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

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END-OF-LIFE CARE RESEARCH GROUP

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Need of full population data

CHALLENGE *for EOLC research*

- Developping a public health approach
- A focus on total populations instead of individuals at risk

DIFFICULTY

- Selection bias, recall bias and non-response bias and difficult-to reach populations

NEED

- Administrative data provide the opportunity to *identify, monitor and evaluate* EOLC on a full population level and across different trajectories of dying

Value big data and need of linking

VALUE

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

DIFFICULTY *using administrative data*

- Not specifically designed for research purposes
- Not structured in readily available variables
- Lack of essential diseasespecific or relevant socio-demographic information.
- Stored in separate databases owned and handled by different organizations.

CHALLENGE

- Collect, link, integrate, store and process administrative data for EOLC research

Project goals

Mapping direct costs and resource use near the end of life

Monitoring quality of end-of-life care on a population level

Available administrative population-level data provide 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

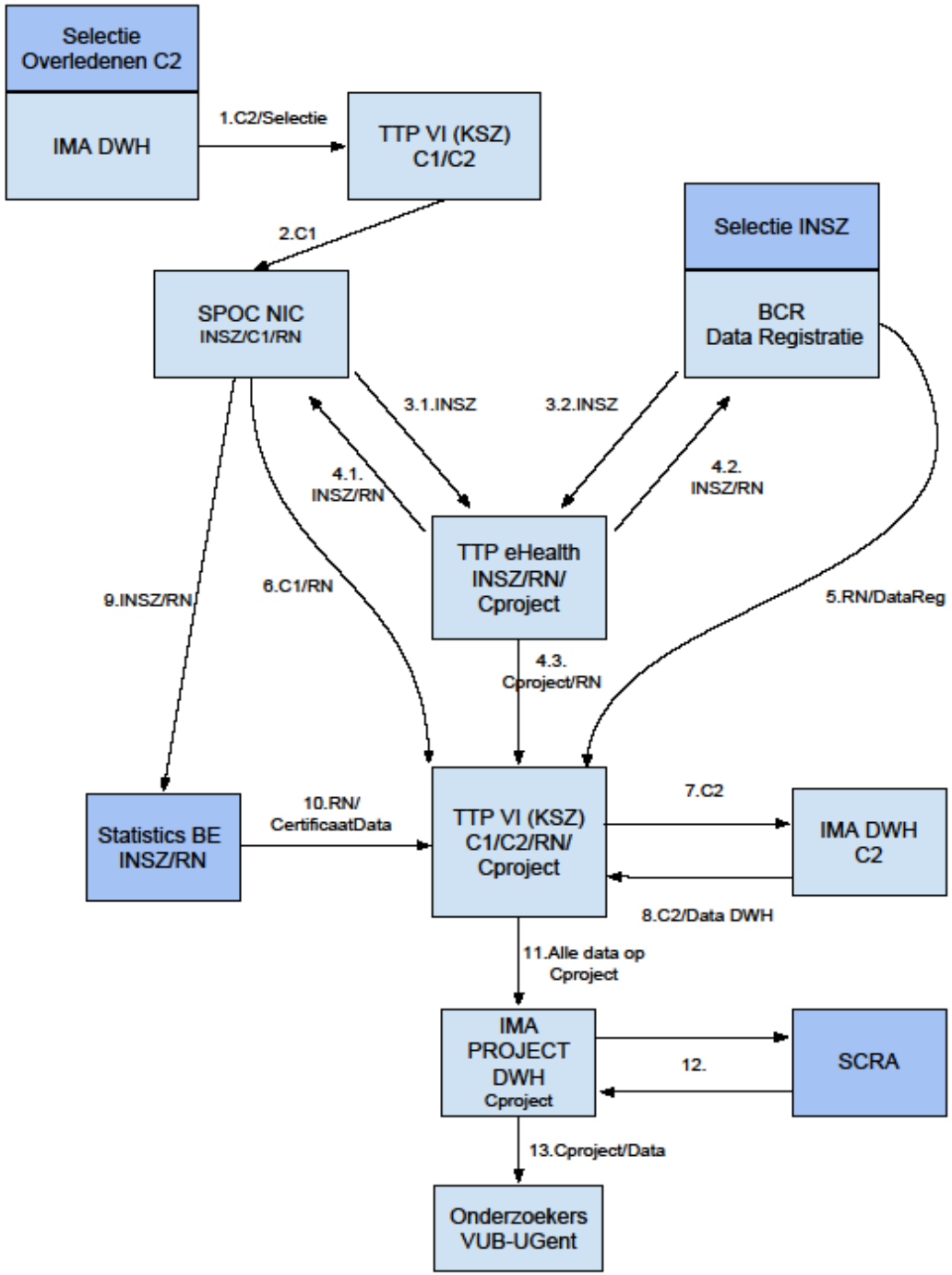
Hospital database
All hospital treatment

Pharma database
All prescribed medication

Health claims database
All reimbursed treatment

Overview of data linked

Database administrator	Database
Belgian Cancer Registry	*Cancer registry*
Intermutualistic Agency	*Health claims* *Pharmanet* *Hospital* *Population*
Statistics Belgium	*Death Certificate* *Census (2001, 2011)*
	Fiscal database


Selectie Overledenen C2
IMA DWH
1.C2/Selectie
TTP VI (KSZ) C1/C2
2.C1
Selectie INSZ
SPOC NIC INSZ/C1/RN
BCR Data Registratie
3.1.INSZ
3.2.INSZ
4.1. INSZ/RN
4.2. INSZ/RN
TTP eHealth INSZ/RN/ Cproject
9.INSZ/RN
6.C1/RN
5.RN/DataReg
4.3. Cproject/RN
Statistics BE INSZ/RN
10.RN/ CertificaatData
TTP VI (KSZ) C1/C2/RN/ Cproject
7.C2
IMA DWH C2
8.C2/Data DWH
11.Alle data op Cproject
IMA PROJECT DWH Cproject
12.
SCRA
13.Cproject/Data
Onderzoekers VUB-UGent

Overview of most important variables

1. Variables related to linking and coding

2. Variables related to the population

- Overview of demographic and socio-economic variables related to specific resource use and costs.
- E.g. OMNIO, MAF, invalidity, chronic disease, … (IMA)
- E.g. profession, housing comfort, educational level, income, nationality, householdtype,… (statbel)

3. Variables related to healtcare use

- Crucial for operationalization of indicators, costs and resources
- E.g. nomenclature, service codes, type prescriber, date of act, costs …

4. Variables related to medication use (Pharmanet)

- E.g. ATC-code, prescriber, pharmacist, quantity, costs, …

5. Variables related to the death certificate

- E.g. cause of death – primary, itermediate, …

6. Variables related to cancer diagnosis

- E.g. cancer diagnosis, date,…

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 then 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

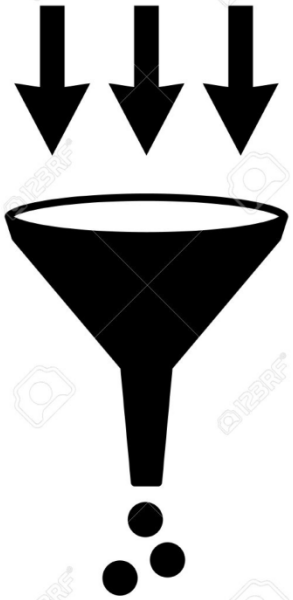
Cancer, COPD, Alzheimer's disease

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

Monitoring the quality of end-of-life care on a population level

Administrative Data

Quality indicators



Measurement of quality of care

Quality indicators

We developed 26 quality indicators

Indicating either appropriate or inappropriate care

On 5 domains: agressiveness of care, pain and symptom treatment, palliative care, place of treatment and death, continuity of care

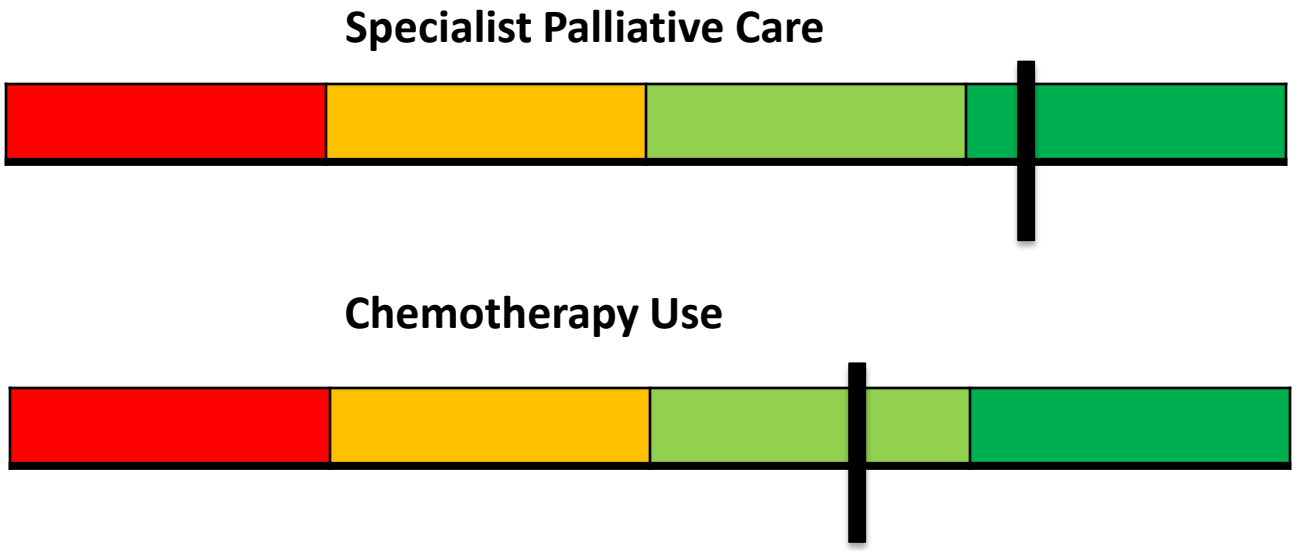
Specifically designed to be measured with administrative data

Examples

"When *x*% of the patient population has an emergency room visit, 2 weeks before death or later, that is an indication of possibly inappropriate end of life care"

"If we see a higher occurence of intensive care unit admission in the last 2 weeks before death in Ontario when compared to Alberta, without a reasonable explanation, this indicates more inappropriate care is occuring in Ontario.

Fair comparison: risk adjustment



Taking into account: age, level of education, socio-economic position, etc.

Resource use and costs of End-Of-Life Care For Non-Cancer Patients In Belgium:

a health resource and economic analysis.

How are constantly growing health care expenditures and health care resources distributed across different non-cancer diseases?

10-25% of all healthcare expenditures can be related to the LYOL

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?

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

Statbel, IMA and BCR data

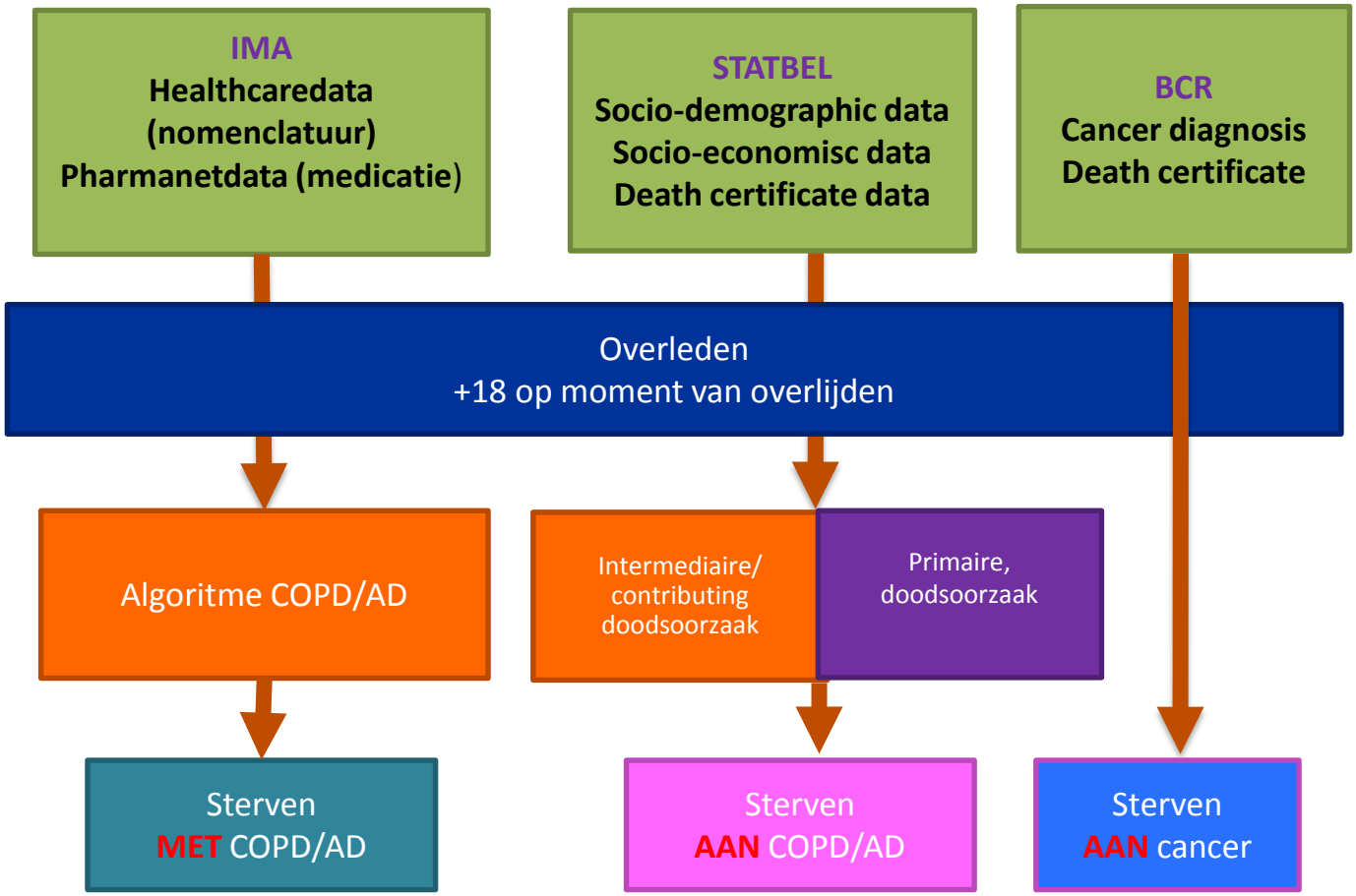
Nomenclature codes
ATC-codes
and
Cause of death

Cost and resource components

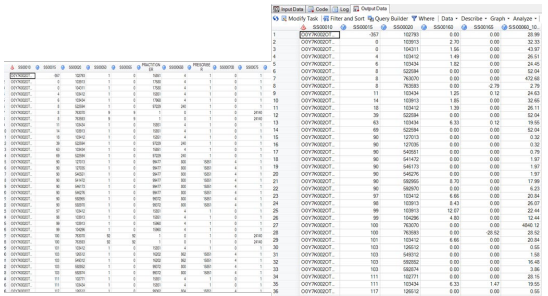
Specific non-cancer diseases

Resource use and costs of EOLC

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



Resource use and cost components



Based on nomenclature codes and ATC-codes

Development of specific cost components

Identification of specific resource use

Time before death: based on date of act or dispension

Only direct medical reimbursed resource use and costs

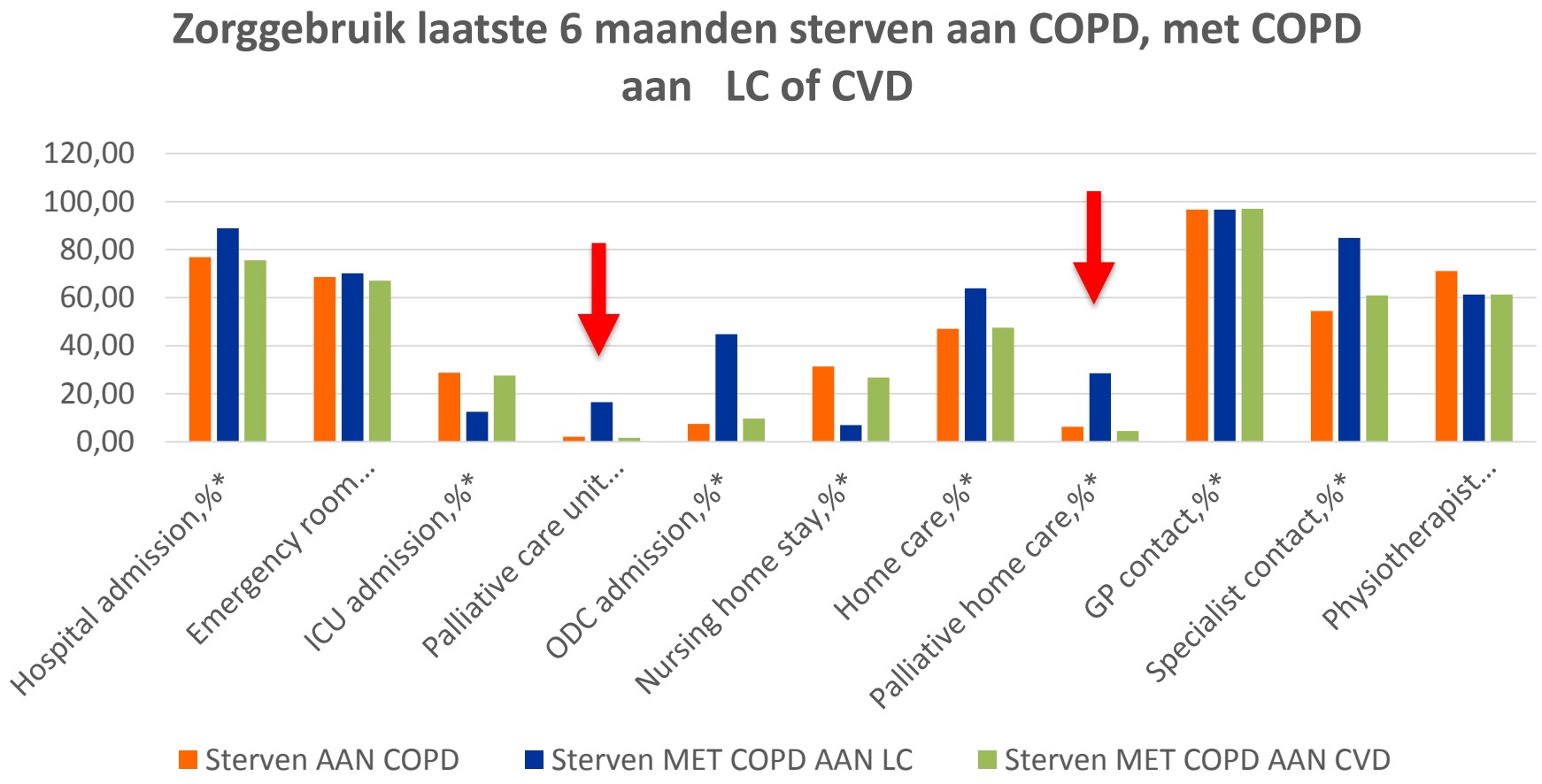
Results from Belgium

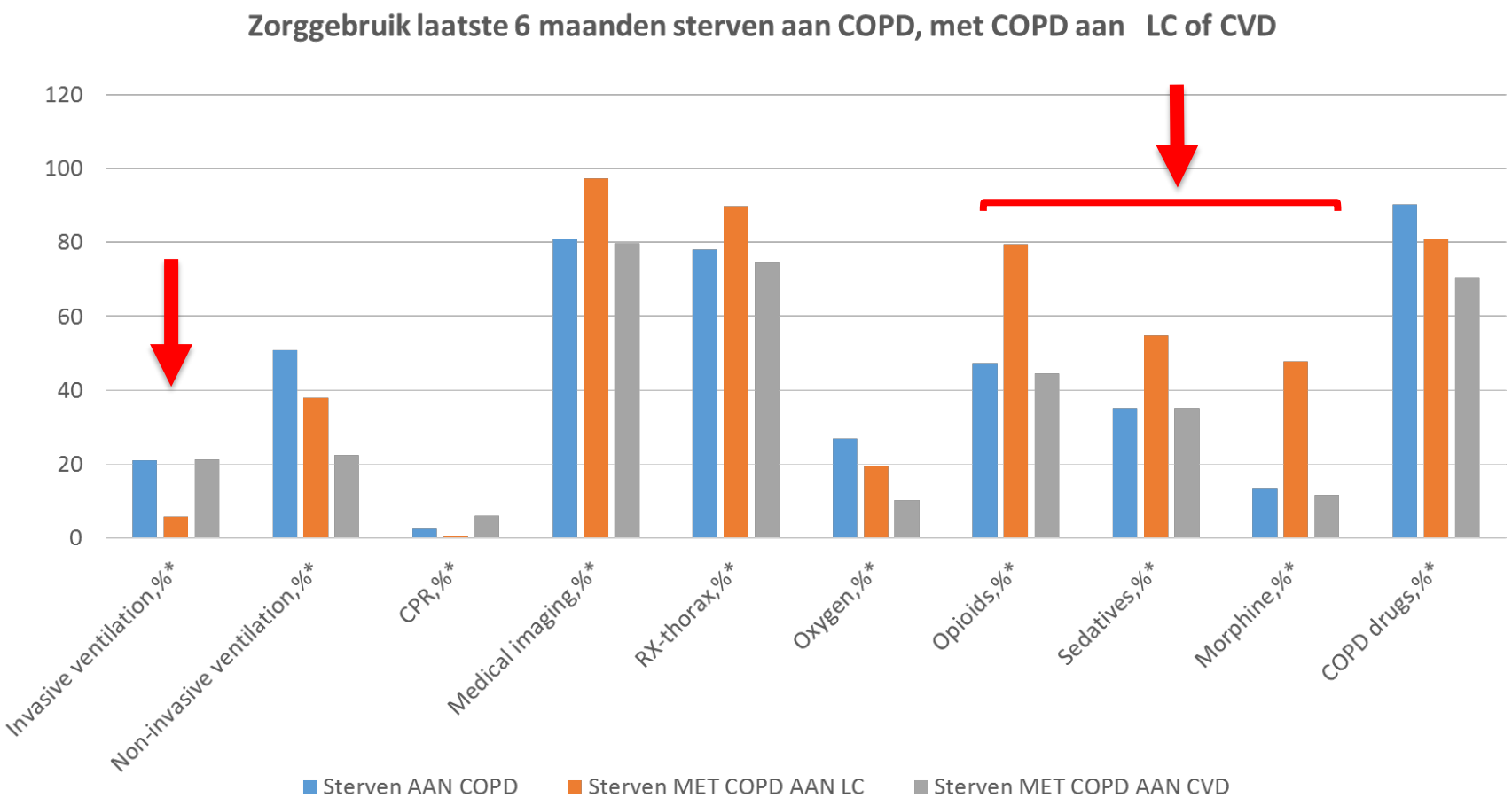
1. Does Lung cancer and CVD influence resource use in COPD patients at life's end?

2. Is dying with AD influenced by AD related morbidities?

3. What specific cost-components influence end-of-life care costs during the last year of life between cancer, COPD and AD

1.Does Lung cancer and CVD influence resource use in COPD patients at life's end?




Zorggebruik laatste 6 maanden sterven aan COPD, met COPD aan LC of CVD
120
100
80
60
40
20
0
Invasive ventilation,%*
Non-invasive ventilation,%*
CPR,%*
Medical imaging,%*
RX-thorax,%*
Oxygen,%*
Opioids,%*
Sedatives,%*
Morphine,%*
COPD drugs,%*
Sterven AAN COPD
Sterven MET COPD AAN LC
Sterven MET COPD AAN CVD

2. Is dying with AD influenced by AD related morbidities?

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			Ot, 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)			

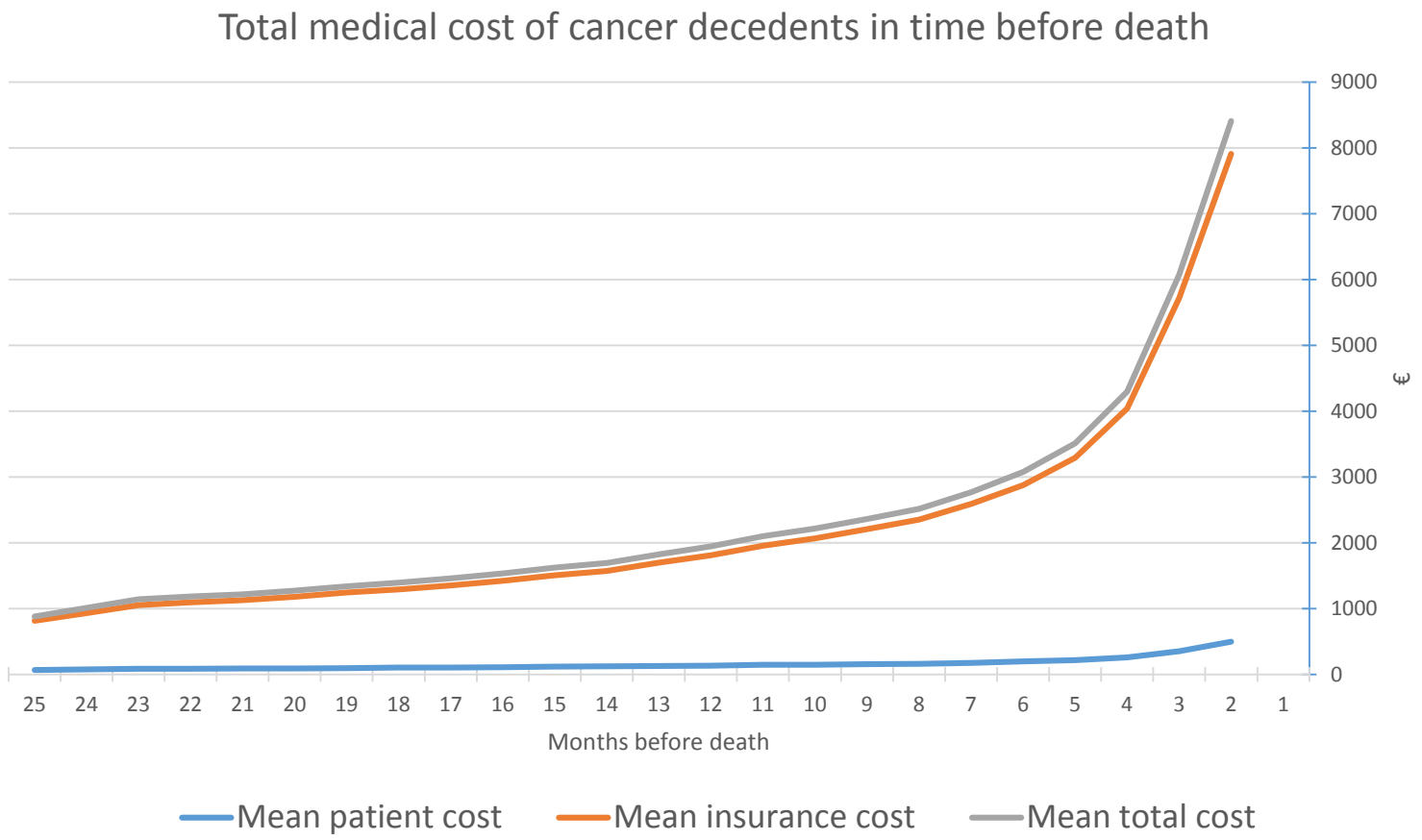
CI=confidence interval; ICU=intensive care unit; LOS=length of stay; PCU=palliative care unit.

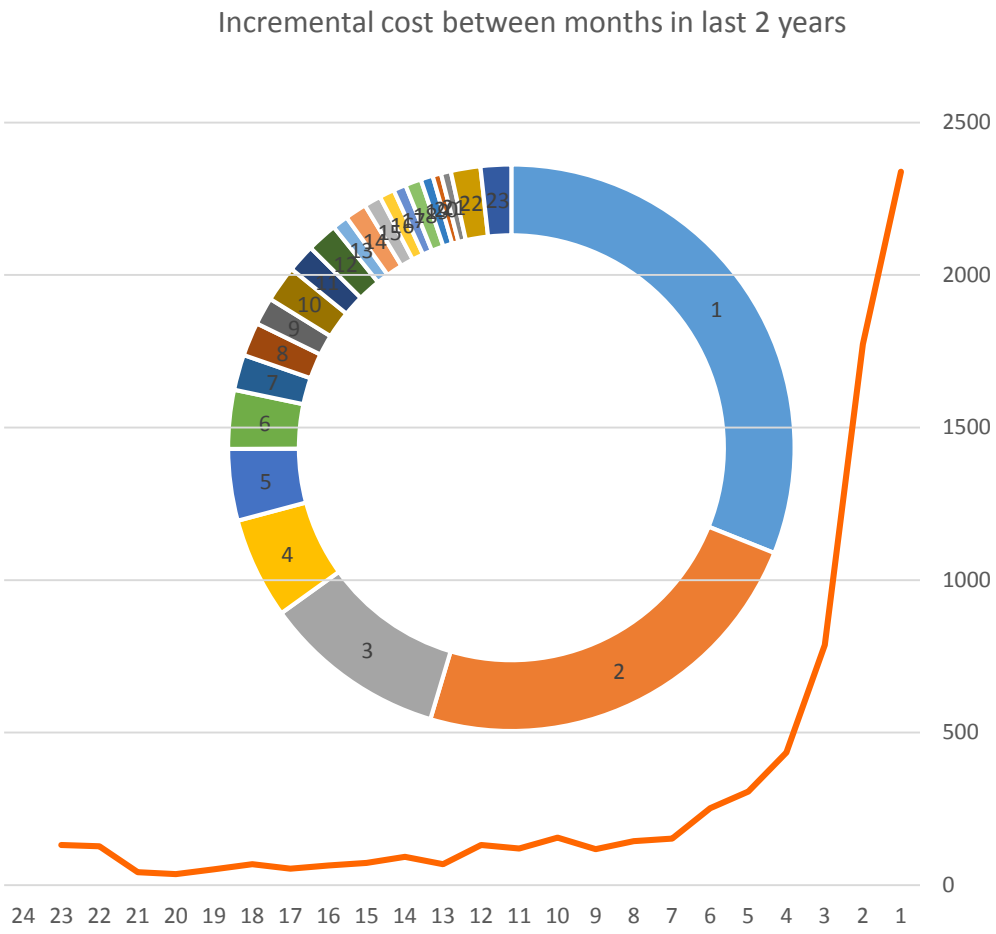
Table 3. Procedures and Medication Use During Last 180, 90, and 30 Days of Life of Individuals Dying with and of Alzheimer's Disease

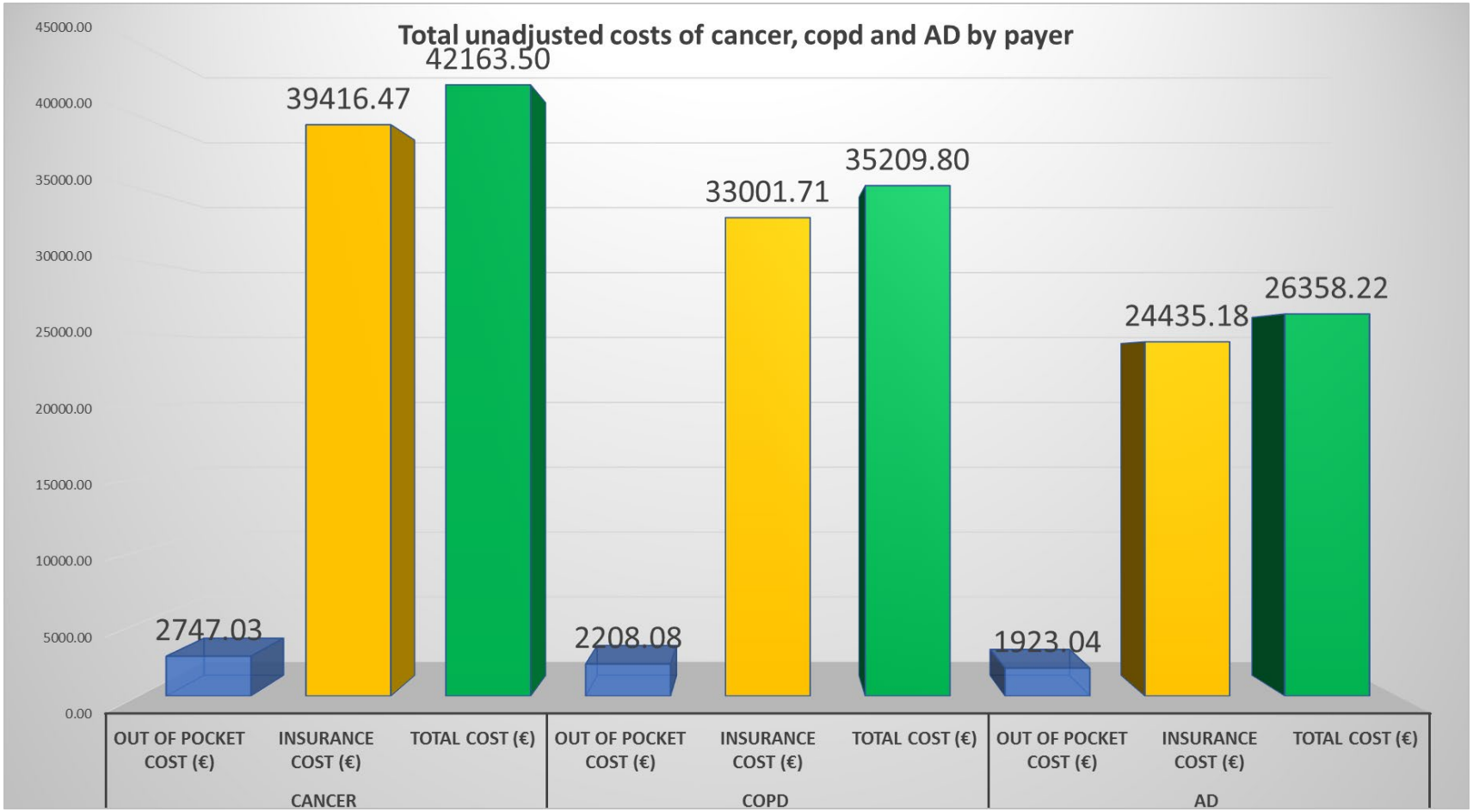
Procedure	With, n=8,804			Ot, n=2,606			Relative Risk (95% CI)		
	180 days	90 days	30 days	180 days	90 days	30 days	180 days	90 days	30 days
Invasive ventilation, %	5.4	4.9	4.4	0.9	0.9	0.8	6.1 (4.0–9.2)	5.6 (3.7–8.5)	5.4 (3.5–8.4)
Days of invasive ventilation, mean (95% CI)	2.0 (1.0–6.0)	2.0 (1.0–6.0)	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	39.8	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.

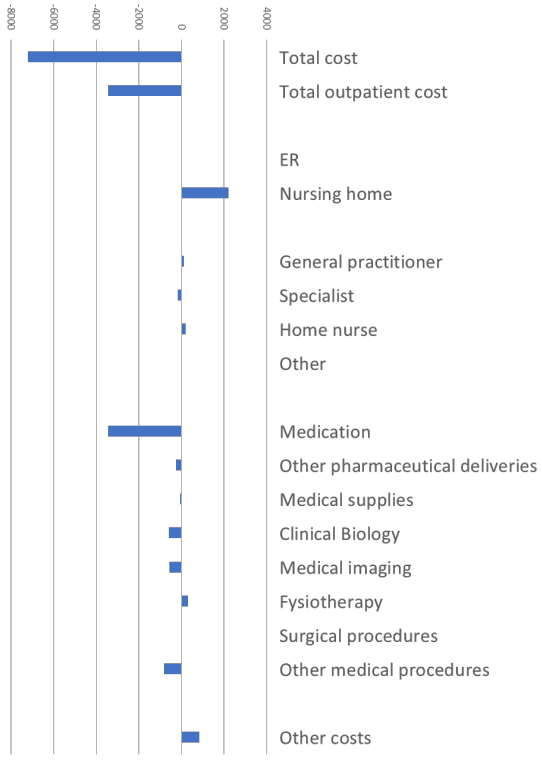
3. What specific cost-components influence end-of-life care costs during the last year of life in cancer, COPD and AD



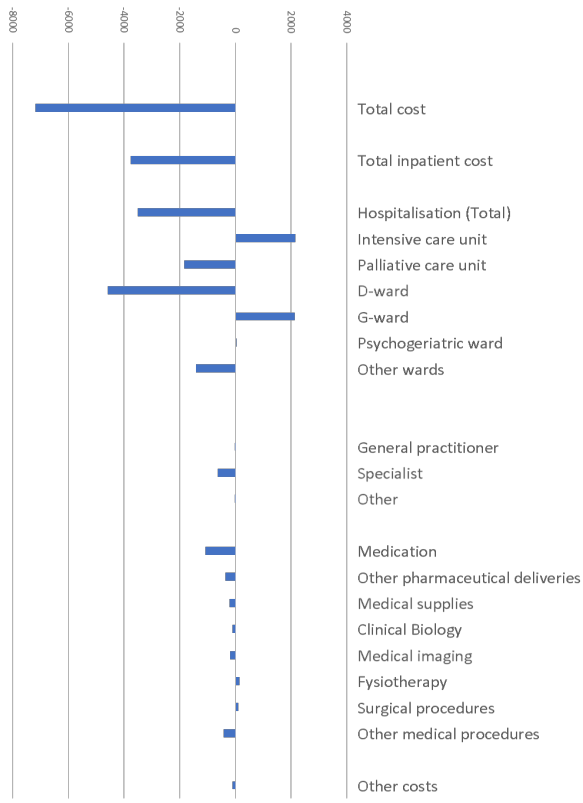

Incremental cost between months in last 2 years
2500
2000
1500
1000
500
0
24 23 22 21 20 19 18 17 16 15 14 13 12 11 10 9 8 7 6 5 4 3 2 1
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23


Total unadjusted costs of cancer, copd and AD by payer
45000.00
40000.00
35000.00
30000.00
25000.00
20000.00
15000.00
10000.00
5000.00
0.00
2747.03
39416.47
42163.50
2208.08
33001.71
35209.80
1923.04
24435.18
26358.22
OUT OF POCKET COST (€)
INSURANCE COST (€)
TOTAL COST (€)
CANCER
OUT OF POCKET COST (€)
INSURANCE COST (€)
TOTAL COST (€)
COPD
OUT OF POCKET COST (€)
INSURANCE COST (€)
TOTAL COST (€)
AD

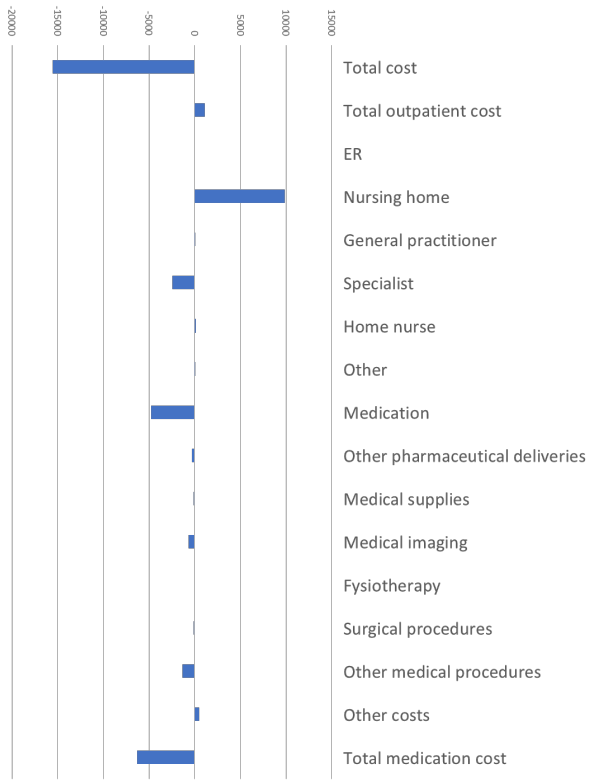
OUTPATIENT

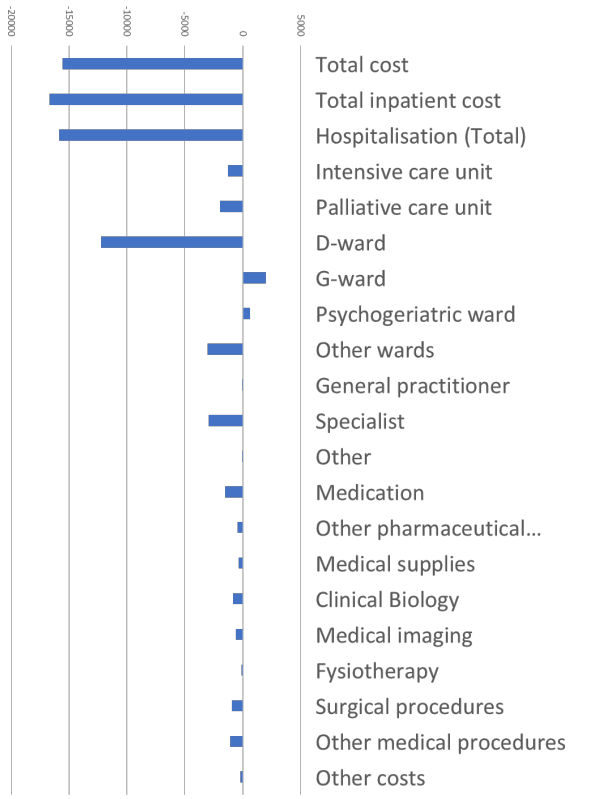


INPATIENT



COPD v Cancer





AD v Cancer

Evaluating end-of-life resource use and costs on a full population basis is feasible with administrative data!

Population level resource use and costs analysis identifies goals for health care improvement and cost reductions!

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