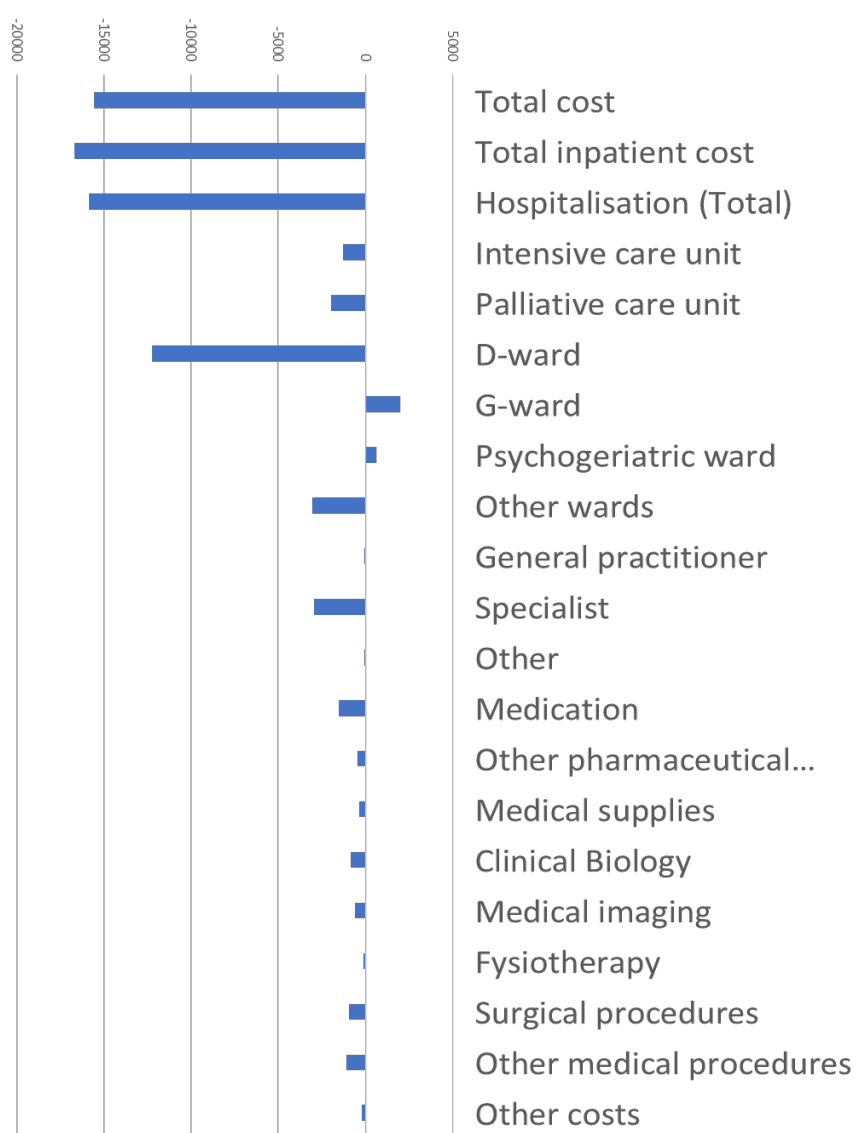
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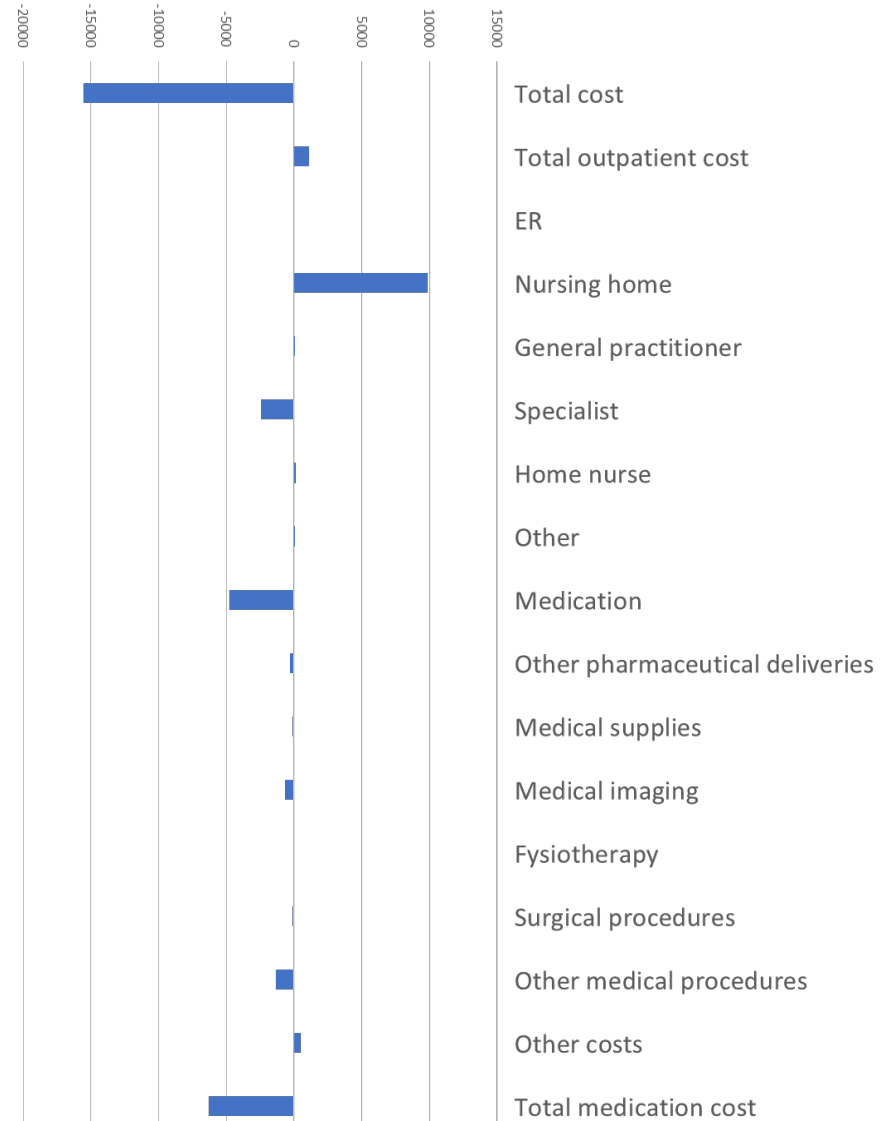


AD v Cancer

INPATIENT



OUTPATIENT





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<http://www.publichealth.ugent.be/index.cfm/research/units/health-economics/mission-and-staff/>