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# Population-level evaluation of the appropriateness of end-of-life care in Belgium

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*Non-judgment illuminates deep phenomena*

- a quote generated by [wisdomofchopra.com](http://wisdomofchopra.com), on 08-08-2020

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## List of abbreviations

ACP	Advance Care Planning
ATC	Anatomical Therapeutic Chemical Classification
BCR	Belgian Cancer Registry
CBSS	Crossroads Bank for Social Security Crossroads Bank for Social Security
COPD	Chronic Obstructive Pulmonary Disease
ED	Emergency department
ICD-10	International Statistical Classification of Diseases and Related Health Problems
IMA	Intermutualistic Agency
KCE	Federaal Kenniscentrum voor de Gezondheidszorg
PDCA	Plan-Do-Check-Act
PROMS	Patient Reported Outcome Measures
QI	Quality indicator
RIZIV	National Institute for Health and Disability Insurance
Statbel	Statistics Belgium
TNM	Tumour Node Metastasis
TTP	Trusted Third Party
VPN	Virtual Private Network

# Chapter 1: Introduction

## 1. Importance of appropriate end-of-life care

Worldwide, the average age across populations is rising.<sup>1,2</sup> Life expectancy has been dramatically increasing for over a century, with the exception of the two world wars.<sup>1</sup> In the last decades, the fertility ratio has been dropping in western countries, contributing to the increasing average age of the population.<sup>2</sup> Medical knowledge and medical technology are growing steadily, to a point that many once common and deadly diseases can be treated or prevented.<sup>3</sup> Highly effective emergency care enables possibly life-saving interventions. Progress in hygiene measures during medical interventions greatly increases the success rate of most medical treatments.<sup>4</sup> It is not surprising that faith in medicine has increased as well. However, there are still diseases that cannot be cured with the current medical technology and their prevalence in the population increases. For instance, although treatability for certain types of cancer is increasing and survival rates are higher, the percentage of people dying from cancer has increased across the population.<sup>5</sup> The percentage of people with dementia is also growing and is expected to grow the coming decennia.<sup>6,7</sup> There currently is no cure for Chronic Obstructive Pulmonary Disease (COPD).<sup>8</sup> Due to an increasingly aging population the prevalence of these currently incurable diseases rises among the most prevalent causes of death.<sup>5</sup> This creates a growing subpopulation suffering from incurable diseases in an end-of-life situation, with no realistic hope of recovery, with often a relatively predictable trajectory of functional decline, depending on the diseases they suffer from.<sup>9</sup> In this situation, care goals can gradually shift towards an increasing emphasis on comfort care.<sup>10</sup> As such, what is deemed appropriate care can shift as well and previously appropriate curative

care may become inappropriate in the end-of-life care context.<sup>11</sup> The European Association for Palliative Care has expressed its concern with the treatment of people near the end of life and estimates an increasing number of people in need of palliative care.<sup>12</sup> With an increasing number of people living with incurable diseases, providing high quality and appropriate end-of-life care grows in importance.<sup>10,13</sup>

*What is appropriate end-of-life care?*

Appropriate end-of-life care has been defined as '*treatment and/or medication for which the expected health benefit (i.e. improved quality of life, increased life expectancy, pain relief, improvement of functional status) exceeds possible negative outcomes (i.e. mortality, decrease in quality of life, pain, symptom burden)*'.<sup>11,14</sup>

Inappropriate end-of-life care, then, is the opposite, where the benefits do not exceed possible negative outcomes. Examples of inappropriate end-of-life care could include unwanted transfer to hospital close to death, people not dying in their preferred place, aggressive life-prolonging treatments that have a negative effect on the patient's quality of life and receiving medication close to death that should only be used for long-term prevention.<sup>15-17</sup> Some treatments have considerable burdensome side-effects and are very stressful for the patients and those close to them.<sup>15,16</sup> Such an aggressive approach to treatment, especially with patients near the end of their lives, could be considered inappropriate care.

## 2. Concerns for inappropriate end-of-life care

Inappropriate end-of-life care is a thoroughly discussed topic in Belgian health care literature.<sup>18,19</sup> In 2017, the KCE (Federaal

Kenniscentrum voor de Gezondheidszorg) published a detailed report on the current state of "appropriate care at the end of life" in Belgium<sup>10</sup> In this report, the authors draw on a large evidence base to illustrate their point that inappropriate care at the end of life in Belgium is a major problem, and that there is a consensus that it should and can be reduced. Similar concerns have risen in other countries, for example in the USA, Canada and Germany.<sup>3,20,21</sup>

#### *A palliative care approach*

For people suffering from life-limiting conditions such as cancer, COPD or dementia, appropriate end-of-life care often includes some form of palliative care.<sup>22,23</sup> During the last weeks, months or even years of their life, care goals ideally gradually shift from primarily prolonging life to primarily improving comfort and quality of life.<sup>24</sup> A palliative care approach can combine life-prolonging elements with increasing attention for patient's physical, social, mental and existential well-being, as well as care for family caregivers and bereavement care.<sup>25</sup> Early initiation of palliative care, advance care planning and high quality terminal care are an integral part of appropriate end-of-life care and could increase well-being considerably in people suffering from advanced life-threatening conditions.<sup>26-28</sup> Appropriate end-of-life care also includes avoiding unnecessary care transitions, unnecessary treatment and medication, and being cared for by people who know and respect the patient's wishes for end-of-life care, among other aspects of care.

### *Contributing factors*

The 2017 KCE report mentions a list of determinants and contributing factors that might be directly or indirectly influencing the occurrence of inappropriate end-of-life care, related to the health care professionals involved, the patients, the patient's relatives and societal and health care organizational factors.<sup>10</sup> The report delineates the end-of-life care context as a complex situation where health care professionals might feel inexperienced, where patients, relatives and care professionals are not comfortable to talk about their wishes or expectations and where the society as a whole and the health care system supports aggressive treatment, rather than clear communication, care planning and focus on quality of life.

With this many important factors possibly contributing to the occurrence of inappropriate end-of-life care, recently concerns have been rising among health care professionals, policy makers and researchers, about inappropriate care provision for patients who are suffering from incurable diseases and approach the end of their life.<sup>29,30</sup> Therefore, efforts have been made to study and improve the appropriateness of end-of-life care in Belgium.<sup>10,31,32</sup>

### 3. Appropriateness of care as an indicator of performance of the health care system

Studying the appropriateness of end-of-life care can be done at the level of the health care system.<sup>15,33,34</sup> Appropriateness of care is often perceived from the individual patient's or the clinical perspective. Especially near the end of life, tailoring care to the patient's wishes

is essential. However, all health care patients receive takes place in the context of the health care system. Providing, evaluating and promoting appropriate care to people near the end of life is not just a concern of the individual patient, it is a public health issue.<sup>35,36</sup> In previous research, in Belgium and abroad, the quality of care has been evaluated in specific settings, such as hospitals, specialist palliative care services or nursing homes.<sup>17</sup> However, to evaluate the appropriateness and inappropriateness of end-of-life care in an entire health system, e.g. Belgium, we need to assess health care use at regional and national level, rather than within the context of one isolated specific health care service. The registration of health care use on a national level by the National Institute for Health and Disability Insurance (RIZIV) provides us with an opportunity to study the practice of end-of-life care on a population level.<sup>37-39</sup>

#### *The Belgian health care system*

In Belgium, the government has a major influence on the provision of health care, through reimbursement policy. Every Belgian citizen is obliged to have a health insurance by joining or registering with one of the seven sickness funds. Reimbursement covers a substantial percentage of health care costs.<sup>40</sup> The Belgian government, through the National Institute for Health and Disability Insurance (RIZIV)<sup>40</sup>, determines what health care is reimbursed, which will determine to a certain extent what health care is offered to and used by a large proportion of the population. Reimbursements are processed by the sickness funds (also called mutualities).<sup>41</sup> For administrative reasons, they register all reimbursements and transfer these registrations to a central national database managed by the Intermutualistic Agency



(IMA/AIM)<sup>42</sup>. For each reimbursement, a selection of variables is stored, including details on the patient, the prescriber, the institution where a treatment was given and the date of prescription and provision. This presents us with unique research opportunities in Belgium. The IMA databases contain data on all reimbursed treatments and medication for almost the entire Belgian population. If we can access these data, we can measure the occurrence of treatments and medication that are considered indicators of appropriate or inappropriate end-of-life care. Provided there is a way to identify valid indicators of appropriateness, we can use reimbursement data to evaluate the performance of the Belgian health system in terms of appropriateness of end-of-life care. Studying health care use by analyzing reimbursed care can inform policy makers about the appropriateness of care provided by the health system.<sup>33,34,43</sup>

#### 4. Using quality indicators of appropriateness and inappropriateness of end-of-life care

##### *Quality indicators*

Health care that could be considered appropriate or inappropriate end-of-life care can be expressed in quality indicators.<sup>44,45</sup> Quality indicators are 'well-defined and measurable aspects of care'<sup>34</sup>, and are considered to be a valid method of evaluating quality and appropriateness of care within a given health care system. They have been employed in various contexts, including children's health care<sup>46</sup>, and performance assessment of primary care<sup>47</sup> or hospital care on a

system level<sup>48</sup> An example of a quality indicator of inappropriate end-of-life care could be:

"The percentage of people who died from cancer who received surgery during the last 30 days prior to death."

As seen in this example a quality indicator consists of:

1. A numerator, identifying the care that could be inappropriate, in this case *the number of people who received surgery*;
2. A denominator, identifying the population the indicator is measured for, in this case *the number of people who died from cancer*;
3. A specification about the time period the quality indicator is measured, in this case *30 days prior to death*. This is optional, as some quality indicators are not measured in a specific time period.

Each quality indicator provides us with a percentage across a population. This expression at an aggregate level (e.g. a country, region, health care service) is an important distinction of quality indicators with outcome measures, which are expressed at individual patient level.<sup>17,49,50</sup> When this percentage is above or below a certain threshold, this provides an indication that inappropriate or appropriate care is occurring. Determining this threshold, however, requires the establishment of standards. In some domains of health care such standards have been established based on evidence on what is an acceptable quality.<sup>51,52</sup> However, in the absence of such a clear evidence-base for standards - as is the case with end-of-life care - relevant questions to set standards are: Is the percentage higher or lower than measured in other, comparable populations? Is the percentage higher or lower than previous measurements in the same

population? Is it higher or lower than the expectations of relevant policy makers? Quality indicator results provide meaningful information only in comparison. Repeated measurements of quality indicators are one way to provide extra insight in possible evolutions.<sup>50</sup> In the studies in this dissertation, we employed geographical comparison across regions in Belgium and comparison with other countries, as well as comparison through time by using repeated measurements.

### *Developing standards*

Measuring quality indicators with population-level health care data enables us to describe selected aspects of end-of-life care practice in Belgium. To go beyond describing practice towards evaluating the performance of the health care system in terms of appropriateness of end-of-life care, performance standards are required.<sup>33,53</sup> These standards answer the question: what is our preferred performance for each indicator? For example, if "*the percentage of people receiving specialist palliative care in the last year of life*" is an indicator of appropriate end-of-life care, what percentage of the population receiving specialist palliative care could be aimed for? Setting standards can be done in several ways: standards can either be predetermined (e.g. by government or service policy makers) or data-driven.<sup>44,54</sup> Predetermined standards for some aspects of appropriateness of end-of-life care are currently in development<sup>18</sup>, but are mainly lacking. Measuring quality indicators on population level provides us with the opportunity to suggest data-driven relative standards based on the measurement results. In previous research, the best scoring decile or quartile have been suggested as possible data-driven

standards.<sup>33</sup> For example, if 25% of all health care regions in Belgium achieve the standard of 35% or more of their population receiving specialist palliative care in the last year of their life, this could be a Belgian standard for all health care regions. Relative data-driven standards have the benefits of being both achievable and ambitious, as they take the existing situation into account and aim to improve by using best performers as standards.<sup>33</sup> Studying the variation across the population has the added benefit of pinpointing room for improvement.<sup>50</sup> Some quality indicators will have more variation across the population than others, indicating there is a larger gap between better and worse performing regions.

#### *A fair comparison*

Establishing relative standards is only relevant if we can establish a fair comparison within the full population (in our example: comparing health care regions in Belgium). A fair comparison requires us to control for confounding variables (e.g. age, sex, household type, diagnostic characteristics, care dependency) that vary between subpopulations (e.g. regions) and affect the care provision, but are not a sign of the quality of care provided.<sup>55-57</sup> This reinforces the attributional validity of our results: if we find differences between regions while controlling for these confounding variables, we can attribute them to real differences in health care practice, rather than differences in population characteristics.<sup>56,58</sup> For example, the average age can differ between regions and has an impact on the care patients receive.<sup>57</sup> If, for example, older people receive less palliative care near the end of life and on average, and people in one region are older than people in another, we will find less palliative

care in the first region, even when people at each age are treated equally in both regions. This does not reflect a difference in the quality of end-of-life care practice between the two regions but a difference in risk profile. Therefore, when measuring quality of end-of-life care, we control for age and numerous other confounders to eliminate their influence from the equation and leave us with real health care differences between regions. As such, having access to several relevant socio-demographic, clinical and socio-economic variables that might be confounding factors is essential.<sup>59,60</sup>

## 5. Cancer, COPD and dementia

Efforts to improve the quality of end-of-life care and appropriateness of care have historically mostly focused on patients with cancer. Palliative care provision is higher in people with cancer than in other populations.<sup>23</sup> However, people suffering from other progressive illnesses have equal needs of palliative care and appropriate care near the end of life.<sup>22</sup> The literature has distinguished three types of end-of-life trajectories: a terminal disease with acute decline in physical functioning (mostly cancer), organ failure with long term limitations and acute exacerbations with partial recovery (e.g. COPD, cardio-vascular diseases) and frailty with low physical functioning and prolonged gradual decline (e.g. dementia).<sup>9,61</sup> Patient's needs in term of care are likely to vary according to their dying trajectory, so appropriateness of care will also at least partially vary between populations suffering from these diseases.<sup>24</sup> According to the WHO, dementia and COPD were the third and fifth most common cause of death in high-income countries in 2016, with different types of cancer taking

several spots in the top 10 list.<sup>5</sup> Globally, 47 million people were estimated to live with dementia in 2015, other estimates ranging from 5 to 7 percent of those aged 60 and older in most regions of the world.<sup>62-64</sup> The prevalence of COPD has been estimated to be at 10.7 percent of the global population of 30 years and older, with an increase of 68.7 percent between 1990 and 2010.<sup>65</sup> Other studies found similar results and stress that the prevalence of COPD is expected to rise in coming years.<sup>66,67</sup> For cancer, the WHO reports 9.6 million cancer deaths and an incidence of 18.1 million new cases worldwide in 2018.<sup>5,68</sup> If we measure appropriateness of end-of-life care in populations from these three disease trajectories, we cover the most prevalent trajectories in the dying population.

## 6. Objective and aims

The main objective of this dissertation is to assess the performance of the Belgian health care system in terms of appropriateness of end-of-life care for people dying from cancer, COPD or dementia by developing and measuring quality indicators of appropriate and inappropriate end-of-life care. This objective can be divided into 4 aims.

**Aim 1:** Developing indicators of appropriate and inappropriate end-of-life care for people with Alzheimer's disease, cancer or COPD for population-level administrative databases. We aim to identify treatments and medications that, when received by a large proportion at the level of a population, indicate the occurrence of appropriate or inappropriate end-of-life care.

**Aim 2:** Using linked administrative and disease-specific databases to study end-of-life care on a population level. We aim to explore several Belgian national databases with health care, diagnostic, sociologic, economic and demographic data that enable us to measure quality indicators on end-of-life care and how these databases can be linked.

**Aim 3:** Evaluating appropriateness of end-of-life care in people dying from cancer, from COPD or with dementia in Belgium by measuring quality indicators in linked administrative databases. We aim to use administrative data to measure the developed indicator set (aim 1) for each disease group (cancer, COPD and dementia) across the Belgian population, for all people who died within the same year. We also aim to examine what risk factors may influence exposure to potentially appropriate or inappropriate end-of-life care for people dying from cancer. For end-of-life COPD and dementia care, we aim to suggest relative performance standards based on the variation across health care regions.

**Aim 4:** Describing trends in indicators of appropriateness or inappropriateness of end-of-life care for people dying from cancer, COPD or with dementia between 2010 and 2015 in Belgium. We aim to use administrative data to describe trends in the developed indicator sets for each disease group (cancer, COPD and dementia) across the Belgian population, for all people who died between 2010 and 2015.

## 7. Methods

### 7.1 The quality indicator development process

We developed indicators measurable with available administrative health care databases, limiting indicators to reimbursed treatment and medication and excluding other important aspects of appropriateness of end-of-life care such as communication or care planning. As indicators of appropriate or inappropriate end-of-life care might differ across disease groups, we developed quality indicators for three groups of patients: people suffering from cancer, COPD or dementia. These represent very different disease trajectories and together, they represent a large group of people who are dying from non-communicable, relatively predictable diseases that require palliative care in most patients in the final stages of the diseases.<sup>9</sup>

The development process involved three steps:

1. A literature search to identify existing candidate indicators;
2. Interviews with experts in care for patients with cancer, COPD or dementia to suggest additional candidate indicators;
3. Expert panels to evaluate all candidate indicators listed in steps 1 and 2 and construct a valid set of indicators for cancer, COPD and dementia.

We started our literature search from the 2013 updated systematic review by De Roo et al.<sup>69</sup> on quality indicators for palliative and end-of-life care, followed by a cascading hand search. Since existing quality indicators specifically on end-of-life care were limited, we performed an additional literature review on appropriate or



inappropriate treatments and medication at the end-of-life for cancer, COPD or dementia that can be adapted to measurable quality indicators. We also interviewed physicians involved in the treatment of patients near the end of life with cancer, COPD or dementia, to suggest quality indicators from personal experience with end-of-life care practice in Belgium. To evaluate the candidate quality indicators found in literature and interviews, we presented them to three expert panels, one for cancer, one for COPD and one for dementia. Each panel consisted of 10-12 physicians and nurses of the disciplines involved with end-of-life care for these diseases. Only indicators on which consensus was reached were retained for the final quality indicator sets, following the RAND/UCLA appropriateness method stipulations.<sup>70</sup> The indicators developed cover five domains: aggressiveness of care, pain and symptom treatment, palliative care, place of treatment and place of death, coordination and continuity of care. A detailed description of all indicators as presented to the expert panels, can be found in the appendix as supplementary material S.1, S.2 and S.3. (only available in Dutch)

#### *Limitation in scope*

Because we developed indicators to be measured with administrative data, we a priori excluded several aspects of appropriate end-of-life care that are not currently reimbursed by the Belgian health care system, such as patient-physician communication, patient's wishes and care for relatives. They are included in previous studies that did not target indicators measurable with administrative data.<sup>69,71</sup> However, due to the level of detail and broadness of spectrum of the available data in Belgium, we found a relatively large number of quality

indicators, compared to other studies developing quality indicators measurable with routinely collected data.<sup>15,34</sup>

### *Adapting the quality indicators*

After the quality indicator development process, where the most relevant aspects of appropriateness and inappropriateness of end-of-life care are selected for each disease, statistical measures have to be employed to evaluate the quality indicator sets. Quality indicators must be statistically relevant. For example, aspects of care that occur in less than 1% of the relevant population are not meaningful as a quality indicator.<sup>44</sup> When measurement results are close to 100% or 0% or vary too little across the populations to provide any useful information, they may not prove to be useful in practice, even if approved by experts.<sup>33</sup>

Chapter 2 describes the quality indicator development process and the resulting quality indicator sets for people with cancer, COPD or dementia.<sup>72</sup> Following a design based on the RAND/UCLA appropriateness method<sup>70</sup>, candidate indicators were drawn from literature and interviews with experts in end-of-life care in general and from each disease group specific. All indicators were consequently evaluated and validated by expert panels.

## 7.2 Administrative databases

To evaluate the appropriateness of end-of-life care in Belgium across the population, population-level data are required. Collecting such

data through interviews or questionnaires would be a titanic endeavor, outside the scope of this project. However, in Belgium databases exist that contain health care data on a national level, covering almost the entire Belgian population.

Seven Belgian health insurance organisations ('mutualiteiten') register all reimbursed health care for reimbursement and funding purposes. The Intermutualistic Agency (IMA)<sup>42</sup> collects reimbursement data from the insurers. Reimbursement data of all Belgian residents are available in the IMA database, since health insurance is mandatory in Belgium. The IMA administers three databases relevant for our research: (1) a socio-demographic database; (2) a health care database with all reimbursed treatments and medication, except medications delivered by public pharmacies and (3) a pharmaceutical database containing medication data from public pharmacists. When used to measure valid quality indicators, these data enable us to evaluate the appropriateness of end-of-life care in Belgium.

The Belgian Cancer Registry (BCR) manages a database with diagnostic information on all incidences of cancer in Belgium, including date of diagnosis and type of cancer.<sup>59</sup> No similar registries are available to identify people who died with COPD or dementia.

However, the death certificate database, managed by Statistics Belgium (StatBel)<sup>60</sup>, can be used to identify all direct ('underlying') and indirect ('associated' and other) causes of death. Statistics Belgium also manages the national demographic database, containing the household composition of every Belgian household and data from the nationwide Socio-Economic Survey in 2001 and the national Census in 2011 with information about the highest educational level attained,

the occupation and housing characteristics of every Belgian citizen. They also manage the national fiscal database with data on net taxable income. All socio-economic and demographic factors mentioned have been identified as affecting end-of-life care patterns<sup>73,74</sup> and therefore are meaningful to be used as control variables in population-level measurement of quality indicators.

#### *Methodological opportunities*

The IMA, BCR and StatBel databases are not designed to be used for research. They do, however, contain high quality data. With each reimbursement, several pieces of information about the patient, the care provider and the date and place of provision are registered and stored. That data can be used to study the occurrence of certain types of health care in detail.<sup>42</sup> If we can identify specific treatments and medication as indicators of appropriate or inappropriate care, we can use this big volume of detailed health care data as a tool to map the appropriateness of end-of-life care in Belgium. Selecting the data necessary to measure a selection of quality indicators requires medical and database expertise. As such, the expert knowledge of IMA-employed physicians who regularly work with the claims databases is invaluable to our research. They are repeatedly consulted during the indicator development process and the indicator measurement process.

The aims of this research project only scratch the surface of opportunities with administrative health claims data. Within the end-of-life care research domain, examples from other research include an evaluation of resource use and costs in end-of-life care, examining the effectiveness of government measures to support palliative home care, or describing discontinuation of medication near the end of

life.<sup>38,39,75-77</sup> Access to such detailed high quality full-population data is unique in an international context, with similar research in other countries using only service-specific or population-specific databases.<sup>33,43</sup> Administrative databases offer several advantages compared to sample-based primary data-collections, such as a minimised selection bias, recall bias and non-response bias.<sup>78</sup> They have a clearly defined population, including populations that tend to be under-represented in surveys or observational studies due to practical or ethical considerations. People near the end of life are a prime example of a population difficult to reach for ethical reasons.<sup>79</sup> Administrative data registrations are usually continuously collected, which enables trend analyses and longitudinal studies. Specifically when working with quality indicators, continuous collection provides repeated measurements and enables comparison of indicator scores over time.<sup>18</sup> Moreover, since the data have already been collected, they are relatively inexpensive when compared with original data collections, with the main cost being data storage and access to the data.<sup>33,79</sup> In Belgium, the IMA, BCR and StatBel database administrators are currently increasingly engaged in sharing data for research purposes.<sup>80,81</sup> The increased availability and overall high quality of the data available make them more than ever interesting to use in health care research.

Chapter 3 describes the database linking procedure.<sup>37</sup> All databases were linked in an ethically responsible manner and, in accordance with Belgian law, approvals for access to all databases were obtained from the two relevant national sectoral committees for privacy protection: the 'Sectoral Committee of Social Security and Health, Section Health' and the 'Statistical Supervisory Committee', whose responsibilities

were recently transferred to the 'Informatieveiligheidscomité'<sup>82</sup>. Both were at the time of approval subcommittees of the Belgian Commission for the Protection of Privacy, which recently became the official Belgian data protection authority<sup>83</sup>.

### 7.3 Evaluating the appropriateness of end-of-life care in people with cancer, dementia and COPD

#### *Study design and data*

To measure the indicators in the Belgian population, we conducted three decedent cohort studies, one to describe the indicators for people with cancer, one for COPD and one for dementia. For the indicators on cancer, we selected all people who died from cancer in Belgium in 2012. For the indicators on COPD, we selected all people who died from COPD in Belgium in 2015. For the indicators on dementia, we selected all people who died with dementia in Belgium in 2015. We used cohort data from all selected population-level databases, managed by IMA, BCR and StatBel mentioned above. As for socio-economic and demographic variables, we included decedents' age, sex, education level, region of residence, the degree of urbanicity of the municipality of residence, type of household, housing comfort and net taxable income.

#### *Analysis*

To examine the population characteristics of people who died from cancer, COPD or with dementia and to calculate the quality indicators, we use descriptive statistics. Additionally, for people dying from cancer, we examine risk factors for exposure to appropriate or inappropriate end-of-life care. We perform a principal component

analysis to reduce the list of quality indicators to a smaller set of main components. We consequently perform analysis of variance to evaluate which population characteristics are associated with higher or lower scores for the components.

For people dying from COPD or with dementia, additionally, we perform a comparison on indicator scores between health care regions in Flanders and Brussels, followed by a suggestion of relative benchmarks. The division in health regions is based on natural patient flow towards major hospitals in each region. As to this date, no official similar regions exist in Wallonia. To obtain a fair comparison, we perform risk adjustment procedures. We select a set of possible risk factors based on relevance for end-of-life care and availability of data in the current dataset. We will suggest relative performance standards for each indicator, based on the best scoring quartiles across health care regions.

All analyses are conducted with SAS Enterprise Guide, version 7.1.

#### 7.4 Examining trends in the appropriateness of end-of-life care

To evaluate the trends in appropriateness of end-of-life care in Belgium between 2010 and 2015 in people dying from cancer, from COPD or with dementia, we conduct a decedent cohort study. Again, data from all linked databases are used. We use all three validated sets of quality indicators mentioned above. To present real evolutions in appropriateness of end-of-life care, we control for variables that might influence health care use and changed between the selected years, based on a selection of available data. We show trends over the six

years for which data were available (2010-2015) and calculate the differences between 2010 and 2015 for all risk adjusted indicator scores. We rank all these risk adjusted differences from most positive to most negative.

## 8. Outline of this dissertation

The introduction of this dissertation describes the context, the objectives and methodology of this research project. **Part one** includes two chapters concerning the methodological basis of our research: the development of the quality indicators (chapter two)<sup>72</sup> and the linking of the relevant administrative databases (chapter three)<sup>37</sup>. **Part two** describes the results of the quality indicator measurements and an evaluation of the current state of appropriate and inappropriate end-of-life care for people with cancer (chapter four), COPD (chapter five) or dementia (chapter six) in Belgium. It concludes with an evaluation of trends in appropriateness of end-of-life care between 2010 and 2015 in Belgium (chapter seven). Lastly, **part three** discusses the meaning of our findings. It summarizes the main results and concerns the consequences of these findings, with some concluding words.



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**PART I: Developing indicators  
and using big data**





**Chapter 2:** Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study.

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## **Abstract**

**Background:** A substantial amount of aggressive life-prolonging treatments in the final stages of life has been reported for people with progressive life-shortening conditions. Monitoring appropriate and inappropriate end-of-life care is an important public health challenge and requires validated quality indicators (QIs).

**Aim:** To develop indicators of appropriate and inappropriate end-of-life care for people with cancer, COPD or Alzheimer's disease, measurable with population-level administrative data.

**Design:** modified RAND/UCLA appropriateness method

**Setting/participants:** Potential indicators were identified by literature review and expert interviews and scored in a survey among three panels of experts (one for each disease group). Indicators for which no consensus was reached were taken into group discussions. Indicators with consensus among the experts were retained for the final QI sets.

**Results:** The final sets consist of 28 QIs for Alzheimer's disease, 26 QIs for cancer and 27 QIs for COPD. The indicator sets measure aspects of aggressiveness of care, pain and symptom treatment, specialist palliative care, place of care and place of death, and coordination and continuity of care.

**Conclusion:** We developed a comprehensive set of QIs of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or COPD, to be used in population-level research. Our focus on administrative health care databases limits us to treatment and medication, excluding other important quality aspects such as communication, which can be monitored using complementary approaches. Nevertheless, our sets will enable an efficient comparison of health care providers, regions and countries in terms of their performance on appropriateness of end-of-life care.

## Introduction

Treatment goals for people with progressive life-shortening conditions ideally move seamlessly from curative or life-prolonging to comfort care<sup>1</sup> as they approach the end of life and the benefits of curative treatment no longer outweigh the negative effects.<sup>2-6</sup> Nonetheless, a substantial amount of aggressive life-prolonging treatment in the final stages of life has been reported for people with life-shortening conditions such as cancer.<sup>7-10</sup> The high prevalence of aggressive care near the end of life in certain patient groups suggests the importance of critical evaluation of the appropriateness of care near the end of life in health care systems.

Appropriate care can be defined as 'treatment and/or medication for which the expected health benefit (i.e. improved quality of life, increased life expectancy, pain relief, improvement of functional status) exceeds possible negative outcomes (i.e. mortality, decrease in quality of life, pain, symptom burden)'.<sup>11,12</sup> While potentially inappropriate care has been evaluated in several domains of healthcare, it remains under-investigated in end-of-life care, particularly in groups other than people with cancer. Quality indicators (QIs) i.e. 'well-defined and measurable aspects of care'<sup>13</sup>, are considered to be a valid method of evaluating quality and appropriateness of care within a given health care system. QIs have been used to evaluate appropriateness of care in various other contexts, ranging from substance abuse treatment in adolescents<sup>14</sup>, children's health care<sup>15,16</sup> and surgery for neonatal children<sup>17</sup>, to assessing the performance of primary care<sup>18</sup> or hospital care on a system level<sup>19</sup>. A limited number of recent efforts have been undertaken to develop QIs specifically for end-of-life care.<sup>20</sup> However, these sets of indicators are limited to populations using a specific health service (e.g. a hospice or palliative care service) or to specific disease groups such as cancer.<sup>13,20-25</sup>

Additionally, to evaluate health care system performance in terms of end-of-life care, it is necessary to develop population-level quality indicators of end-of-life care focusing on health care use across populations, settings and services instead of individual patients receiving a certain health care service.<sup>13,22,26</sup> Such population-level

evaluations allow assessment of the performance of the health care system as a whole. Additionally, variation by countries, regions, health care settings, or socio-economic and cultural background can be studied<sup>27</sup>.

Population-level use of QIs requires population-level data. In many countries, including Belgium<sup>28</sup>, full population health insurance data are collected routinely, due to the legal obligation for all citizens to have health insurance and the central gathering of information by government database administrators. Previous studies have demonstrated that routinely collected data from health care insurance organisations provide a reliable source for effective measurement of population-level QIs.<sup>22,29,30</sup> Using routinely collected data also avoids specific problems of data collection in an end-of-life care context and has low costs.<sup>31,32</sup>

However, previous efforts to develop and calculate population-level QIs for end-of-life care have had a number of limitations. Firstly, existing indicators have been developed specifically for measurement in the existing health claims databases of the United States of America and Canada (e.g. Medicare databases). Countries in Europe and other parts of the world may have different databases which changes and/or increases the number of candidate measurable QIs. Secondly, the selection of QIs was primarily done through expert consultations with clinicians from the USA. However, what care is deemed appropriate near the end of life may be influenced by the health care system, cultural differences and socio-demographic variations and thus may be different in different countries.<sup>33-35</sup> Thirdly, the existing indicators focus on a limited population: cancer patients age 65 and older (because Medicare data do not cover the younger population which would be about half of all cancer-related deaths<sup>22</sup>). In Belgium, for instance, full population health insurance data are available, without restriction on age, disease or socio-demographic variables. Fourthly, QIs for populations other than cancer who have similar end-of-life care needs but typically have different care and dying trajectories<sup>36,37</sup> are needed to adequately monitor health care system performance in terms of end-of-life care. QIs need to be included, for instance, for patients with Alzheimer's disease and COPD. Both are leading causes of disease

burden in high-income countries<sup>38 39</sup> and life-shortening illnesses with predictable disease trajectories and clear end-of-life stages.<sup>22</sup> Cancer, Alzheimer's and COPD have different possible health care interventions near the end of life (and the extent of appropriateness of these interventions differs). This implies that different QIs for end-of-life care are warranted for the different disease populations.

The aim of this study is to develop a set of QIs (well-defined and measurable on a population level) of appropriate and inappropriate health care at the end of life for people dying with cancer, COPD or Alzheimer's disease, to be used in administrative population-level databases across health care settings.

## **Methods**

A design based on the RAND/UCLA Appropriateness Method was used<sup>39</sup> to develop three different sets of QIs: one for Alzheimer's disease (AD), one for cancer, one for COPD.

The focus of our approach was explicitly based on possibilities with available administrative health care databases, which was limited to treatment and medication (and excluded other important quality aspects such as communication, which cannot be evaluated with administrative data).

The approach involved three steps:

1. Searches of the relevant literature to select candidate indicators for each set
2. Interviews with relevant experts in the field of Alzheimer's disease, cancer and COPD to suggest additional candidate indicators (not in the original RAND/UCLA method)
3. Expert evaluations to define a valid set of indicators for Alzheimer's disease, cancer and COPD

## *Definitions & Criteria*

Throughout the QI development process, the following definitions were used:

Quality indicators (QIs) are defined as 'explicitly defined measurable items referring to the outcomes, processes, or structure of care. They are usually described with a numerator, denominator, and/or performance standard. Quality indicators can indicate either poor or good quality in relevant care domains.'<sup>25,40</sup> They express quality at an aggregated level, usually the level of a healthcare service, institution, region or country and are generally expressed as a number or percentage.<sup>41</sup> They are not used to evaluate the quality of care for individual patients.

Appropriate care is defined as treatment and/or medication in which 'the expected health benefit (e.g., increased life expectancy, relief of pain, reduction in anxiety, improved functional capacity) exceeds the expected negative consequences (e.g., mortality, morbidity, anxiety, pain, time lost from work) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost.'<sup>11,12</sup>

Inappropriate care is then defined as treatment and/or medication in which the expected health benefit (e.g., increased life expectancy, improved functional capacity) does not exceed the expected negative consequences (e.g., morbidity, anxiety, pain) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost.

Additionally, selected QIs needed to meet all following criteria:

1. Providing a valid indication of appropriate or inappropriate care at the end of life
2. Relating to people with Alzheimer's disease, cancer or COPD
3. Being well defined, without ambiguity
4. Being measurable on a population level
5. Being measurable with available administrative data

### *Literature search*

Our primary literature source was the 2009 systematic review by Pasman et al.<sup>24</sup>, updated in 2013 by De Roo et al.<sup>25</sup> on QIs for palliative and end-of-life care. Co-authors of this paper (LD, JC) were involved in both reviews. We used the search string from the review to perform an updated search from September 2014 until November 2015. Additionally, a cascading hand search was performed starting from the references from the review of De Roo et al.<sup>25</sup>.

Existing end-of-life care QIs are limited and we did not want *a priori* to limit the set of candidate indicators to QIs published in literature. Therefore, to identify QIs not yet identified or developed as such, an additional literature review was done focusing on appropriate or inappropriate treatments and medication at the end-of-life for COPD, Alzheimer's disease or cancer. We used search strings combining keywords related to COPD, Alzheimer's disease, neoplasms/cancer and quality of life and hand-selected literature relevant to the end-of-life care context. Those aspects identified in literature as appropriate or inappropriate end-of-life care that could be translated into a QI, meeting all the predefined criteria (cf. above), were retained for the candidate QI list.

Both search strategies were limited to publications in English.

### *Interviews with relevant experts*

To identify additional candidate QIs (and in addition to the standard RAND/UCLA appropriateness method), we conducted interviews, between March 2015 and November 2015, with 14 physicians involved in the treatment of patients near the end of life with Alzheimer's disease, cancer or COPD. The 14 experts in oncology, pharmacology, pneumology, family medicine and neurology from different university hospitals were asked to suggest candidate QIs and for each one to formulate the numerator, denominator, possible exclusion criteria and reasoning as to why the indicator should be included. Prior to the interview, experts were sent the definitions of QIs, appropriateness and inappropriateness of care and the five selection criteria. During the

interview, experts could freely bring up QIs from personal experience with end-of-life care practice in Belgium, while guided by the interviewer in what information was required about each one (numerator, denominator, reasoning, inclusion criteria).

#### *Expert evaluation of candidate QIs*

To evaluate the candidate QIs found in literature and interviews, they were presented to expert panels. In advance, QIs from literature and interviews were collected, re-evaluated and refined by the researchers where needed to meet all criteria mentioned above. Three sets of candidate QIs were composed: one for people suffering from Alzheimer's disease, one for people with cancer and one for people with COPD. Each set of QIs was presented to a panel of 10-12 physicians and nurses of the relevant disciplines involved in the treatment of patients with these diseases in an end-of-life context. (*Table 1*) The RAND/UCLA appropriateness method suggests seven to 15 experts in each panel.<sup>42</sup> To cover different perspectives involved in end-of-life care, equal numbers of doctors and nurses were included.



**Table 1: experts included in panels**

	Doctor	Nurse	Total
<b>Expert panel Cancer</b>	<b>5</b>	<b>5</b>	<b>10</b>
Pneumology (lung cancer expert)	1	1	2
Oncology	1	1	2
Radiotherapy	1	1	2
Family medicine	1	1	2
Palliative Care	1	1	2
<b>Expert panel COPD</b>	<b>6</b>	<b>6</b>	<b>12</b>
Pneumology (COPD expert)	2	2	4
Family Medicine (with specific COPD experience)	2	2	4
Palliative Care (with specific COPD experience)	2	2	4
<b>Expert panel Alzheimer's disease</b>	<b>5</b>	<b>5</b>	<b>10</b>
Family Medicine	1	1	2
Neurology	1	1	2
Pharmacology	1	1	2
Palliative Care	1	1	2
Geriatrics	1	1	2

Experts were first contacted by phone to invite them and inform them about the research goals and methods. Every expert was sent instructions, a list of all candidate QIs within the patient population they were selected for and a scoring form. In this form, experts were asked to score QIs on a scale [1-9], where '1' means 'this indicator is very unsuitable' and '9' means 'this indicator is very suitable' to evaluate appropriateness or inappropriateness of end-of-life care.

Based on the returned scoring forms, the scores for each indicator were calculated and one of three possible decisions was made: (1) the indicator was accepted, (2) the indicator was rejected or (3) selection of the indicator was undecided and needed to be discussed in the expert panel. For this decision, the rules provided by the RAND/UCLA Appropriateness Method manual<sup>42</sup> based on median and consensus were used. (See box 1)

**Box 1: Decision model based on median and consensus**

Scoring results		Decision
Median score*	Indication of consensus	
In range 7-9	2 or fewer experts score in range 1-3	indicator = suitable; <b>accepted;</b>
In range 7-9	3 or more experts score in range [1-3]	indicator = undecided; <b>to be decided</b> in plenary expert panel
In range 4-6	(any)	indicator = undecided; <b>to be decided</b> in plenary expert panel
In range 1-3	3 or more experts score in range 7-9	indicator = undecided; <b>to be decided</b> in plenary expert panel
In range 1-3	2 or fewer experts score in range 7-9 ;	indicator = unsuitable; <b>rejected</b>

\*Score ranged from 1 to 9 with 1= 'this indicator is very unsuitable' and 9 = 'this indicator is very suitable'

One half-day expert panel was organized for each set of indicators in February-March 2016. During the panel meeting, all undecided QIs were discussed. Experts could freely suggest adaptations to QIs. After about 15 minutes of discussion about each indicator, experts were asked to vote for the QI to be (1) rejected, (2) adapted and taken into the final set, or (3) taken into the final set without adaptations. Only indicators for which consensus was reached (see box 1) were taken into the final set.

*Ethical approval*

The study was approved by the Medical Ethics Committee of the University Hospital Brussels, Belgium. (reference number B.U.N. 143201627075)

**Results**

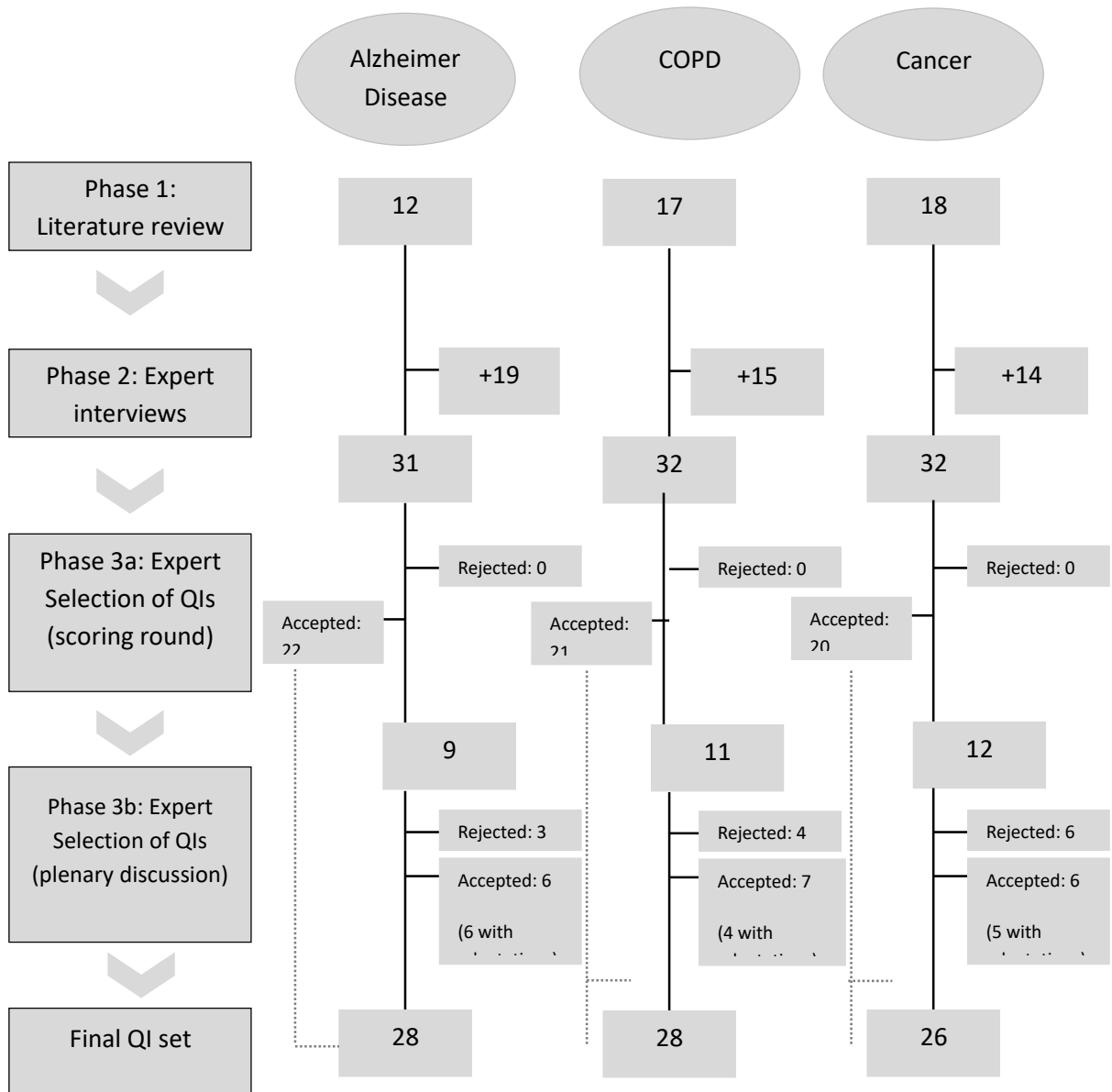
Figure 1 displays the QI development process and how many indicators resulted from each step. In the literature search, 23 unique QIs were identified. Expert interviews resulted in 32 additional unique indicators. Indicators selected based on literature referred almost equally to appropriate (12) and inappropriate (14) care, while

indicators from interviews rarely referred to appropriate care (6) and often referred to inappropriate care (26).

For the expert evaluation of the candidate QIs, 1/32 experts did not participate (doctor in neurology for panel in Alzheimer's disease); 63/95 of the QIs were accepted directly into the final set (22/31 for Alzheimer's disease, 20/32 for cancer, 21/32 for COPD); 32 potential QIs were discussed in expert panels (Alzheimer's disease: 9, Cancer: 12, COPD: 11) Expert panels eventually rejected 13 and adapted 14 QIs, evenly divided between the panels.

The final set consists of 28 QIs for Alzheimer's disease (*Table 2*), 26 QIs for cancer (*Table 3*) and 27 QIs for COPD (*Table 4*). For Alzheimer's disease, indicators of appropriate care (7) were less common than indicators of inappropriate care (21). For cancer, indicators of appropriate (12) and inappropriate (14) end-of-life care were evenly divided. For COPD, indicators of appropriate care (9) were again less common than those of inappropriate care (19). A total of 14 QIs were found valid in the three pathology groups, albeit with slight variations in the time period of measurement.

*Figure 1: the QI development process: literature search and expert interviews to select QIs, followed by expert panels to establish consensus.*



**Table 2: the final set of 28 QIs for people with Alzheimer's disease**

Indicator (brief description)	Indicator of appropriate (A) or inappropriate (I) care	Numerator (Number of people who died with Alzheimer's disease who*)	Denominator (*Number of people who died with Alzheimer's disease)
<b>Domain**: aggressiveness of care</b>			
Tube feeding or intravenous feeding <sup>†§</sup>	I	*received tube feeding or intravenous feeding in the last month prior to death	*
Reanimation <sup>†§</sup>	I	*were reanimated in the last 2 weeks prior to death	*
Blood transfusion <sup>†§</sup>	I	*received blood transfusion in the last month prior to death	*
Diagnostic testing <sup>†§</sup>	I	*had diagnostic testing (spirometry OR radiography OR blood drawn OR electrocardiogram) in the last month prior to death	*
Neurologist visit <sup>†\</sup>	I	*received treatment from a neurologist in the last month prior to death	*
Port-a-cath installment <sup>†§</sup>	I	*had a port-a-cath installed in the last 2 weeks prior to death	*
Surgery <sup>†§</sup>	I	*received surgery in the last [6,3, 1] months prior to death	*
Statins <sup>†§</sup>	I	*received statins and did not have declining statin use in the last [12,6,1] months prior to death	* and received statins
Gastric protectors <sup>†\</sup>	I	*received two or more prescriptions of gastric protectors in the last 6 months prior to death (ie prescription until death)	*
Anti-hypertensives <sup>†§</sup>	I	*received antihypertensives in the last [6,3,1] months prior to death	*
Calcium vitamin D <sup>†§</sup>	I	*received calcium or vitamin D in the last [6,3,1] months prior to death	*
NOACs or vitamin K antagonists <sup>†\</sup>	I	*received a prescriptions for novel oral anticoagulants OR vitamin K antagonists in the last 3 months prior to death (i.e. prescription until death)	*
Prophylactic gout medication <sup>†\</sup>	I	*received a prescriptions for prophylactic gout medication in the last 3 months prior to death	*
Serotonin reuptake inhibitors <sup>†\</sup>	I	*received serotonin reuptake inhibitors in the last 3 months prior to death	*
Chemotherapy for cancer patients with Alzheimer's disease <sup>†\</sup>	I	* had a cancer diagnosis and received chemotherapy in the [12, 6] months prior to death	* and had a cancer diagnosis
<b>Domain: Pain and symptom treatment</b>			
Morphine and neuropathic medication <sup>†§</sup>	A	*received neuropathic medication when receiving morphine in the last 2 years prior to death	*
<b>Domain: Palliative care</b>			
Specialized palliative care <sup>†§</sup>	A	*received specialized palliative care (Hospital palliative unit OR palliative daycare centre OR multidisciplinary home care) in the last 2 years prior to death	*
Official palliative care status <sup>†§</sup>	A	*received official palliative care status, enabling financial government support for palliative care at any point prior to death	*

Late initiation of palliative care <sup>†§</sup>	I	<b>*had a first referral to specialized palliative care OR received the official palliative statute in the last week before death</b>	*
<b>Domain: Place of treatment and place of death</b>			
Hospital admissions <sup>†§</sup>	I	<b>*had one or more hospital admissions in the last [6, 3, 1] month/s prior to death</b>	*
ICU admissions <sup>†§</sup>	I	<b>*had one or more admissions to the intensive care unit in the last month prior to death</b>	*
ED admissions <sup>†§</sup>	I	<b>*had one or more emergency department visit/s in the last [6, 3, 1] month/s prior to death</b>	*
Died in hospital <sup>†§</sup>	I	<b>*died in hospital</b>	*
Home death <sup>†§</sup>	A	<b>*died at home</b>	*
Home death or death in nursing home of residence <sup>†§</sup>	A	<b>*lived and died in a nursing home OR who died at home</b>	*
<b>Domain: Coordination and continuity of care</b>			
GP contact <sup>†§</sup>	A	<b>*an increase in average number of contacts with a family physician in the last month prior to death compared to the previous 23 months</b>	*
Primary caregiver contact <sup>†§</sup>	A	<b>Sum of number of contacts with a family physician or other primary care professional in the last 3 months prior to death</b>	*
ICU admissions from nursing home <sup>†§</sup>	I	<b>*lived in a nursing home and had one or more intensive care unit admissions in the last month prior to death</b>	<b>*and lived in a nursing home</b>

<sup>†</sup>Indicator from literature, <sup>‡</sup>Indicator from expert interviews, <sup>§</sup>Accepted in phase 3a scoring round, <sup>¶</sup>Accepted in phase 3b plenary discussion, <sup>||</sup>Adapted and accepted in phase 3b plenary discussion.

\*\*Subdivision in domains was not part of the original methodology, but added later to facilitate interpretation and was based on existing classification of quality domains in end-of-life-care<sup>43</sup>

Bold denotes indicators that are common across all three pathologies (cancer, COPD, Alzheimer's).

**Table 3: the final set of 26 QIs for people with cancer**

Indicator (brief description)	Indicator of appropriate (A) or inappropriate (I) care	Numerator (Number of people who died with cancer who*)	Denominator  (*Number of people who died with cancer)
<b>Domain**: aggressiveness of care</b>			
Tube feeding or intravenous feeding <sup>†§</sup>	I	*received tube feeding or intravenous feeding in the last month prior to death (excluding people with gatro-intestinal cancer)	*
Blood Transfusion <sup>†\ </sup>	I	*received blood transfusion in the last month before death (for people with a hematologic condition in the last 2 weeks)	*
Diagnostic Testing <sup>†§</sup>	I	*had diagnostic testing (spirometry OR radiography OR blood drawn OR electrocardiogram) in the last month prior to death	*
Port-a-cath installment <sup>†§</sup>	I	*had a port-a-cath installed in the last 2 weeks prior to death	*
Surgery <sup>†§</sup>	I	*received surgery in the last [6,3, 1] month/s prior to death	*
Chemotherapy <sup>†\ </sup>	I	*received 1 or more chemotherapy treatments in the last month prior to death	*
Chemotherapy interval <sup>†\ </sup>	I	Number of days between last chemotherapy treatment and death	*
Chemotherapy new Line <sup>†§</sup>	I	*had a new chemotherapy line initiated in the last 3 months prior to death	*
Cisplatin in old age <sup>†§</sup>	I	*received Cisplatin and were age 80 or older	*and were age 80 or older
New anti-depressant <sup>†\ </sup>	I	*had initiation of a new anti-depressant treatment in the last 2 months prior to death	*
<b>Domain: Pain and symptom treatment</b>			
Opioids <sup>†§</sup>	A	*received opioids in the last [6,3, 1] months prior to death	*
Morphine and neuropathic medication <sup>†§</sup>	A	*received neuropathic medication when receiving morphine in the last 2 years prior to death	*
Anti-emetics with chemotherapy <sup>†§</sup>	A	*received strong anti-emetics when receiving chemotherapy in the last 2 years prior to death	* and received chemotherapy
Radiotherapy with Bone Metastases <sup>†§</sup>	A	*had bone metastasis and received radiation therapy in the last 2 years prior to death	*and had bone metastasis
Radiotherapy with small cell lung cancer <sup>†§</sup>	A	*died with small cell lung cancer and received analgic radiotherapy in the last 2 years prior to death	*and had small cell lung cancer
<b>Domain: Palliative care</b>			
Specialized palliative care <sup>†§</sup>	A	*received specialized palliative care (Hospital palliative unit OR palliative daycare center OR multidisciplinary home care) in the last 2 years prior to death	*
Official palliative care status <sup>†§</sup>	A	*received official palliative care status, enabling financial government support for palliative care at any point prior to death	*

Late initiation of palliative care <sup>†¶</sup>	I	*had a first referral to specialized palliative care OR received official palliative status in the last week before death	*
<b>Domain: Place of treatment and place of death</b>			
Hospital admissions <sup>‡§</sup>	I	*had one or more hospital admissions in the last [6, 3, 1] months prior to death	*
ICU admissions from nursing home <sup>‡§</sup>	A	* lived in a nursing home and had one or more intensive care unit admissions in the last [6, 3, 1] months prior to death	*and lived in a nursing home
ED admissions <sup>‡§</sup>	I	*had one or more emergency hospital visits in the last [6, 3, 1] months prior to death	*
Home death <sup>‡§</sup>	A	*died at home	*
Death in nursing home of residence <sup>†¶¶</sup>	A	*died in the nursing home where they lived	*and lived in a nursing home
<b>Domain: Coordination and continuity of care</b>			
GP contact <sup>‡§</sup>	A	* had an increase in average number of contacts with a family physician in the last month prior to death compared to the previous 23 months	*
Primary caregiver contact <sup>‡§</sup>	A	Total number of contacts with a family physician or other primary care professional in the last 3 months prior to death	*
Multi-disciplinary Oncologic Consult <sup>‡§</sup>	A	*had a Multidisciplinary Medical Consult	*

<sup>†</sup>Indicator from literature, <sup>‡</sup>Indicator from expert interviews, <sup>§</sup>Accepted in phase 3a scoring round, <sup>¶</sup>Accepted in phase 3b plenary discussion, <sup>¶¶</sup>Adapted and accepted in phase 3b plenary discussion.

\*\*Subdivision in domains was not part of the original methodology, but added later to facilitate interpretation and was based on existing classification of quality domains in end-of-life-care<sup>43</sup>

Bold denotes indicators that are common across all three pathologies (cancer, COPD, Alzheimer's).



**Table 4: the final set of 27 QIs for people with COPD**

Indicator (brief description)	Indicator of appropriate (A) or inappropriate (I) care	Numerator  (Number of people who died with COPD who*)	Denominator  (*Number of people who died with COPD)
<b>Domain: aggressiveness of care</b>			
Tube feeding or intravenous feeding †§	I	*received tube feeding or intravenous feeding in the last month prior to death	*
Endotracheal intubation or tracheotomy †§	I	*received endotracheal intubation or tracheotomy in the last [12, 6, 3, 1] months prior to death	*
Continuous endotracheal intubation †§	I	*received continuous endotracheal intubation for 5 days or more in the last [12, 6, 3, 1] months prior to death	*
Repeated intubation †§	I	*received intubation 2 or more times in the last [12, 6, 3, 1] months prior to death	*
Reanimation after intubation †§	I	*were reanimated after intubation in the last week prior to death	*
Late physiotherapy †¶	I	*started physiotherapy treatment in the last 2 weeks prior to death	*
Blood transfusion †\\	I	*received blood transfusion in the last month prior to death	*
Port-a-cath installment †§	I	*had a port-a-cath installed in the last 2 weeks prior to death	*
Lung volume reduction surgery †§	I	*received Lung Volume Reduction Surgery in the last 3 months prior to death	*
Coronary or abdominal surgery †§	I	*received coronary or abdominal surgery in the last 3 months prior to death	*
Surgery †§	I	*received surgery in the last [6, 3, 1] months prior to death	*
Diagnostic testing †§	I	*had diagnostic testing (spirometry OR radiography OR blood drawn OR electrocardiogram) in the last month prior to death	*
Starting Antidepressants †\\	I	*received antidepressants in the last month prior to death and did not receive antidepressants before	*
<b>Domain: Pain and symptom treatment</b>			
Opioids †§	A	*received opioids in the last [6,3, 1] months prior to death	*
Inhalation therapy †§	A	*received inhalation corticosteroids OR anticholinergics OR Beta-2-memetics in the last [6, 3, 1] months prior to death	*
<b>Domain: Palliative care</b>			
Specialized palliative care †§	A	*received specialized palliative care (hospital palliative unit OR palliative daycare centre OR multidisciplinary home care) in the last 2 years prior to death	*
Official palliative care status †§	A	* received official palliative care status, enabling financial government support for palliative care at any point prior to death	*
Late initiation of palliative care †¶	I	* had a first referral to specialized palliative care OR received official palliative status during the last week before death	*

Domain: Place of treatment and place of death			
Hospital admissions <sup>†¶</sup>	I	* had one or more hospital admission/s in the last [6, 3, 1 ]months prior to death	*
ICU admissions <sup>‡§</sup>	I	* had one or more admissions to the intensive care unit in the last month prior to death	*
ICU admissions from nursing home <sup>‡§</sup>	I	*lived in a nursing home and had 1 or more ICU visits in the last month prior to death	*and lived in a nursing home
ED admissions <sup>†\\</sup>	I	* had one or more emergency hospital visits in the last [6, 3, 1 ]months prior to death	*
Hospital death <sup>†¶</sup>	I	*died in hospital	*
Home death <sup>†§</sup>	A	*died at home	*
Death in nursing home of residence <sup>†§</sup>	A	*lived and died in a nursing home	*and lived in a nursing home
Domain: Coordination and continuity of care			
GP contact <sup>†§</sup>	A	*had an increase in average number of contacts with a family physician in the last month prior to death compared to the previous 23 months	*
Primary caregiver contact <sup>†§</sup>	A	Sum of number of contacts with a family physician or other primary care professional in the last 3 months prior to death	*

<sup>†</sup>Indicator from literature, <sup>‡</sup>Indicator from expert interviews, <sup>§</sup>Accepted in phase 3a scoring round, <sup>¶</sup>Accepted in phase 3b plenary discussion, <sup>\\</sup>Adapted and accepted in phase 3b plenary discussion.   
\*\*Subdivision in domains was not part of the original methodology, but added later to facilitate interpretation and was based on existing classification of quality domains in end-of-life-care<sup>43</sup>

Bold denotes indicators that are common across all three pathologies (cancer, COPD, Alzheimer's).

Supplementary table S.4 (see appendix) presents all QIs that were rejected by the expert panels with a reason for rejection. The most common reasons were: (1) the lack of an alternative given the patient's medical status, thus not inappropriate; (2) the QI would only be relevant to a specific subpopulation that is unidentifiable with available data; (3) strong individual variation between patients determines appropriateness, therefore population-level measurement cannot be valid; (4) the QI is not measurable in a reliable or valid manner with the currently available administrative data.

## **Discussion**

### *Summary of main findings*

We developed a set of quality indicators that can be measured using routinely collected administrative data for population level measurement of the appropriateness of end-of-life care for patients with COPD, Alzheimer's disease or cancer. Consensus was reached by multidisciplinary expert panels on a total of 82 indicators across the three pathologies, all measurable with administrative data.

### *Strengths and limitations*

Our study used a RAND/UCLA appropriateness method to select QIs, which is a widely accepted consensus method.<sup>40,42</sup> The addition of expert interviews broadened the scope of our search for candidate indicators, while still using the same strict criteria for indicator evaluation by consensus in the expert panels. Our focus of measurability with available administrative data limited the number of candidate QIs when compared with previous studies that did not target indicators based on administrative data<sup>25,43</sup>. As a result, several important quality aspects, such as communication, patient satisfaction or psychosocial wellbeing are not included in the current set. As soon as countries systematically start to record this information the QI sets can be complemented with indicators covering these quality of care aspects. Another limitation of our study is that we did not include certain groups of stakeholders that can provide additional perspectives on quality of care, such as patients and families<sup>44</sup>. However, this choice was based on to the medical-administrative approach of our study. We limited our study to medical experts (doctors and nurses) with potential expertise on what could be validly operationalized with the available health claims and administrative data and who would have sufficient technical and medical understanding of which techniques, interventions and medications would indicate potential inappropriateness at an aggregated level. Nevertheless, we believe that the missing perspectives can be reintroduced as soon as scores for the quality indicators are presented and discussed in an interdisciplinary group, as a form of additional face validation.

### *Comparison with previous research*

Previous studies developing and validating population-level QIs for end-of-life care measurable with administrative data were strongly focused on cancer<sup>21-23,25,29</sup>. Compared with these studies, we identified a larger number of QIs. This is mainly the result of the level of detail and broadness of spectrum of the available administrative data in Belgium that contain detailed health care information<sup>45</sup>. Because it is very likely that such data are also available in other countries our indicator set may have a broader international relevance and applicability.<sup>46</sup> However, a particularly important addition in our study compared to the state of the art is the development and validation of QI sets for end-of-life care, measurable with administrative data, in COPD and Alzheimer dementia. These patient groups can be identified using either diagnostic data (e.g. death certificate data) or validated algorithms based on specific treatments and medication use. The use of these sets in different national and international evaluations of end-of-life care may be an important contribution to an increased attention to monitoring and improving end-of-life care in COPD and Alzheimer Dementia.

### *Implications for policy, practice and research*

The QIs developed in this study have multiple uses. They allow the provision of evidence for the level of appropriate and inappropriate end-of-life care within a country, comparison between regions and health care providers (and provider types), or between subgroups of patients determined, for instance, by age, gender, educational attainment, income, etc.<sup>47</sup> The QIs cannot serve as indicators for appropriate or inappropriate care at the level of individual patients, because clinical factors justifying an intervention or personal preferences can widely vary between individual patients. Rather, QIs provide a snapshot of the performance of the health care system, with respect to appropriateness of end-of-life care. The use of the QIs can pinpoint discrepancies between health care use and government policy goals, uncover possible inequities in end-of-life care delivery, and eventually isolate underlying factors explaining differences<sup>48</sup>. This provides a unique perspective on use, access and availability of appropriate care across subpopulations. A strength of our QI sets is

that their reliance on routinely collected administrative data provides a large amount of information without incurring any measurement burden on health care staff or institutions<sup>49</sup>.

An important goal for these QIs is to establish benchmarks for policy makers and care professionals that would indicate areas of good practice or underperformance<sup>50</sup> that could then serve as relative standards to improve the quality of care. For the current QI set no such benchmarks have been validated in the literature.<sup>21,22,29</sup> However, we could use descriptive statistics to show the distribution of appropriate and inappropriate care across the population. Earle, for example, suggests using the best decile as a desirable benchmark. This was applied to eight indicators in the set from Earle et al. for cancer patients (e.g. the best decile benchmark for 'percentage of patients with more than one hospitalization in the last month of life' was set at <4%).<sup>22</sup> Using such a data driven approach provides the advantage of setting realistic norms that are attainable by default.<sup>51</sup> Moreover, they can be recalculated as the quality of care improves, stimulating continuous quality development.<sup>22</sup> However, before these benchmarks are used when comparing regions or care providers, determining appropriate risk adjustment is essential<sup>52</sup>. Relevant variations in patient population that have a considerable effect on the indicator scores need to be controlled for in order to increase the so-called attributional validity, i.e. the conviction that observed outcome differences causally relate directly to quality of care rather than to other factors. Moreover, even with sophisticated risk adjustment strategies caution is needed about the manner in which our end-of-life care QI sets are used in comparisons. Examples from other domains of health care have shown how the use of performance indicators in pay-for-performance models have led some clinicians or health-care facilities to 'game' the system by avoiding patients who can lower a performance score<sup>52</sup>.

While the purpose of QIs is often to measure quality of care at an organizational level for internal monitoring<sup>53,13,21,40</sup>, our sets can provide a basis for cross-regional and cross-national measurement and comparison. Although the validity of the sets may not necessarily transfer to other countries, they can be relevant for all countries

where administrative health care databases are accessible. Several indicators can be transferred directly and used in an international context (e.g. because they are derived from international literature), others may demand country-specific translations.

#### *Further research questions*

Developing these QIs is only a first step. The next step would be to measure them using the available administrative databases. Our QI sets have now been evaluated for validity and acceptability (through the expert meetings) and feasibility (measurability with the existing administrative data as a premise), although other countries that wish to use the indicator set may want to evaluate acceptability and feasibility within their own national context. In measuring the QIs quantitatively we can further evaluate reliability (e.g. when measured across health care settings) and sensitivity to change.<sup>40</sup> QIs must also relate to enough patients to make comparing data feasible - for example, by excluding those aspects of care that occur in less than 1% of clinical audit samples.<sup>40</sup> Some of the QIs developed in this study may not prove to be useful in practice, even if approved by experts, e.g. because measurement result may have a ceiling effect (close to 100% or 0%) or vary too little across subpopulations to provide any useful information. Finally, necessary additional measures are needed to go from measuring quality towards improving it. The QIs indicate end-of-life care areas that need improvement but it requires QI-based policy-setting, which can include appropriate end-of-life care training, financial incentives or infrastructure to actually improve care.

#### **Conclusion**

We developed comprehensive sets of QIs of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or COPD, to be used in population-level research and monitoring using administrative health care databases. Our approach focusing on options provided by administrative health care databases is limited to treatment and medication and excludes other important quality aspects, such as communication, which are ideally monitored using complementary approaches. Nevertheless, our sets will enable an

efficient comparison of health care providers, regions and countries in terms of their performance on appropriateness of end-of-life care.

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**Chapter 3:** Using linked administrative and disease-specific databases to study end-of-life care on a population level.

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## **Abstract**

**Background:** The use of full-population databases is under-explored to study the use, quality and costs of end-of-life care. Using the case of Belgium, we explored: (1) which full-population databases provide valid information about end-of-life care, (2) what procedures are there to use these databases, and (3) what is needed to integrate separate databases.

**Methods:** Technical and privacy-related aspects of linking and accessing Belgian administrative databases and disease registries were assessed in cooperation with the database administrators and privacy commission bodies. For all relevant databases, we followed procedures in cooperation with database administrators to link the databases and to access the data.

**Results:** We identified several databases as fitting for end-of-life care research in Belgium: the InterMutualistic Agency's national registry of health care claims data, the Belgian Cancer Registry including data on incidence of cancer, and databases administrated by Statistics Belgium including data from the death certificate database, the socio-economic survey and fiscal data. To obtain access to the data, approval was required from all database administrators, supervisory bodies and two separate national privacy bodies. Two Trusted Third Parties linked the databases via a deterministic matching procedure using multiple encrypted social security numbers.

**Conclusion:** In this article we describe how various routinely collected population-level databases and disease registries can be accessed and linked to study patterns in the use, quality and costs of end-of-life care in the full population and in specific diagnostic groups.

## Background

It has been argued that there is a particular challenge for end-of-life care research to develop a public health approach<sup>1</sup> which would include, among other things, the need for a focus on total populations instead of individuals at risk or those receiving a certain health care service. This means that many, often 'hidden', publics also need to be studied.<sup>1,2</sup> End-of-life care research indeed often suffers from selection bias, recall bias and non-response bias<sup>3-5</sup> and difficult-to-reach populations tend to be under-represented due to ethical and practical considerations<sup>6</sup>.

Administrative data can provide a major opportunity in this respect. They allow not only the monitoring of usage, quality and costs of end-of-life care on a population level<sup>7</sup>, but also identifying populations dying of or dying with a specific disease such as cancer, chronic obstructive pulmonary disease (COPD) or Alzheimer's disease in order to evaluate patterns of end-of-life care within and across different trajectories of dying.<sup>8</sup> Many healthcare institutions generate, store and exchange large amounts of individual patient data.<sup>9</sup> Increasing digitalisation in recent years has further facilitated and improved this process.<sup>10</sup> Although big data serve administrative purposes particularly (e.g. billing, tracking of health care reimbursement) they can provide useful research material from a public health perspective.<sup>11</sup> They often have a well-defined population and include subgroups or difficult-to-reach populations.<sup>6</sup> Because administrative data registrations are usually standardized and continuously collected they enable trend analyses and longitudinal studies. Moreover, since the data have already been collected, they are relatively inexpensive when compared with original data collections.<sup>2,12</sup> The expanding availability and quality of data input make them increasingly interesting to use in health research. Although full-population databases have been used to study end-of-life care since the late nineties (e.g. in Australia<sup>13</sup> and Canada<sup>14</sup>), the use of such data in end-of-life care research is still under-explored.

End-of-life care researchers may face several challenges when using administrative data. Administrative data are, for instance, not specifically designed for research purposes and therefore not directly

usable for the evaluation of quality of care or quality of dying. They are not structured in readily available variables for analysis and may often lack the essential disease-specific or relevant socio-demographic information needed in end-of-life care research. Additionally, healthcare data, socio-demographic data, socio-economic data and clinical data gathered on every citizen are stored in separate databases that are owned and handled by different organisations. Also, data security and confidentiality must be publicly guaranteed when using administrative databases for healthcare research. The challenge is thus to collect, link, integrate, store and process them so that they provide a useful input for end-of-life care research.

Using the case of Belgium, we describe how several full-population data sources can be accessed, linked, handled and stored in order to obtain a rich database for evaluating the use, quality and costs of end-of-life care. Our research questions are: (1) what data and databases are available that provide information about end-of-life care, (2) what are the procedures to obtain/use these data, (3) what is needed to integrate separate databases, and (4) what variables are available in these databases to study use, quality and costs of end-of-life care.

## **Methods**

To address our research aims we systematically collected the necessary information in four phases:

1. First, we had to identify what databases provide information on the health care use, quality and costs near the end of life. We aimed to retrieve healthcare use data from all decedents for the two years prior to their death. A group of end-of-life researchers and health economics experts explored what data are available on healthcare and medication use that additionally (1) allow identification of people dying with or from cancer, Alzheimer's disease or COPD; and (2) provide relevant socio-economic and demographic information that is known from literature to influence end-of-life care patterns. Health claims data were used as the starting point as they provide critical data about patterns in formal care and medication prescription at the end of



life. Other administrative databases and disease registries were explored to supplement the health claims database.

2. Once the databases and the data handling organisations were identified, the associated access procedures and permissions as well as linking possibilities were explored.

3. To complete the linking procedure, technical aspects and privacy protection measures were determined, explored and followed.

4. Finally, we composed an overview of available variables through this process. We examined how they can be used to study use, quality and costs of end-of-life care.

## **Results**

### *Identification and selection of databases*

A total of seven population-level databases handled by three different organizations were identified as providing the necessary information (Table 1).

Table 1: Overview of population-level databases identified as relevant for end-of-life care research

Database administrators	Database name	Population	Information provided in database
Inter Mutualistic Agency (IMA)	Population Database	Every Belgian citizen who is a member of one of the seven (compulsory) Belgian sickness funds, information in Population Database is updated twice each year from 2002 onwards	Socio-demographic characteristics (age, sex, date of death, place of residence, family composition, use of supportive measures)
	Pharmanet Database		Medication supply characteristics (substance, quantity, prescriber, expenses, refunds, delivery date)
	Medical Claims Database		Health and medical care use characteristics (quantity of use, reimbursement, supplier, supplier institution, length of treatment)
Belgian Cancer Registry	Cancer registry	Every new cancer diagnosis of Belgian residents, registered by oncological care programs and laboratories for anatomic pathology	Diagnostic characteristics (date of diagnosis, type of cancer, TNM gradation)
Statistics Belgium	Death certificate database	Every Belgian decedent with a registered death certificate	Direct and indirect causes of death (in ICD-10 codes), socio-demographics about the deceased, place of death
	Demographic dataset	Every Belgian citizen	Nationality group, household composition
	Socio-economic survey (SES) 2001 and Census 2011	Every Belgian citizen, information gathered from multiple external administrative databases using social security number (Census 2011)	Highest attained education level, occupation, housing comfort
	IPCAL dataset	Every Belgian citizen	Net income by category
<b>Identified but not used in our research</b>			
Belgian Ministry of Health	Minimal Hospital Dataset	Every hospital admission in non-psychiatric general hospitals	Medical, nursery and personnel data for in-hospital care

The Inter Mutualistic Agency (IMA) manages the databases that included all reimbursement data of health care consumption from all seven healthcare insurers. Since health insurance with one of these insurers is legally mandatory in Belgium, reimbursement data of all legal residents are available in the IMA database. Moreover, thorough quality procedures result in reliable usability of the database for healthcare research. The IMA manages three databases: (1) a population database containing socio-demographic data of all insured persons; (2) a health care database containing health care use and costs data of both ambulatory and hospital care and (3) a pharmaceutical database containing medication prescription and costs data. The databases thus provide information on an individual level across the entire Belgian population. The IMA databases contain no information regarding medical diagnoses or any disease specific information.

The Belgian Cancer Registry was identified as a database to identify people who died with cancer. All Belgian oncological care programmes of hospitals and laboratories for anatomic pathology are legally bound to register each new cancer diagnosis with the cancer registry. The latter manages a database with diagnostic information on all incidences of cancer i.e. date of diagnosis, type of cancer and TNM (tumour node metastasis) classification of malignant tumours.<sup>16</sup>

However, the cancer registry data does not make it possible to distinguish between those who died 'from' cancer and those who died 'with' cancer. Additionally, since no similar registries were available to identify those who died with or from Alzheimer's disease and COPD we identified the death certificate data as a necessary additional database. Death certificate data in Belgium are collected by three administrations (corresponding to the three semi-autonomous regions in the country, i.e. Brussels, Flanders and Wallonia) and are integrated by Statistics Belgium into one national database for cause of death statistics. This database provides the causes of death and associated causes of death (coded in ICD-10 [10th revision of the International Statistical Classification of Diseases and Related Health Problems] codes) for all decedents.

Statistics Belgium also manages the national demographic database, derived from the population register<sup>17</sup> and containing for example the

household composition of every citizen and data from the Socio-Economic Survey 2001 and Census 2011, nationwide full population surveys based on the tradition of population count<sup>18</sup>. The database contains information about the highest educational level attained, the last held occupation (as a measure of socio-economic position) and housing characteristics, which are all socio-economic factors that have been identified in previous studies as affecting end-of-life care patterns.<sup>19-21</sup> Finally a database containing fiscal data (i.e. net taxable household income), also managed by Statistics Belgium, was identified as providing additional socio-economic variables of influence on end-of-life care patterns.

For more specific clinical data, the Minimal Hospital dataset, providing clinical information associated with hospitalizations, was looked at for possible inclusion. This dataset has high quality data and provides diagnostic information (in ICD-codes), which allows for a more exact clinical description of the study population. It is however limited to in-hospital data, limiting the study population. Additionally, clinical information can be abstracted from health care claims data using specific algorithms. Obtaining cause of death information and using healthcare claims data makes up for the lack of clinical data. Therefore inclusion of the Minimal Hospital dataset was found to be unnecessary.

The combination of identified databases would provide information on formal health care and medication prescription, causes of death, main diagnosis (through the cancer diagnostic information of the cancer registry and algorithmic estimation methods in the IMA databases), and various relevant socio-demographic and socio-economic information.

#### *Access procedures*

Two types of approval were needed for every database: (1) internal approval from database administrator organisations and (2) approval from the relevant Belgian Privacy Commission bodies.

(1) To obtain access to the IMA and cancer registry databases several steps are required. First, a declaration of interest needs to be set up between researchers and IMA and cancer registry programme managers. Research goals, databases, variables and linking possibilities (see

Data linkage procedure) need to be discussed. After IMA and cancer registry programme managers agree on cooperation, the research project (research goals and requested data) is presented to IMA and cancer registry directory boards for approval.

To obtain access to the databases administered by Statistics Belgium, no formal approval of the directory board is required, since Statistics Belgium is legally committed to providing data for research. Based on the requested data, variables and linking possibilities (see Data linkage procedure) the statisticians of Statistics Belgium deliver non-binding advice. Data requests should be filed directly to the Privacy Committee.

All involved partners then discuss the final selection of data and variables and initiate preparations for the linking procedure. The linking of the databases is a main issue for approval by the involved Privacy Commission bodies.

(2) We needed the approval of two separate national sectoral committees for privacy protection for access to the various databases and the database integrating all databases: the 'Sectoral Committee of Social Security and Health, Section Health' and the 'Statistical Supervisory Committee'. Both are subcommittees of the Belgian Commission for the Protection of Privacy. The former is responsible for privacy protection of health care data (IMA and cancer registry databases), the latter for privacy of national statistical data (Statistics Belgium databases). The application to the Sectoral Committee of Social Security and Health, Section Health consists of two phases. Phase 1 is the submission of the application and a first assessment by the committee in a plenary meeting. The primary investigator of the study presents the research goals and data linkage procedure to the committee at this plenary meeting. In our application special attention was given to the selection of different variables to receive data with sufficient detail for analysis, but at the same time reducing the risk of re-identification of deceased individuals and their families in order to preserve privacy. Changes in the linking procedure and storage on a separate server were requested (see section on data linkage for more details). Phase 2 is the formal approval during a second plenary meeting of the committee, after having received

additional information from the applicant. In our case, the committee requested an additional risk analysis to ensure privacy of the included individuals, which was not requested in the first phase. Formal approval was granted only after a third plenary meeting. The full process took six months from application to formal approval.

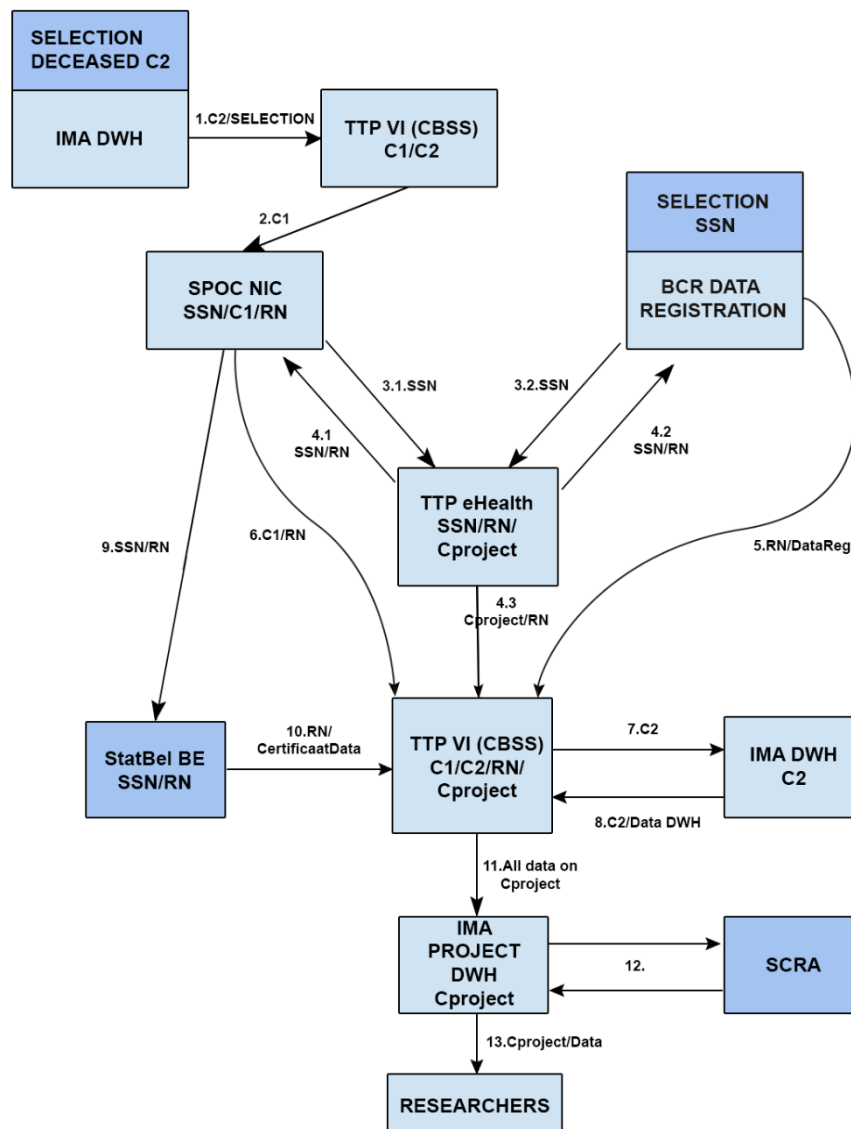
The Statistical Supervisory Committee application procedure consists of one phase in which the application is assessed and discussed on a plenary meeting. Formal approval was granted after the first meeting.

#### *Data linkage procedure*

All eligible databases needed to be linked into one integrated database for analysis; a common unique identifier (i.e. social security number) made deterministic linking possible. Although the death certificate database does not contain this unique identifier, Statistics Belgium performed a linkage between the death certificate database and the national registry database based on date of birth, sex, and municipality of residence in order to include this unique identifier as a variable. Unique linkage was possible for 98.4% of deaths .

For privacy reasons, Trusted Third Parties (TTPs) 'eHealth' and 'Crossroads Bank for Social Security (CBSS)' were responsible for the simple deterministic one-to-one record linkage of the IMA, cancer registry and Statistics Belgium databases. The linkage procedure (Figure 1) consisted of 13 steps of data-coding or decoding and data transfers needed to ensure that none of the involved parties would have access to both the sensitive data and the social security numbers or to their own databases enriched with data from one of the other parties. Only the researchers have access to the complete linked database without unique identifiers using a Virtual Private Network (VPN) connection with secure token.

Figure 1: The linkage procedure



Linkage of all data for deaths in 2012 (including health care information about the two years prior to death) were completed in a first phase of the project. In a second phase all data for all deaths 2010-20xx are linked, where data from subsequent years will be added upon availability. A major consideration in the decision to adopt this phased approach is the size of the linked database. The linked database (deaths in one year) will be used for the initial analysis, after which a selection of variables and/or information can be made.

Variables with too many missing data or variables that are inaccurate can be dropped. Additionally, the initial analysis will inform on what health care interventions or medications are suitable for further analyses. Finally, based on this first analysis phase, detailed information can be aggregated. The second and third delivery will therefore include more cases with more condensed information per case.

Since all databases depend on submission by individual organisations or institutions, a two-year delay is common. Linkage can only be initiated after all data are complete.

#### *Available information and data handling*

Variables selected in this study include data on health care use, prescribed medication, demographics, socio-economics and use of special reimbursement rules. A complete list of variables can be found in the appendix, supplementary table S.5.

*Several steps were necessary to make the data analysis-ready:*

1. In the IMA databases, health care and medication data are coded as nomenclature and Anatomical Therapeutic Chemical Classification (ATC) codes. In order to answer research questions, nomenclature numbers had to be interpreted and possibly aggregated by the researchers into meaningful categories.

2. Due to privacy concerns, no raw dates (e.g. date of birth, prescription date) were provided by database administrators. Dates of medication delivery or health service provision were therefore transformed into a number of days before death. Combinations of these recoded dates and nomenclature or ATC codes are used to determine whether certain interventions occur within a certain time period before death.

3. Since no data were provided on diagnosis in the current set of linked databases (only causes of death are available), algorithms were used to abstract diagnostic information from health care and medication prescription data. Algorithms were developed to identify people with COPD or Alzheimer's disease, based on treatments and medication received. The algorithms were developed using existing evidence<sup>22-24</sup> and were validated by medical experts and medical data



experts from the IMA. They were then applied by the IMA, prior to the linking procedure, because data were used that were not available to the researchers; data provided to the researchers were limited to two years prior to death, while data used for identification of patients with Alzheimer's disease went back to six years before death. Combinations of the algorithmic identification of diagnosis and the causes of death (including the associated causes) can be used to identify relevant disease groups in the analyses.

## **Discussion**

### *Summary of main results*

In linking information from seven different datasets we managed to obtain a database that can provide information about patterns in the use, quality and costs of end of life care at the level of the full population and their associations with various clinical, socio-demographic, socio-economic and environmental factors. The process of obtaining this involved detailed identification of databases fitting the study aims, negotiation with and formal approval of three database administrators, three supervisory bodies and two national privacy commissions and eventual linking of all databases through two Trusted Third Parties (TTPs) using multiple encrypted social security numbers.

We believe that the described process can be particularly helpful to researchers in other countries in compiling similar population-level databases on end-of-life care. A number of considerations (limitations, strengths and opportunities) and recommendations can be made based on our experience.

### *Limitations of our study*

Our study involved a systematic and thorough exploration of how several databases providing information on end-of-life care can be accessed, handled and linked into an integrated and enriched database. However, an important limitation is that linkage with information on patient-related outcomes of healthcare services, such as specific Patient Reported Outcome Measures (PROMs) was not explored in our study. Even

though PROMs are important indicators to evaluate whether increased healthcare expenditure results in better health outcomes, their inclusion in a population-level database is only meaningful if there is sufficient standardization in the measurement methodology. In Belgium, a common coding system for PROMs is lacking and would be time-consuming to perform.<sup>25</sup> Future efforts could be made to include PROMs at a population level.

#### *Opportunities of the collected database*

Our efforts resulted in a population-level database with detailed information about formal end-of-life care, the costs of care and demographic, socio-economic and diagnostic information on decedents. The opportunities provided by such a database to study use, quality and costs of end-of-life care are considerable. The main overall advantage is that data are population-level and therefore not subject to sample bias such as in surveys or medical records studies of selected groups of patients. Compared to primary data collection, using linked routinely collected databases as in our case is less expensive and less time-consuming. In the end-of-life care context specifically, primary data collection can be burdensome for patients and caregivers. Furthermore, in routinely collected databases, high-quality data are available on the spot, although they are not deliberately collected for research aims.

Although the linked database does not include certain types of information that are important in evaluating quality of care, such as patient-specific preferences of care, psycho-social information, patient or family reported outcomes and experiences or information about pain and symptom management or communication aspects<sup>26</sup>, the full-population data have the potential to provide robust and population-level measures of the quality of end-of-life care using specific claims-based quality indicators. These quality indicators, e.g. mapping inappropriate end-of-life care, have been used in various studies as measures for the quality of end-of-life care.<sup>27</sup> If preceded by an adequate validation process, they can provide a detailed image of the quality of end-of-life care by regions or health care providers.<sup>27</sup> The linked database also contains data on all direct medical costs and reimbursed service and medication use, which offers

opportunities to study direct medical costs and patterns in the use of specific end-of-life care for full populations. Policy measures that support palliative care include financial compensation directed towards the patient (e.g. monthly lump sum to cover additional costs for palliative home patients). Using this database, patterns in the uptake of these measures can be mapped and compared between population or pathology groups. As the linked database contains individual data, these data can be aggregated on multiple levels, which makes longitudinal, disease-, treatment- or provider-specific analyses possible. As a result, it is also possible to evaluate the influence of certain policy measures and governmental support programmes. Without the rich population-level data we collected it would be impossible to answer these example research questions without facing major issues of reliability, generalizability, feasibility and costs.

Data allow us to follow back the treatment history and costs of those treatments up to two years before death. Although a shorter period before death may be sufficient to study several aspects of end-of-life care in specific disease groups, for other (particularly non-cancer) longer time periods are warranted. The decision to request all health care and medication data up to two years before death (irrespective of when the diagnosis was made) was also made for practical reasons as going further back would substantially increase storage and analysis requirements.

#### *Limitations of the collected database*

A limitation of these types of routinely collected population-level data is that services not covered by insurers are not included. Researchers from other countries that wish to compile a similar database need to remember that what is not covered by insurance (and hence not found in the data) may be country- or even region-specific. In Belgium, data are relatively complete, for health care services in the hospital, nursing homes and at home. Nevertheless use of certain services cannot be identified because there is no individual reimbursement (e.g. mobile hospital palliative care teams) or such reimbursement is not regulated or generalized (e.g. consultations of a psychologist). Secondly, total out-of-pocket spending is not available in the integrated database. This results in an overall

underestimation of the total cost of end-of-life care. Nevertheless, administrative data are an essential source of information for studies on the financial burden of end-of-life care for the health care budget and are valuable for policymakers in informing their decisions on health care policy.<sup>8</sup>

*Considerations and actions for researchers considering similar database constructions (Table 2)*

The linkage process is crucial in obtaining a useful population-level database. It enables the enriching of the population-level data on formal end-of-life care and the costs of that care with putative demographic, socio-economic and diagnostic information for the study of end-of-life care patterns. This allows the development of explanatory models and the provision of public health information to policy makers, for example on social differences and differences between pathology groups. It can support discussions on the organization of the health care system, based for instance on possible existing inequities.

*Table 2: Considerations for researchers planning to link databases*

<b>Topics</b>	<b>Considerations</b>
Exploring relevant databases	Are my research questions clear and well-defined? What data are needed to answer them?
	What is/are my study population(s)? What data are needed to identify it?
	What database(s) contains the core data and could thus be selected as a starting point?
	When a starting database is chosen, what data are lacking to fully address the research questions? Where can we find them?
	How can we establish contact with the database administrators of the databases? Obtain principal approval from all administrators (e.g. by presenting the study to the board of directors)
	What is the cost associated with each database?
Variable selection	What specific variables do we need from the selected databases to answer our research questions?
	Are the variables we want available and linkable between the different databases?

	Does the preferred selection of variables complicate the linking procedure considerably? Balance the gain in information with the increase in complexity and time.
	What is the required level of detail for each variable? Balance the preferred level with what is allowed in terms of data protection (e.g. through small cells risk analysis to determine risk of re-identification based on a combination of variables)
	Do we have sufficient storage capacity and analysis hardware to store and analyze all the data we want?
Access procedures	What ethical and privacy procedures need to be followed to link and access the selected database?
	What technical procedures need to be followed to link and access the selected databases?
Infrastructure	How will data be stored safely? Is infrastructure provided by researchers or by database administrators? What is the cost for this infrastructure?
	How will data be protected? Physical and digital protection need to be guaranteed.
	How can data be accessed in a safe and easy way? What hardware and software do we need to access and analyze the requested data?

The flip side is that the linking can create additional difficulties in the process of obtaining the data. While deterministic linking is relatively easy to complete on a technical level (even without identical unique identifiers a deterministic linking is possible based on a combination of variables), the main challenges for researchers lie in the fact that 1) several separate organizations have to be convinced to cooperate and 2) special attention needs to be given to privacy-related issues.

Databases across health and social care may not always contain a unique identifier variable, or not always contain accurate and fully available information that allows identifying unique persons. In such cases where the possibility to perform deterministic linkage is limited the method of probabilistic linking can present a solution. In this approach the likelihood of a correct linking is calculated and a linking is done when the likelihood is sufficiently large.<sup>28</sup> Several tools have been developed to perform this probabilistic linking.<sup>29</sup> Nevertheless, a lack of accurate and fully available personal identifiable information constrains a probabilistic linking method.

A final consideration for researchers who wish to have access to similar data in their country is that establishing and maintaining good relationships with database administrators is crucial. Gaining access to administrative data is an iterative process that requires a lot of preparatory work. Database administrators are the researchers' access points to the data and have all the information about internal procedures. Strict procedures need to be followed, in close cooperation with database administrators. We were able to arrange an updated dataset where data from subsequent years will be added upon availability in the same approval and agreement, which limits the time of going through all necessary permissions each time an updated dataset is needed. Since administrative data are often not gathered with the intention of research, or only for internal use, the process of making the data analysis-ready can take time. Researchers must adapt to how data are registered and stored, before they can effectively use them for research.

## **Conclusion**

Linking and accessing various routinely collected population-level databases involves challenges but offers substantial opportunities to study patterns in the use, quality and costs of end-of-life care both in the full population and for specific diagnostic groups. This study has identified that it is possible to combine data from different databases in order to obtain a rich database for such analysis, including information about all reimbursed care and medication as well as disease, demographic, socio-economic and environmental information. While some aspects may be specific to the Belgian context, our study has a much broader application as most developed countries collect similar population-level databases. The process described in our study can be a helpful aid for researchers in these countries to compile similar data and eventually develop an international comparative end-of-life care research agenda using administrative health care data.

## **Declarations**

### *Ethics approval and consent to participate*

In accordance with Belgian law, approvals for access to the various databases and the database integrating all databases were obtained from two separate national sectoral committees for privacy protection: the 'Sectoral Committee of Social Security and Health, Section Health' and the 'Statistical Supervisory Committee'. Both are subcommittees of the Belgian Commission for the Protection of Privacy. Additionally, the ethics committee of the Ghent University Hospital provided approval (B670201422382).

### *Authors' contributions*

AM, RDS and KF have equally contributed as first authors. All authors have contributed to the design of the study. All authors have been involved in critically revising the first draft and read and approved the final manuscript.

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**PART II: Measuring quality  
indicators for end-of-life care  
in Belgium**



**Chapter 4:** Applying quality indicators for administrative databases to evaluate end-of-life care for cancer patients in Belgium

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## **Abstract**

**Background:** End-of-life cancer care has been criticized for being too frequently aggressive. To evaluate to what extent end-of-life cancer care is appropriate within a health care system, population-level quality indicators can be used. We aim to evaluate end-of-life cancer care using quality indicators measured with population-level data.

**Methods:** We conducted a retrospective observational study of all cancer decedents in 2012 in Belgium. We use full-population databases with health care use, cancer diagnostics, demographic and socio-economic variables. Indicators of appropriate care are calculated, covering aggressiveness of care, pain and symptom treatment, continuity of care, palliative care and place of death.

Principal component analysis and analysis of variance are used to examine associations between dimensions underlying the quality indicator set and patient characteristics.

**Results:** In 2012 in Belgium, 26,464 (24.54% of all deaths) people died of cancer. 52% received specialist palliative care; 29% died at home. In the last 30 days, 17% received chemotherapy and 82% received diagnostic testing. For 16%, palliative care was initiated only in the last 14 days.

**Discussion:** Our study suggests an overuse of inappropriate cancer care at the end of life and an opportunity to increase the proportion of people receiving specialist palliative care and dying at home.

## Background

Health care at the end of life in people with cancer has often been criticized for being too frequently inappropriate and aggressive.<sup>1-4</sup> Curative and life-prolonging care goals often, even in the final phases of cancer, prevail over comfort-oriented care even though the benefits no longer outweigh the possible negative impacts.<sup>3,5-10</sup> Research in the USA, Canada and Australia has, for instance, evaluated end-of-life care in cancer patients using several indicators of aggressiveness of care and has found substantial proportions of patients receiving chemotherapy in the last 7 days before death, having multiple hospitalizations or emergency room visits in the last 30 days of life and a large number of patients dying in an acute care institution.<sup>11-14</sup> These studies also found large variations between geographical and health regions.<sup>11-13,15</sup> A large international comparison study measuring health care use found large variations between countries in death in acute care hospitals and ICU admissions in the last months of life of people dying with cancer.<sup>16</sup>

Inappropriate care can be defined as 'treatment and/or medication for which the expected health benefit (e.g. improved quality of life, increased life expectancy, pain relief, improvement of functional status) does not exceed possible negative outcomes (e.g. mortality, decrease in quality of life, pain, symptom burden)'.<sup>17,18</sup> In addition to a quality-of-care dimension inappropriate care also has an economic and justice dimension, for instance, through its incurred opportunity cost: where resources are used for treatments with little effectiveness and possibly several negative effects, the same resources cannot be used more efficiently for other aspects of care that are more beneficial for the patient, such as comfort care.

Providing optimally appropriate end-of-life care to people with cancer is a major public health priority which requires an adequate assessment of the performance of health care systems<sup>19,20</sup>. Ideally, such assessments are done at a population level as it reduces the risk for selection bias, and under-representation of difficult-to-reach populations<sup>21-24</sup> Additionally, population-level assessments of end-of-life care, due to the use of larger numbers and its inclusivity of all

populations, better allow identifying variation by countries, regions, health care settings, or socio-economic and cultural background of patients.

To detect any quality issues in health care in the final stages of life (and evaluate whether available resources in the health care system are effectively used) we need to measure and evaluate the appropriateness of end-of-life care within different populations in a valid way.<sup>25</sup> Quality indicators, defined as 'well-defined and measurable aspects of care'<sup>26</sup> are considered to be a valid way to measure and evaluate quality and appropriateness of care in general and end-of-life care more specifically.<sup>27-30</sup> Quality indicators require a clear and unambiguous definition of what is to be measured, express quality at an aggregated level (usually the level of a healthcare service, institution, region or country) and are generally expressed as a number or percentage.<sup>31</sup> They are not used to evaluate the quality of care for individual patients.

Previous research using quality indicators of end-of-life care has a number of limitations: it is often limited to relatively small groups of patients and specific care services<sup>26,29</sup>, focused only on a limited set of quality indicators as they were developed specifically for measurement in the existing health claims databases of the United States of America and Canada (e.g. Medicare databases) - as such excluding indicators that may be measurable in health claims databases in other countries - and were selected by experts in countries that may not necessarily share the same views on appropriate care near the end of life as other (e.g. European) countries<sup>32-34</sup>. Also, previous studies often focused on a limited population: cancer patients aged 65 years and older (because Medicare data do not cover the younger population, which would be about half of all cancer-related deaths<sup>11</sup>). In the context of these limitations in previous research a set of 26 quality indicators for end-of-life cancer care measurable with routinely collected administrative data was developed including indicators of aggressiveness of care, pain and symptom management, palliative care, place of treatment and place of death and coordination and continuity of care.<sup>21</sup>



Using the developed indicator set, this study will evaluate end-of-life care in people dying from cancer on a population level in Belgium using quality indicators measured with linked routinely collected population-level data. The specific research objectives are:

1. To assess end-of-life care in people dying from cancer in Belgium using 26 validated quality indicators of potentially appropriate and inappropriate end-of-life care.
2. To examine the risk factors for exposure to potentially appropriate or inappropriate end-of-life care including cancer type, socio-demographic and socio-economic variables.

## **Method**

### *Study design and data sources*

We conducted a retrospective observational study of all individuals who died from cancer in 2012 in Belgium. For this, cohort data from eight routinely collected population-level databases, handled by three different organizations, were linked into one database for analysis<sup>35</sup> (see more detailed description of databases in the appendix S.3):

- (1) Population database with socio-demographic data of all individuals with healthcare insurance (legally mandatory in Belgium);
- (2) Health care database containing all reimbursed health care use data of ambulatory and hospital care;
- (3) Pharmaceutical database containing all reimbursed medication data;
- (4) Belgian Cancer Registry<sup>36</sup> data with diagnostic information on all incidences of cancer including date of diagnosis and type of cancer;
- (5) Death certificate data containing cause of death information of every death case;
- (6) Population registry data containing information about citizens' nationality and household composition;

(7) Census data (including educational level and housing characteristics, identified in previous studies as affecting end-of-life care,<sup>37-39</sup>);

(8) Fiscal database (including net taxable household income);

After acquiring the necessary approvals for use of the databases and from the relevant data protection agencies, the databases were linked into one integrated database for analysis. All databases were linked in a secure and ethically responsible manner, guaranteeing anonymity of the deceased to all researchers and database administrators. The databases, the data protection approvals and the linking procedure are described in detail in a previous publication.<sup>35</sup>

### *Population*

All cancer deaths in 2012 were identified based on the recorded underlying cause of death in the death certificate data: ICD-10 codes [10th revision of the International Statistical Classification of Diseases and Related Health Problems]<sup>40</sup>: C00-C97. We selected our cohort based on cancer as an underlying cause of death rather than having a cancer diagnosis in order to select a more homogeneous population (those ever having had a diagnosis may more likely die from other causes and not necessarily receive care or treatment as a cancer patient).

### *Data*

For this study we used all available data on health care use including medication use, treatment, dates of treatment and prescription and admission to hospitals and nursing homes. Several variables for socio-economic and demographic information were selected, including age, gender, region of residence, degree of urbanization of the municipality of residence and type of household. The different cancers were classified into 9 main categories.

### *Quality indicators of appropriate and inappropriate end of life cancer care*

We previously developed and validated a set of 26 quality indicators for end of life cancer care using the RAND/UCLA Appropriateness Method,

measurable using administrative databases (table 1).<sup>21</sup> These quality indicators are meant to indicate both potential appropriate and inappropriate end-of-life care. They measure the prevalence of specific medication types (selections based on the Anatomical Therapeutic Chemical Classification System [ATC] codes) or healthcare interventions (recorded as nomenclature codes for reimbursement purposes) within a specified period before death. For example, the quality indicator on chemotherapy in the last 30 days of life is calculated by dividing the number people who died from cancer and received chemo medication (all reimbursed medication with an ATC-code containing L01\*) in the last 30 days prior to death by the total number of people who died from cancer (table 1).

*Table 1: the set of quality indicators (QIs) for people dying from cancer*

<b>Indicator (brief description)</b>	<b>Indicator of appropriate (A) or inappropriate (I) care</b>	<b>Numerator (Number of people who died from cancer who*)</b>	<b>Denominator (*Number of people who died from cancer)</b>
Tube feeding or intravenous feeding	I	*received tube feeding or intravenous feeding in the last month prior to death (excluding people from gastro-intestinal cancer)	*
Blood transfusion	I	*received blood transfusion in the last month before death (for people with a hematologic condition in the last 2 weeks)	*
Diagnostic testing <sup>†</sup>	I	*had diagnostic testing (spirometry OR blood drawn OR electrocardiogram OR echography OR radiography) in the last month prior to death	*
Port-a-cath installment	I	*had a port-a-cath installed in the last 2 weeks prior to death	*
Surgery	I	*received surgery in the last [6, 3, 1] month/s prior to death	*
Chemotherapy	I	*received 1 or more chemotherapy treatments in the last month prior to death	*
Chemotherapy interval	I	Number of days between last chemotherapy treatment and death	*
Cisplatin in old age	I	*received Cisplatin and were age 80 or older	*and were age 80 or older
New anti-depressant <sup>‡</sup>	I	*had initiation of a new anti-depressant treatment in the last 2 months prior to death	*
Opioids	A	*received opioids in the last [6, 3, 1] months prior to death	*
Opioids and neuropathic medication	A	*received neuropathic medication while receiving morphine in the last 2 years prior to death	*
Specialized palliative care	A	*received specialized palliative care (Hospital palliative unit OR palliative daycare center OR multidisciplinary home care) in the last 2 years prior to death	*

Official palliative care status	A	*received official palliative care status, enabling financial government support for palliative care at any point prior to death	*
Late initiation of palliative care	I	*had a first referral to specialized palliative care OR received official palliative status in the last two weeks before death	*
Hospital admissions	I	*had one or more hospital admissions in the last [6, 3, 1] months prior to death	*
ICU admissions from nursing home	I	* lived in a nursing home and had one or more intensive care unit admissions in the last [6, 3, 1] months prior to death	*and lived in a nursing home
ED admissions	I	*had one or more emergency hospital visits in the last [6, 3, 1] months prior to death	*
Home death	A	*died at home	*
Death at home or in nursing home of residence	A	*died at home or in the nursing home where they lived	*
Family physician contact increase	A	* had an increase in average number of contacts with a family physician in the last month prior to death compared to the previous months	*
Primary caregiver contact	A	Total number of contacts with a family physician or other primary care professional in the last 3 months prior to death	*
Multi-disciplinary Oncology Consult	A	*had a Multidisciplinary Oncology Consult	*

Four indicators from the original QI set were omitted in this study because they were immeasurable with the current data set: Chemotherapy new Line, Anti-emetics with chemotherapy, Radiotherapy with Bone Metastases and Radiotherapy with small cell lung cancer. <sup>†</sup>For blood drawn, we included clinical biology analysis but excluded monitoring analyses. <sup>‡</sup>Non-selective monoamine reuptake inhibitors (ATC-code: N06AA) were excluded from this indicator to avoid including neuropathic pain medication.

In those quality indicators where time before death is relevant, we calculated the quality indicator in 7 time intervals (7, 14, 30, 90, 180, 360 and 720 days before death). The time intervals for which each quality indicator was validated by the expert panels in previous research<sup>21</sup> is indicated in tables 3 and 4.

### *Statistical Analyses*

The characteristics of people who died from cancer and the quality indicators are calculated using descriptive statistics.

To examine the predictors (or risk factors) for the outcomes of end-of-life care corresponding to the developed set of quality indicators, we performed a principal component analysis (PCA) on the quality indicators with the aim of data reduction. Using PCA allowed us to identify underlying components of the 24 measured quality indicators. (Appendix, supplemental material S.6 and S.7) We performed exploratory PCA, combining quality indicators with a logical consistency within a

specific quality of care theme (e.g. aggressive cancer treatments, appropriate pain medication). The scores for selected components were saved for each individual in the cohort.

We then performed an analysis of variance to evaluate which patient characteristics are associated with higher or lower scores for these components (and hence propensity for appropriate or inappropriate end-of-life care).

All analyses were conducted with SAS Enterprise Guide, version 7.1.

### *Ethics*

The study was approved by the committee for medical ethics of the University Hospital Brussels (UZ Brussels) (B.U.N. 143201627075).

## **Results**

### *Cohort characteristics*

A total of 26,464 people who died from cancer in 2012 were included in the analysis, of which 56.5% were men (table 2). The mean age at death was 77.9. The majority lived with a partner (55.7%); 34% lived in a low comfort home without central heating and 59% lived in an area with strong morphologic urbanization. The most prevalent types of primary cancer were digestive tract (29.7%), and respiratory tract (27.0%) cancers.

Table 2: Characteristics of all deaths from cancer, Belgium, 2012.

		Number*	Percent
<b>All deaths from cancer</b>		26,464	100.0
<b>Gender</b>	Male	14,965	56.5
	Female	11,499	43.4
<b>Age</b>	0-17	49	0.2
	18-64	6,375	24.1
	65-74	6,238	23.6
	75-84	8,386	31.7
	85 and older	5,416	20.5
<b>Nationality</b>	Belgian	25,161	95.1
	Other	1,303	4.9
<b>Household type</b>	Single person	7,874	29.8
	Couple with no children living at home	11,605	44.0
	Couple with children living at home	3,093	11.7
	Single parent family	1,391	5.3
	Collective household	1,870	7.1
	Other	559	2.1
<b>Housing comfort</b>	High	11,998	49.6
	Average	3,960	16.4
	Low	8,221	34.0
<b>Level of education</b>	Higher education	3,255	13.8
	Upper secondary education	4,556	19.3
	Lower secondary education	6,494	27.6
	Primary education	7,506	31.9
	No education	1,758	7.5
<b>Level of urbanization of residence</b>	Very high	8,045	30.6
	High	7,472	28.4
	Average	7,077	26.9
	Low	3,690	14.0
<b>Net Taxable Income</b>	<= 10,000	18,062	16.8
	]10,000 - 15,000]	42,331	39.3

	]15,000 – 20,000]	27364	25.4
	> 20,000	20083	18.6
<b>Type of cancer</b>	Digestive tract	7862	29.7
	Respiratory tract	7153	27.0
	Breast	1961	7.4
	Urinary tract	1643	6.2
	Female genital organs	1371	5.2
	Male genital organs	1167	4.4
	Head and neck	860	3.3
	Melanoma	521	2.0
	Other	3925	14.8

\*May not always add up to 26,464 because of missing values, which were always lower than 2.5%, except for level of education (10.9%).

#### *Quality indicators of appropriate end-of-life care*

From the people who died from cancer in 2012, 69% received opioid prescriptions in the last 30 days of life (table 3). Just over half (52%) received specialist palliative care (admission to a hospital palliative care unit, palliative daycare center or multidisciplinary home care); 29% died at home (increasing to 39% when also including those dying in a nursing home where they had been resident for at least 180 days before death).

The average number of family physician contacts per 7 days increased as people were closer to death (from 0.11 in the last 720 days, to 0.40 in the last 7 days). The number of contacts with a family physician increased for 22% in the last week and for 30% in the last two weeks compared to earlier periods.

Table 3: Quality indicators indicating appropriate end-of-life care, within the total population dying from cancer (N=26,464), Belgium, 2012

Indicator	Time period (number of days before death until death)							
	No time specification	7d	14d	30d	90d	180d	360d	720d
Opioids	-	43.3	57.5	68.6	75.9	79.1	82.1*	85.2*
Opioids and neuropathic medication	-	2.9	4.7	7.3	10.6	12.1	13.5	14.6
Specialist palliative care	51.8	-	-	-	-	-	-	-
Official palliative care status	38.3	-	-	-	-	-	-	-
Home death <sup>‡</sup>	29.3	-	-	-	-	-	-	-
Death at home or in nursing home of residence <sup>‡</sup>	38.7	-	-	-	-	-	-	-
Family physician contact increase	-	22.2	30.0	33.5	38.9*	44.5*	51.6*	**
(average number of family physician contacts) <sup>§</sup>	-	0.40	0.28	0.21	0.15*	0.14*	0.13*	0.11*
Average number of primary caregiver contact <sup>¶</sup>	-	2.01	1.93	1.87	1.71	1.52*	1.28*	1.01*
Multi-disciplinary Oncology Consult	-	3.8	7.0	13.2	28.6	42.2	57.0	68.0

\*The indicator was not validated for this time period by the expert panel during QI development.

<sup>†</sup>This indicator was not calculated for the entire population. The denominator includes only people who received chemotherapy during the same time period.

<sup>‡</sup>This indicator is only measured at the moment of death. Therefore, time periods are irrelevant.

<sup>§</sup>This indicator is not presented by percentages. It depicts the average number of contacts across the population during the indicated time period.

<sup>\*\*</sup>This period has no prior period to compare with. It serves as a reference category for subsequent periods.

#### Quality indicators of inappropriate end-of-life care

Of the people dying from cancer 17% received chemotherapy in the last 30 days before death, 4% in the last week (table 4). In the last 30 days of life 7% received tube feeding or intravenous feeding, 82% received diagnostic testing (decreasing to 52% in the last week). Surgery was performed on 30% during the last 180 days and 4% in the last 7 days. For 16% of people dying from cancer, palliative care was initiated only in the last 14 days and for 10% only in the last 7 days. 63% was admitted to the emergency department in the last 180



days, 13% in the last week; 86% was hospitalized in the last 180 days, 33% in the last week.

*Table 4: Quality indicators indicating inappropriate end-of-life care, within the total population dying from cancer (N=26,464), Belgium, 2012.*

Indicator	Time period (number of days before death until death)						
	7d	14d	30d	90d	180d	360d	720d
Chemotherapy	3.9	8.6	17.2	35.6*	45.6*	52.6*	56.5*
Tube feeding or intravenous feeding <sup>†</sup>	5.7	6.2	7.2	8.3*	9.0*	9.6*	10.1*
Cisplatin in old age <sup>‡</sup>	0.0	0.1	0.2	0.5	0.9	1.6	2.12
Diagnostic testing	52.0	67.4	81.6	93.1*	96.8*	98.4*	99.0*
Port-a-cath installment	0.2	0.5	1.1*	2.8*	4.5*	5.7*	5.7*
New antidepressant	2.0	3.7	6.7	12.7	17.4*	23.6*	**
Surgery	3.5	5.7	9.7	20.0	30.0	44.0*	58.6*
Blood transfusion <sup>¶</sup>	2.2	3.9	7.1*	12.9*	16.4*	19.1*	21.0*
Late initiation of palliative care	10.0	16.1	-	-	-	-	-
ED admissions	12.9	20.6	33.8	53.2	62.6	70.2*	76.5*
Hospital admissions	32.6	45.6	61.6	78.5	85.8	91.1*	94.7*
ICU admissions from nursing home	0.8	1.5	2.9	4.8	5.8	5.9	6.3

\*The indicator was not validated for this time period by the expert panel during QI development.

<sup>†</sup>This indicator was not calculated for the entire population. The denominator does not include people who died from gastro-intestinal cancer.

<sup>‡</sup>This indicator was not calculated for the entire population. The denominator consists of all people who died from cancer age 80 and older at the time of death.

<sup>¶</sup>This indicator was not calculated for the entire population. The denominator does not include people who died from any hematological cancer.

\*\*This period has no prior period to compare with. It serves as a reference category for subsequent periods.

#### *Risk factors for exposure to potential appropriate or inappropriate end-of-life care*

The PCA component analysis revealed 4 dimensions (supplemental table S.7) within all outcomes of end-of-life care corresponding to the quality indicators: (1) aggressive tumor treatment (chemotherapy in the last 30 days; surgery in the last 30 days), (2) hospital

transitions and hospital care (ED admissions and hospital admission in last 30 days; diagnostic testing in last 14 days), (3) comfort and palliative care (received the official palliative care status; received specialized palliative care; family physician contact increase in last 30 days; average number of primary caregiver contact in the last 30 days and death at home or in nursing home of residence) and (4) pain and symptom treatment (opioids and opioids with neuropathic pain medication in the last 30 days).

A multivariable ANOVA analysis (table 5) indicated that component scores for aggressive tumor treatment decrease with increasing age, and are higher in couples, compared to people living alone.

*Table 5: Associations between 4 components of potential appropriate and inappropriate end-of-life care and patient characteristics, unbalanced ANOVA analysis\**

	<b>Component 1: Curative tumor treatment</b>	<b>Component 2: Hospital transitions and hospital care</b>	<b>Component 3: Comfort and palliative care</b>	<b>Component 4: Pain and symptom treatment</b>
Number of cases in regression analysis <sup>†</sup>	26,464 <sup>†</sup>	26,284 <sup>†</sup>	24,017 <sup>†</sup>	26,464 <sup>†</sup>
<b>Gender</b>				
Male	-	0.10‡	-	-0.057‡
Female	-	(ref. cat.)	-	(ref. cat.)
<b>Age</b>				
0-17	0.713‡	0.210	-	0.142
18-64	0.508‡	0.374‡	-	0.520‡
65-74	0.446‡	0.334‡	-	0.299‡
75-84	0.250‡	0.222‡	-	0.152‡
85+	(ref. cat.)	(ref. cat.)	-	(ref. cat.)
<b>Region</b>				
Brussels	-	0.068	-0.330‡	-
Wallonia	-	0.087‡	-0.147‡	-
Flanders	-	(ref. cat.)	(ref. cat.)	-
<b>Household type</b>				

Couple no children	0.171 <sup>‡</sup>	-	0.259 <sup>‡</sup>	-
Couple with children	0.211 <sup>‡</sup>	-	0.297 <sup>‡</sup>	-
Single parent family	0.193 <sup>‡</sup>	-	0.186 <sup>‡</sup>	-
Collective household	0.134 <sup>‡</sup>	-	-0.513 <sup>‡</sup>	-
Other	0.207 <sup>‡</sup>	-	0.181 <sup>‡</sup>	-
Single person	(ref.cat.)	-	(ref. cat.)	-
<b>Level of urbanization of residence</b>				
Very high	-	(ref. cat.)	-	-
High	-	-0.037	-	-
Average	-	-0.040 <sup>‡</sup>	-	-
Low	-	-0.146 <sup>‡</sup>	-	-
<b>Type of cancer</b>				
Digestive tract	-	-	0.094 <sup>‡</sup>	0.009
Female genital organs	-	-	0.123 <sup>‡</sup>	0.044
Head and neck	-	-	-0.030	0.066
Male genital organs	-	-	0.037	0.188 <sup>‡</sup>
Melanoma	-	-	-0.013	0.151 <sup>‡</sup>
Respiratory tract	-	-	0.032	0.098 <sup>‡</sup>
Urinary tract	-	-	0.130 <sup>‡</sup>	0.151 <sup>‡</sup>
Other	-	-	-0.061	-0.027
Breast	-	-	(ref. cat.)	(ref. cat.)

\*Results from ANOVA using the SAS General Linear Model (GLM) procedure with factor scores for the different components as dependent variables (with an overall mean of 0 and standard deviation of 1). Presented results are estimates of the differences of least squares means and represent the increase or decrease on the factor score compared with the reference category.

<sup>†</sup>number of cases in analysis might differ from 26,464

<sup>‡</sup> p-value for difference between this category and the reference category is <0.01

Potentially inappropriate hospital transitions and hospital care are more prevalent in younger (75 years old or younger) than in to older people, and less likely in people living in rural areas.

Potentially appropriate comfort and palliative care are associated with region (more likely in Flanders than in Wallonia and Brussels) and with household type (more likely in couples than in people living single and people in collective households) and is most likely in

those with urinary tract, female genital organs or digestive tract cancers.

Potentially appropriate pain and symptom treatment is more likely in women and in younger adults and is more likely in those dying from male genital cancer, urinary tract cancer, melanoma, or respiratory tract cancer than in those dying from other cancer types.

## **Discussion**

Using a set of validated quality indicators of end-of-life care, we were able to provide a snapshot of the performance of the Belgian healthcare system in terms of end-of-life care in people who died from cancer. Of all patients, more than half received an opioid prescription in the final 2 weeks (57.5%) and received specialist palliative care (51.8%) but also more than half had diagnostic testing in the final 2 weeks (67.4%) or acute care hospital admissions in the final month (61.1%). About a third (33.8%) had an ED admission in the final month and a similar proportion had increased contacts with their family physician in the last two weeks.

Several of the presented validated quality indicators had not been measured before. Future systematic comparison of different countries using our set of indicators would allow qualification of end-of-life care performance of health care systems (such as the Belgian one) and identification of the most pertinent quality issues. Nevertheless, a number of the quality indicators used have already been reported in studies from other countries and these provide a reference to evaluate Belgian end-of-life cancer care. While the proportion of people dying from cancer having an ED admission in the last 30 days (34%) seems high (higher than in Germany for instance<sup>16</sup>), it is lower than the percentages reported for the USA (46%), England (48%) and Canada (58%).<sup>16</sup> The percentage of people receiving palliative care (52%) is comparable to some other countries (e.g. in Canada 47.3% received palliative home care<sup>15</sup>) but lower than the proportion receiving hospice care in the USA (59.5% in 2009)<sup>41</sup>. The proportion dying at home (29.3%) varies highly among countries, with Belgium being at the same level of Spain (31.6%) and England (26.1%). This is much lower than, for

instance, in The Netherlands (46.3%), but higher than Canada (16.1%) or France (19.1%).<sup>42</sup> We found lower percentages of chemotherapy use in the last 14 days (8.6%) than the standard considered appropriate by Earle et al (10.0%)<sup>11</sup>. However, we found a higher use in the last 30 days compared to all countries reported in an international study executed in 7 countries.<sup>16</sup> Therefore, although further international comparison for all quality indicators is required, this limited comparison suggests an overuse of chemotherapy near the end of life in Belgium and that there is a margin for improvement to increase the proportion of people receiving specialist palliative care and dying at home.

*Using quality indicators for systematic comparisons and setting quality standards*

The quality indicators we measured on a population level in Belgium can be used to compare health care practice on a national level, as well as on an international level. Based on both national and international benchmarking, health care policy can focus on reducing the occurrence of inappropriate end-of-life care and optimizing the use of appropriate end-of-life care.

On an international level, differences between health care systems, such as payment models, health insurance and access to health care can be evaluated on their effect on quality of care provided by the system.

On a national level, differences between health care providers or regions can be used to set benchmarks for all the quality indicators, for example based on best practice example as established in the USA by Earle et al.<sup>11</sup>, e.g. using the best scoring quartile or decile for each quality indicator. To allow a correct comparison between health care providers or regions a risk-adjustment should be made to increase the 'attributorial validity' of the quality indicators (i.e. the conviction that observed quality indicator differences causally relate directly to quality of care rather than to other contributing factors such as a different patient mix).<sup>43</sup> Our findings regarding the patient characteristics associated with different aspects of appropriate or inappropriate end-of-life care suggest that age, household type, type of cancer, and living in a rural or urban environment are important

risk adjusters for various quality indicators. We found that younger patients are more likely to receive potentially appropriate pain and symptom treatment than older patients, but at the same time are also more likely to receive potentially inappropriate tumor treatment, hospital transitions and hospital care at the end of life. Furthermore, people living with a partner and those living in a single parent household are more likely to receive appropriate comfort and palliative care at the end of life than those who live alone. However, people who live in a collective household, such as a nursing home, are less likely to receive appropriate comfort and palliative care at the end of life. Type of cancer is a risk factor for the occurrence of specific treatments, but there does not seem to be one cancer type that is consistently related to more potentially appropriate and less potentially inappropriate care at the end of life. Gender was not a significant risk factor for appropriate or inappropriate end-of-life care.

#### *Strengths and limitations*

Our use of routinely collected administrative data entails several strengths. Compared to using sample data, our study does not suffer from selection bias, it avoids non-response bias inherent to surveys and avoids recall bias.<sup>44,45</sup> It has a clearly defined population and includes difficult-to-reach subgroups that tend to be under-represented in surveys or observational studies. Administrative data are relatively inexpensive in comparison with original data collections.<sup>23</sup> These data are routinely collected by health insurance companies and since health insurance in Belgium is obligatory, these data provide information on 99% of the entire population's health care use.

A disadvantage in using routinely collected data is that the data were not collected to answer the specific research questions and therefore needed to be adapted accordingly. Careful operationalizations of the indicators and several checks with medical experts who are familiar with the used databases and reimbursement codes were done to mitigate this problem. This eventually also led to four quality indicators being withdrawn because a sufficiently valid operationalization was not deemed to be possible with the available administrative data (these

are: Initiation of new regimen of chemotherapy, Radiotherapy in people with bone metastases, Anti-emetics with chemotherapy and Radiotherapy in people with small cell lung cancer). A second limitation is that medication use is measured indirectly through prescription and delivery. Medication might be purchased, but never used. Also, some prescriptions cover the use of medication for longer periods, e.g. several weeks. This makes quality indicators with short time intervals, e.g. opioid use in the last 7 days before death, more complicated to interpret. A third limitation is that only reimbursed treatments and medication are registered in the health insurance databases. We know that people with cancer, especially those treated at a university hospital, frequently receive experimental treatments. We currently have no evidence on how common this practice is. Furthermore, quality indicators measured on a population level provide quantitative information on care provision, but do not provide information about the quality of the care provided. A final limitation of this study is sometimes referred to as 'resurrecting of treatment histories'.<sup>46</sup> In a retrospective design, we cannot say whether treatment was performed with end-of-life intent, especially on an individual level. We mitigate this limitation by interpreting our quality indicators strictly on an aggregate level.

## **Conclusions**

Our study evaluated the performance of the Belgian health care system in terms of end-of-life cancer care and suggests a possible overuse of potentially inappropriate cancer care at the end of life and an opportunity to increase the proportion of people with cancer receiving specialist palliative care and dying at home.

The use of our quality indicators provides health care policy makers with an informative tool to compare the end-of-life care performance of different health care system, health care regions within health care systems, and health care providers within regions. This provides them with the information basis to eventually improve end-of-life care across the population.

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**Chapter 5:** Appropriateness of end-of-life care in people dying from COPD. Applying quality indicators on linked administrative databases.

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## **Abstract**

### **Introduction**

Large-scale evaluations of the quality of end-of-life care in people with COPD are lacking. By means of a validated set of quality indicators, this study aims to:

1. Assess appropriateness of end-of-life care in people dying from COPD,
2. Examine variation between care regions,
3. Establish performance standards.

### **Methods**

We conducted a retrospective observational study of all deaths from COPD (ICD10 codes J41-J44) in 2012 in Belgium, using data from administrative population-level databases. QI scores were risk-adjusted for comparison between care regions.

### **Results**

4,231 people died from COPD. During the last 30 days of life, 60% was admitted to hospital, 11.8% received specialized palliative care. Large regional variation was found in specialized palliative care use (4.0% to 32.0%) and diagnostic testing in the last 30 days of life (44.0% to 69.7%). Based on best performing quartile scores, relative standards were set (e.g.  $\leq 54.9\%$  for diagnostic testing)

### **Conclusion**

Our study found indications of inappropriate end-of-life care in people with COPD, such as high percentages of diagnostic testing and hospital admissions and low proportions receiving specialized palliative care. Risk-adjusted variation between regions was high for several QIs, indicating the usefulness of relative performance standards to improve quality of end-of-life COPD care.

## **Background**

Chronic Obstructive Pulmonary Disease (COPD) is a progressive life-limiting condition and a major cause of mortality worldwide.(1,2) The disease trajectory of people suffering from COPD typically involves slow functional decline with acute life-threatening exacerbations.(3) Patients often experience increasing dyspnea, severe physical disability, loneliness, depression and anxiety.(4,5) They usually survive several exacerbation episodes, while each episode causes sharp functional decline and may result in death. The exact timing of death, however, is difficult to predict.(6) Nevertheless, there are concerns that end-of-life care for COPD patients often involves inappropriate life-prolonging care.(7) Research has confirmed that, despite clear palliative care needs, specialized palliative care is not common practice in people suffering from COPD.(8-10) As for any chronic disease with changing care needs near the end of life, appropriate end-of-life care is of extreme importance for people dying from COPD. This means receiving care of which the expected health benefit (e.g. increased life expectancy or symptom relief) exceeds possible negative outcomes (e.g. mortality, reduced quality of life).(11,12) So far, research on appropriateness of end-of-life care in people with COPD is lacking.

A previous study developed a set of quality indicators for end-of-life care in people suffering from COPD(13), based on literature, interviews with medical experts and a consensus process. The validated set of indicators is meant to evaluate appropriateness of end-of-life care in populations dying from COPD(13), measuring the prevalence of specific diagnostics, medication prescription, treatments or care received during a specific time period prior to death that indicate potential appropriate or inappropriate end-of-life care. The quality indicators were developed to be measured on a population level, using administrative data.

Population-level indicators for appropriateness of end-of-life care in COPD provide a tool for policy makers to evaluate the performance of a health care system(14). Currently, no standards exist for COPD quality indicators. However, by comparing indicator scores across health care regions within a country, taking into account population

differences between regions for a fair comparison (e.g. differences in clinical or socio-demographic characteristics of the populations), relative standards can be established.(15) For example, the best performing quartile of health care regions could be set as a performance standard within the health care system.(16)

Our study has three aims:

1. To assess end-of-life care in people dying from COPD in Belgium using validated quality indicators.
2. To compare the quality indicator scores of end-of-life COPD care between all health care regions in Flanders, Belgium.
3. To establish relative performance standards for quality indicator scores based on the variation across health care regions.

## **Methods**

### *Study design and data sources*

We conducted a retrospective observational study of all people who died from COPD in 2012 in Belgium. We combined data from eight administratively collected population-level databases into one database for analysis(17):

- (1) Socio-demographic database of all individuals with health care insurance (legally mandatory in Belgium);
- (2) Health care database containing all reimbursed health care data of home, nursing home, outpatient and hospital care, except medication dispensed in pharmacies;
- (3) Pharmaceutical database containing all reimbursed medication dispensed in pharmacies;
- (4) Belgian Cancer Registry database with diagnosis and type of cancer data for all incident cancers;
- (5) Death certificate database containing cause of death;



(6) Population registry database including citizens' household composition;

(7) Census database, including educational level and housing characteristics;

(8) Fiscal database, including net taxable income;

After acquiring approvals from the relevant data protection agencies, all databases were linked in an ethically responsible and secure manner, preserving anonymity of the deceased. The linking procedure is described in detail in a previous publication.(17)

### *Population*

All people who died from COPD in 2012 were identified by the underlying cause of death reported on the death certificate (ICD-10 codes J41-J44).

### *Data*

We used health care data, including medication use, other treatments, dates of treatment and prescription and admission to hospitals and nursing homes. Multiple socio-economic, demographic and clinical variables were selected, including age, gender, lung cancer diagnosis, dependence on care, receipt of government support for health care, level of education, household composition, degree of urbanization of residence and net taxable income.

### *Quality indicators*

We used a set of 28 quality indicators for end of life COPD care that are measurable using administrative databases.(13) This set was developed and validated using the RAND/UCLA appropriateness method.(18) All indicators were extracted from literature and expert interviews and validated by a multidisciplinary expert panel of twelve doctors and nurses specializing in pneumology, family medicine or palliative care. The quality indicators demonstrate either appropriate or inappropriate end-of-life care. They measure the prevalence of specific health care interventions or delivery of medication types in

a specified period prior to death. We measured all indicators 7, 14, 30, 90, 180, 360 and 720 days prior to death, except when the periods for a specific indicator were not validated by the expert panel. The time intervals for each quality indicator are described in table 1.

Table 1: quality indicators with detailed description

Indicator (brief description)	Indicator of appropriate (A) or inappropriate (I) care	Numerator (Number of people who died with COPD who*)	Denominator (*Number of people who died with COPD)
<b>Domain: aggressiveness of care</b>			
Lung volume reduction surgery <sup>†§</sup>	I	*received Lung Volume Reduction Surgery in the last 3 months prior to death	*
Endotracheal intubation or tracheotomy <sup>†§</sup>	I	*received endotracheal intubation or tracheotomy in the last [12, 6, 3, 1] months prior to death	*
Continuous endotracheal intubation <sup>†§</sup>	I	*received continuous endotracheal intubation for 5 days or more in the last [12, 6, 3, 1] months prior to death	*
Tube feeding or intravenous feeding <sup>†§**</sup>	I	*received tube feeding or intravenous feeding in the last month prior to death	*
Diagnostic testing <sup>†§</sup>	I	*had diagnostic testing (spirometry OR medical imaging OR electrocardiogram) in the last month prior to death	*
Late physiotherapy <sup>†¶</sup>	I	*started physiotherapy treatment in the last 2 weeks prior to death	*
Port-a-cath installation <sup>†§</sup>	I	*had a port-a-cath installed in the last 2 weeks prior to death	*
Repeated intubation <sup>†§</sup>	I	*received intubation 2 or more times in the last [12, 6, 3, 1] months prior to death	*
Coronary or abdominal surgery <sup>†§</sup>	I	*received coronary or abdominal surgery in the last 3 months prior to death	*
Reanimation after intubation <sup>†§</sup>	I	*were reanimated after intubation in the last week prior to death	*
Starting Antidepressants <sup>†\\</sup>	I	*received antidepressants in the last month prior to death and did not receive antidepressants before	*
Surgery <sup>†§</sup>	I	*received surgery in the last [6, 3, 1] months prior to death	*
Blood transfusion <sup>†\\</sup>	I	*received blood transfusion in the last month prior to death	*

Domain: Pain and symptom treatment			
Opioids <sup>†§</sup>	A	*received opioids in the last [6,3, 1] months prior to death	*
Inhalation therapy <sup>†§</sup>	A	*received inhalation corticosteroids OR anticholinergics OR Beta-2-memetics in the last [6, 3, 1] months prior to death	*
Psychologist visit <sup>†§**</sup>	A	*had at least one psychologist visit in the last 2 months prior to death	*
Domain: Palliative care			
Specialized palliative care <sup>†§</sup>	A	*received specialized palliative care (hospital palliative unit OR multidisciplinary palliative home care) in the last 2 years prior to death	*
Official palliative care status <sup>†§</sup>	A	* received official palliative care status, enabling financial government support for palliative care at any point prior to death	*
Late initiation of palliative care <sup>†¶</sup>	I	* had a first referral to specialized palliative care OR received official palliative status during the last week before death	*
Domain: Place of treatment and place of death			
Home death <sup>†§</sup>	A	*died at home	*
Hospital admissions <sup>†¶</sup>	I	* had one or more hospital admission/s in the last [6, 3, 1] months prior to death	*
ED admissions <sup>†\\</sup>	I	* had one or more emergency hospital visits in the last [6, 3, 1] months prior to death	*
Death in nursing home of residence <sup>†§</sup>	A	*lived and died in a nursing home	*and lived in a nursing home
Hospital death <sup>†¶</sup>	I	*died in hospital	*
Domain: Coordination and continuity of care			
Family physician contact <sup>†§</sup>	A	*had an increase in average number of contacts with a family physician in the last month prior to death compared to the previous 23 months	*
Primary caregiver contact <sup>†§</sup>	A	Sum of number of contacts with a family physician or other primary care professional in the last 3 months prior to death	*
ICU admissions <sup>†§</sup>	I	* had one or more admissions to the intensive care unit in the last month prior to death	*
ICU admissions from nursing home <sup>†§</sup>	I	*lived in a nursing home and had 1 or more ICU visits in the last month prior to death	*and lived in a nursing home

<sup>†</sup>Indicator from literature, <sup>‡</sup>Indicator from expert interviews, <sup>§</sup>Accepted in phase 3a scoring round, <sup>¶</sup>Accepted in phase 3b plenary discussion, <sup>\\</sup>Adapted and accepted in phase 3b plenary discussion, <sup>\*\*</sup>This indicator was not included in the current study, since it could not be measured with the existing data.

### *Risk factors for comparison across health care regions*

We performed risk adjustment procedures for the comparison of QIs across health care regions. The northern part of Belgium has 14 major health care regions, based on natural patient flow.(19) These regions cover the administrative regions of Flanders and Brussels; no equivalent exists in the Walloon region. We therefore limited this analysis to Flanders and Brussels. From a comprehensive list of possible risk factors(20), we identified the following factors as relevant and measurable with the current dataset: age, gender, lung cancer diagnosis, comorbidity status (using all ICD-10 codes on death certificates, including associated and intermediate causes of death), eligible for additional government health care support (based on care dependency), educational level, household composition, degree of urbanization of residence and net taxable income. We used the period of 30 days prior to death for all indicators where timing is relevant, or less if the indicator was validated only for a shorter period prior to death.

### *Statistical analyses*

The characteristics of people who died from COPD and the quality indicators were calculated using descriptive statistics.

The risk-adjusted comparison consisted of several steps: First we listed potential risk factors that could influence quality indicator outcomes, based on literature(21). We evaluated the effects of these potential risk factors on individuals' outcomes for each of the quality indicators separately, using logistic regression. We used stepwise model building, with a significance level of 0.3 for entry and 0.05 to stay. Based on the logistic regression, predicted scores were calculated for each individual.

For each health care region, the average risk-adjusted score was calculated by dividing the average predicted score by the average observed score, multiplied by the average observed score across all regions.

All analyses were conducted with SAS Enterprise Guide, version 7.1.

## Ethics

The study was approved by the Medical Ethics Committee of the University Hospital Brussels (UZ Brussels) (B.U.N. 143201627075).

## Results

### Study Population Characteristics

4,231 people died from COPD in Belgium in 2012 (4 percent of all deaths), of whom 61 percent were men. The mean age at death was 79 (data not shown). 43 percent lived with a partner, either with or without children. 33 percent lived in an area with the highest degree of urbanization. (Table 2)

Table 2: Characteristics of all deaths from COPD, Belgium, 2012.

		People who died from COPD	
		Number*	Percent
<b>All deaths</b>		4,231	100.0
<b>Gender</b>	Male	2,597	61.4
	Female	1,634	38.6
<b>Age</b>	0-17	0	0.0
	18-64	429	10.1
	65-74	833	19.7
	75-84	1,596	37.7
	85 and older	1,373	32.5
<b>Nationality</b>	Belgian	3,971	93.9
	Other	260	6.2
<b>Household type†</b>	Single person	1,380	32.7
	Couple with no children living at home	1,529	36.2
	Couple with children living at home	279	6.6
	Single parent family	211	5.0
	Collective household	732	17.3
	Other	95	2.3
<b>Housing comfort‡</b>	High	1,392	34.8

	Average	809	20.2
	Low	1,575	39.3
<b>Level of education</b>	Higher education	267	14.6
	Upper secondary education	501	11.8
	Lower secondary education	896	21.2
	Primary education	1,548	36.6
	No education	400	9.5
	Unknown	469	11.1
<b>Level of urbanization of residence<sup>§</sup></b>	Very high	1,374	32.5
	High	1,145	27.1
	Average	1,061	25.1
	Low	628	14.8
<b>Net Taxable Income</b>	<= 10,000	521	12.3
	]10,000 - 15,000]	2,001	47.3
	]15,000 - 20,000]	1,131	26.7
	> 20,000	578	13.7

\*May not always add up to 4,231 because of missing values, which were always lower than 1.0%, except for housing comfort (11,1%).

<sup>†</sup>Married and unmarried couples living together were taken together in one group

<sup>‡</sup>Defined by the number of rooms and facilities (e.g. bathroom) available in the persons home

<sup>§</sup>Degree of urbanization as categorized by Eurostat (<http://ec.europa.eu/eurostat>) and OECD (<http://www.oecd.org/>)

### Quality Indicators of Appropriate End-Of-Life Care

Of all people who died from COPD in Belgium in 2012, 32.8 percent received opioid medication and 81.8 percent received inhalation therapy in the last 30 days prior to death; 11.8 percent received specialized palliative care (inpatient palliative care unit or multidisciplinary palliative home care); 24.4 percent died at home; 43.3 percent had an increase in family physician contact during the last two weeks, with an average of 0.56 reimbursed contacts per week. (Table 3)

Table 3: Quality indicators indicating appropriate end-of-life care, within the total population dying from COPD (N=4,231), Belgium, 2012

Indicator	No	Time period (number of days before death until death)							
		time specification	7d	14d	30d	90d	180d	360d	720d
Opioids*	-		18.9	24.8	32.8	41.6	47.0	-	-
Inhalation therapy	-		49.3	66.4	81.8	90.9	93.3	-	-
Specialized palliative care <sup>†</sup>	11.8		-	-	-	-	-	-	-
Official palliative care status	8.6		-	-	-	-	-	-	-
Home death	24.4		-	-	-	-	-	-	-
Death at home or in nursing home of residence	42.2		-	-	-	-	-	-	-
Family physician contact increase	-		29.2	43.3	45.8	-	-	-	-
(average number of family physician contacts per week) <sup>§</sup>	-		0.72	0.56	0.71	-	-	-	-
Average number of primary caregiver contact per week <sup>§</sup>	-		1.11	1.16	1.29	1.52	-	-	-

\*For quality indicators involving medication, the time of delivery was employed, since no information on actual use is provided in our administrative data sources.

<sup>†</sup>This includes care by a hospital palliative care unit and multidisciplinary palliative home care.

<sup>§</sup>This indicator is not presented by percentages. It depicts the average number of contacts per week across the population during the indicated time period.

*Quality Indicators of Inappropriate End-Of-Life Care*

In the last 30 days, 17.8 percent received endotracheal intubation or tracheotomy, while 6.6 percent received continuous endotracheal intubation for 5 or more consecutive days and 15.9 percent received more than one period of intubation during the last thirty days. In the last 14 days prior to death, 56.5 percent was submitted to diagnostic testing (medical imaging, ECG or pulmonary function testing). For 4.6 percent of people who died from COPD, physiotherapy treatment was initiated only in the last two weeks. 6.4 percent received surgery during the last 30 days.

Of those who received specialized palliative care, 31.2 percent only received it in the last week, which corresponds to 3.7 percent of the total population who died from COPD. Of all patients who died from COPD, 40.5 percent was admitted to an emergency department, 60.2 to hospital and 46.2 to ICU during the last 30 days. 54.6 percent of patients died in the hospital. (Table 4)

*Table 4: Quality indicators indicating inappropriate end-of-life care, within the total population dying from COPD (N=4,231), Belgium, 2012.*

Indicator	Time period (number of days before death until death)								
	No	time	7d	14d	30d	90d	180d	360d	720d
	specification								
Lung volume reduction surgery	-		0.0	0.0	0.0	0.1	-	-	-
Endotracheal intubation or tracheotomy	-		13.7	15.6	17.8	20.0	21.6	23.5	-
Continuous endotracheal intubation	-		1.2	3.8	6.6	8.7	9.4	10.5	-
Repeated endotracheal intubation	-		8.2	11.9	15.9	19.6	21.2	-	-
Diagnostic testing (medical imaging, ECG or pulmonary function testing)	-		47.3	56.5	65.9	-	-	-	-



Diagnostic testing - medical imaging	-	-	44.7	54.1	64.1	-	-	-	-
Diagnostic testing - ECG or pulmonary function testing	-	-	21.9	31.8	45.0	-	-	-	-
Late physiotherapy	-		2.5	4.6	-	-	-	-	-
Port-a-cath installation	-		0.0	0.0	-	-	-	-	-
Coronary or abdominal surgery	-		0.6	1.0	1.5	2.8	-	-	-
Reanimation after intubation	-		1.8	-	-	-	-	-	-
Start treatment - antidepressants*	-		2.0	3.4	5.4	-	-	-	-
Surgery	-		2.5	4.1	6.4	11.6	16.3	-	-
Blood transfusion	-		0.9	1.5	2.0	-	-	-	-
Late initiation of palliative care	-		3.7 <sup>†</sup>	4.8 <sup>§</sup>	-	-	-	-	-
ED admissions	-		16.1	25.8	40.5	59.3	67.2	-	-
Hospital admissions	-		36.5	48.3	60.2	71.3	77.3	-	-
ICU admissions	-		27.5	35.2	46.2	62.2	69.8	78.4	87.1
ICU admissions from nursing home	-		19.3	21.3	30.2	46.2	54.6	-	-
Hospital death	54.6		-	-	-	-	-	-	-

\*For quality indicators involving medication, the time of delivery was employed, since no information on actual use is provided in our administrative data sources.

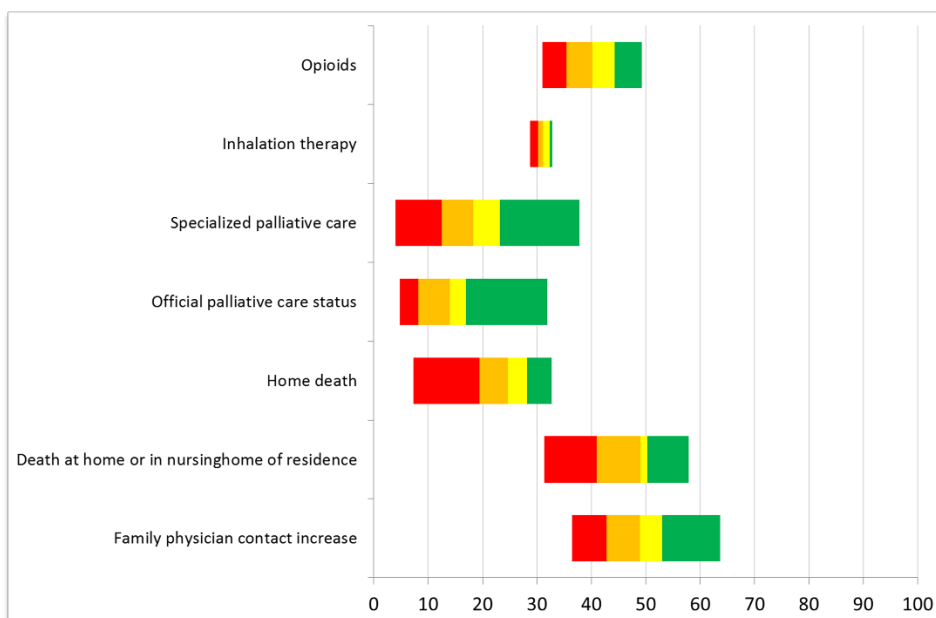
<sup>†</sup>This is 31.2 percent of those who received palliative care.

<sup>§</sup>This is 40.4 percent of those who received palliative care.

### Comparison between health care regions

Risk-adjusted variation between health care regions was found for the indicators of appropriate end-of-life care (Figure 1). Specialized palliative care use varied from 4 to 38 percent with the best scoring quartile achieving 23 percent or more; death at home varied from 7 to 33 percent (best scoring quartile achieving 28 percent or more); increase in contact with the family physician varied between 36 and 64 percent (best scoring quartile scoring 53 percent or more).

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 COPD (N=4,231), Belgium, 2012

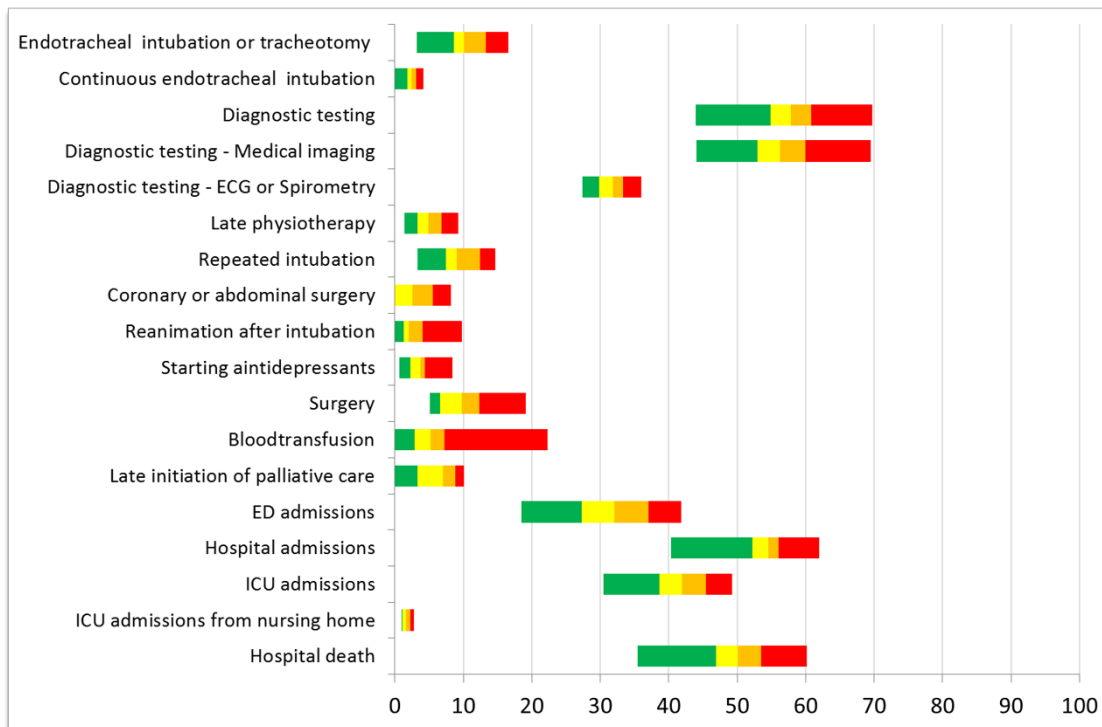


\*We used the period of 30 days before death for all indicators, or closer to death if the indicator was validated only for a shorter period before death. The indicator measuring the average number of primary caregiver contacts per week was not presented in this comparison, since its variation was too low.

Risk-adjusted variation between health care regions was also found in the indicators of inappropriate end-of-life-care (Figure 2). Diagnostic testing (medical imaging, ECG or pulmonary function testing) varied from 44 to 70 percent, with the best scoring quartile scoring below 55 percent. ED admission varied from 18 to 42 percent (best scoring quartile scoring below 27 percent); hospital death varies between 35 and 60 percent (best scoring quartile scoring below 47 percent). Two quality indicators measuring lung volume reduction

surgery and port-a-cath installation are not presented in this comparison, since their variation was too low.

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.

- Worst scoring quartile
- Q1-median
- Median-Q3
- Best scoring quartile and suggested relative standard to be achieved

Based on these results, a relative performance standard for each indicator can be suggested, set at the best scoring quartile, as a goal to be pursued by the different regions in Brussels and Flanders. (Table 5)

Table 5: Suggestions of relative benchmarks for indicators, set at the best scoring quartile of regional comparison in Flanders, as a goal to be pursued on a national level in Belgium.

Quality indicator	Suggested benchmark
Endotracheal intubation or tracheotomy during the last 30 days before death	8.6 
Continuous endotracheal intubation for 5 or more days during the last 30 days before death	1.8
Diagnostic testing (medical imaging, ECG or pulmonary function testing) during the last 30 days before death	54.9
Diagnostic testing - medical imaging during the last 30 days before death	52.9
Diagnostic testing - ECG or pulmonary function testing during the last 30 days before death	29.8
Late physiotherapy during the last 14 days before death	3.3
Repeated intubation during the last 30 days before death	7.5
Coronary or abdominal surgery during the last 30 days before death	0.0
Reanimation after intubation during the last 30 days before death	1.3
Start antidepressant during the last 30 days before death	2.2
Surgery during the last 30 days before death	6.7
Blood transfusion during the last 30 days before death	2.9
Late initiation of palliative care during the last 14 days before death	3.3
ED admissions during the last 30 days before death	27.3
Hospital admissions during the last 30 days before death	52.2
ICU admissions during the last 30 days before death	38.6
ICU admissions from nursing home during the last 30 days before death	1.1
Hospital death	46.9
<b>Opioids during the last 30 days before death</b>	<b>44.3</b> 
Inhalation therapy during the last 30 days before death	32.3

Specialized palliative care	23.2
Official palliative care status	16.9
Home death*	28.2
Death at home or in nursing home of residence*	50.3
Family physician contact increase during the last 30 days before death	53.0

## Discussion

### *Summary of main findings*

Using a set of validated quality indicators of end-of-life care, we were able to provide a snapshot of the performance of the Belgian health care system in terms of end-of-life care in people who died from COPD. Specialized palliative care was scarcely used and often only in the last 2 weeks before death, while diagnostic testing, hospital admissions, ICU admissions and emergency department admissions were relatively frequent in the last 30 days of life. Large regional variation was also found for these quality indicators. Due to our risk adjustment procedure, this variance likely points at differences in terms of quality of end-of-life care.

### *Strengths and weaknesses*

Working with population level data from health insurance administrators allowed us to include the entire population of interest. Possible biases due to population selection and burden on participants were thus avoided. In limiting our study population to those who reportedly died from COPD, we selected a population that presumably had a disease trajectory typical of COPD. Several comorbidities or other underlying diseases are highly prevalent among people suffering from COPD (e.g. lung cancer and/or cardiovascular disease) and these are frequently reported as underlying cause of death. (22)

A major limitation of using administrative data is that health care interventions that are not reimbursed are not measured. Quality of care aspects related to communication, for instance, cannot be measured and the quality indicators were therefore also limited to those measurable with administrative data.(13) Nevertheless, because reimbursement of each health care intervention is dependent on registration, the data can be assumed to reliably reflect actual practice. The linking of eight different databases allowed the performance of an extensive risk adjustment for the comparison between regions, which contributes to a larger attributional validity of the quality indicator scores.(23)

#### *Interpretation and implications*

Our study found indications that a relatively large proportion of people with COPD receives potentially inappropriate end-of-life care. A comparison with people dying from cancer(24), using similar quality indicators, shows several disadvantages for people dying from COPD: they receive opioids considerably less often at the end of life, receive specialized palliative care about four times less and undergo more diagnostic testing near the end of life. Although care preferences are similar in both disease groups(7), discussions on prognosis and advance care planning rarely occurred in people dying from COPD.(25-28) The relatively low use of specialized palliative care in people dying from COPD corroborates previous studies.(9,29-31)

Possible causes of large proportions of COPD patients receiving inappropriate end-of-life care and few patients using specialized palliative care relate to the difficulty to predict the COPD disease trajectory, as well as the high prevalence of comorbidities that may cause unexpected deterioration or death.(22,32) In addition, treating physicians report a hesitation to communicate the prognosis with COPD patients because of several reasons, such as a lack of communication training and a fear of instilling unnecessary anxiety or depression in the patient.(32,33) Because of this lack of communication on prognosis, COPD patients often have little insight in the severity of their condition,(10) inhibiting the discussion of end-of-life care options.(26,32)

One of the surprising findings of our study is the substantial variation between health care regions in the indicators for appropriate and inappropriate end-of-life care. Our extensive risk adjustment procedures rule out that these differences are due to age, gender, lung cancer diagnosis, dependence on care, receipt of government health care support, highest level of education, household composition, degree of urbanization of the municipality of residence and net taxable income. This implies that differences between health care regions likely cannot be explained by differences between the populations in those regions and reflect quality of care differences. From a health care policy and equity perspective, such differences are not acceptable.

#### *Towards quality of care improvement*

The suggested standards based on the comparison between regions are a possible starting point for quality improvement. Particularly the indicators for which there is large variance between regions, and hence a larger room for improvement, require attention. For example, specialized palliative care use can be increased to a (risk-adjusted) percentage of 23.2 percent, diagnostic testing (medical imaging, ECG or pulmonary function testing) in the last 30 days can be limited to a population percentage of 54.9 percent and hospital admissions to 52.2 percent. These standards should be attainable, as currently 25% of regions attain them.

Organizational, national and international health care policy makers can use the suggested benchmarks to further analyze practice, search for reasons for the differences between regions, and develop and test interventions that can improve practice within a region.(34,35) Interventions to improve the timely identification of palliative care needs in COPD may, for instance, have a positive influence on several indicators of appropriate care. They could lead to timely initiation of care planning and inclusion in palliative care and a reduction of avoidable inappropriate end-of-life care.(32) Duenk and colleagues (36) present a list of indicators to identify patients with COPD that could benefit from palliative care. Previous research also found effective communication, decision making and goal setting as main methods for improving end-of-life care in COPD.(37)

The usefulness of quality indicators increases as measurements are repeated; we therefore recommend both repetition of the measurement as well as comparative measurement in an international context. The quality indicators in this study are transferable to other contexts. (13)

## **Conclusion**

We found several indications of potentially inappropriate end-of-life care in people dying from COPD in Belgium, especially for diagnostic testing, hospital admissions and use of specialized palliative care. Risk-adjusted variation between regions was substantial for several QIs, suggesting obvious room for improvement in the care for people dying from COPD. The performance standards set by our study are useful in that respect: set at the best performing 25% of regions, they can be considered ambitious and achievable goals.



## **Acknowledgements**

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## **Author contributions**

Robrecht De Schreye is the primary writer of this manuscript, with full access to the data and responsibility for the integrity of the data and the accuracy of the data analysis. Tinne Smets and Joachim Cohen are major contributing authors, writing parts of the manuscripts, providing feedback and supervising the data analysis on a daily basis. Luc Deliens, Lieven Annemans and Birgit Gielen are contributing authors, providing regular feedback and providing specific expertise.

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**Chapter 6:** Appropriateness of end-of-life care in people dying with dementia. Applying quality indicators on linked administrative databases.

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## **Abstract**

### **Objectives**

Dementia is a progressive incurable life-limiting illness. Previous research suggests end-of-life care for people with dementia should have a symptomatic focus with an effort to avoid burdensome interventions that would not improve quality of life.

This study aims to assess the appropriateness of end-of-life care in people who died with dementia in Belgium and to establish relative performance standards, by measuring validated population-level quality indicators (QIs).

### **Design**

We conducted a retrospective observational study.

### **Setting and participants**

We included all persons deceased with dementia in 2015 in Belgium. Data from eight administratively collected population-level databases was linked.

### **Measures**

We used a validated set of 28 quality indicators for end-of-life dementia care. We compared quality indicator scores across 14 health care regions to establish relative benchmarks.

### **Results**

In Belgium in 2015, 10,629 people died with dementia. For indicators of appropriate end-of-life care, people who died with dementia had on average 1.83 contacts with their family physician in the last week before death, while 68.4 percent died at home or in their nursing home of residence.

For indicators of inappropriate end-of-life care, 32.4 percent were admitted to hospital and 36.3 percent underwent diagnostic testing in the last 30 days before death, while 25.1 percent died in the hospital. In the last 30 days, ED admission varied between 19 and 31 percent, dispensing of gastric protectors between 18 and 42 percent, and anti-

hypertensives between 40 and 53 percent between health care regions, with at least 25% of health regions below 46 percent.

### **Conclusions and implications**

Our study found indications of appropriate as well as inappropriate end-of-life care in people with dementia, including high rates of family physician contact, as well as high percentages of diagnostic testing and ED and hospital admissions. We also found high risk-adjusted variation for multiple QIs, indicating opportunity for quality improvement in end-of-life dementia care.

## Background

Dementia is a progressive incurable life-limiting illness and its prevalence is increasing worldwide. Dementia contributes strongly to functional disability, care dependence and institutionalization in the older population.<sup>1,2</sup> People with dementia experience progressive cognitive and physical impairment and often suffer from burdensome symptoms and clinical complications at the end of life.<sup>3-5</sup> In contrast with people suffering from cancer or organ failure, their disease trajectory is characterized by a gradual functional decline.<sup>6-8</sup>

Because of this irreversible gradual decline, experts advocate the main care goals for people with advanced dementia include providing a comfortable, painless, dignified end of life, while avoiding unnecessary treatment, medication and care transitions.<sup>6,9,10</sup> However, experts are concerned that these goals are often not met and inappropriate end-of-life care for people with dementia is occurring.<sup>6,11,12</sup> Appropriate end-of-life care, regardless of the disease, can be defined as receiving care of which the expected health benefit (e.g. increased life expectancy or symptom relief) exceeds possible negative outcomes (e.g. mortality, loss of quality of life)<sup>13,14</sup>.

Using a RAND/UCLA Appropriateness method, we developed a set of quality indicators that measure aspects of care that may indicate appropriate or inappropriate care at the end of life in people who died with dementia.<sup>10</sup> The set includes indicators on aggressiveness of care, pain and symptom management, specialized palliative care delivery, place of care and death and continuity of care. The indicators were developed specifically to be used at a population level, using administrative health data. The use of the indicators, in a benchmarking of different health care regions, also allows to set relative performance standards as attainable targets for quality improvement.<sup>15</sup> Previous population-level health care research found substantial variation in health care provision across health care regions in Belgium.<sup>16,17</sup> If variation in appropriateness of care is found between regions, although government policy and funding across all regions are equal (e.g. reimbursement of care), this means variation in practice indicates opportunities for improvement in regions where appropriate care is more prevalent. This



is a first step towards improvement of the quality of end-of-life care and it is novel in dementia research.

The aims of our study are threefold:

1. To assess the quality of end-of-life care in all people who died with dementia in Belgium using previously validated quality indicators of potentially appropriate or inappropriate end-of-life care.
2. To compare the quality indicator scores of end-of-life care in people who died with dementia between all health care regions within the country.
3. To establish relative performance standards based on this comparison.

## **Method**

### *Study design and data sources*

We conducted a retrospective observational study of all deceased with dementia in 2015 in Belgium. Data from eight administratively collected population-level databases was linked into one database for analysis<sup>18</sup> (Chapter 3 provides a detailed description of the databases):

- (1) Socio-demographic database of all individuals with healthcare insurance (legally mandatory in Belgium);
- (2) Health care database containing all reimbursed health care use data of home, nursing home and hospital care, except medication dispensed in public pharmacies;
- (3) Pharmaceutical database containing all reimbursed medication data dispensed in public pharmacies;
- (4) Cancer Registry database with diagnostic information on all incidences of cancer including type of cancer and date of diagnosis;
- (5) Death certificate database containing all reported causes of death;

- (6) Population registry database including household composition;
- (7) Census database, including housing characteristics and educational level;
- (8) Fiscal database, including net taxable income;

After acquiring approval from all relevant data protection agencies, all databases were linked in a secure and ethically responsible manner, guaranteeing anonymity of the deceased. The database linking procedure is described in detail in a previous publication.<sup>18</sup>

### *Population*

All people who died with dementia in 2015 were identified based on the underlying, intermediate and associated causes of death reported on the death certificate, coded in ICD-10 codes (F00 or G30).

### *Data*

In the Belgian health care system, health care costs are reimbursed directly to the patient by health insurers and every reimbursement is registered. A central agency collects the data from all health insurance registries in a central health care database and pharmacy database, which were part of the linking procedure mentioned in the methods section. This provides detailed information on every care action that was reimbursed. We used all available data on health care use including medication use, treatment, dates of treatment and prescription and admission to hospitals and nursing homes. Multiple socio-economic, demographic and clinical variables were selected, including age, gender, dependence on care, highest attained level of education, household composition, degree of urbanization of the municipality of residence and net taxable income.

### *Quality indicators*

We used a validated set of 28 quality indicators for end-of-life dementia care. It was developed and validated using a RAND/UCLA Appropriateness method.<sup>10,19</sup> The expert panel consisted of neurologists, pharmacologists, nursing home coordinating and advisory physicians,

geriatricists and palliative care specialists. The quality indicators measure the prevalence of specific healthcare interventions in a specified period before death. We measured all indicators 7, 14, 30, 90, 180, 360 and 720 days prior to death, except the periods for which the specific indicators were not validated by the expert panel (as indicated in table 1). One indicator on tube feeding or intravenous feeding could not be measured, as they are reimbursed as a package in the hospital context, not as individual interventions.

Table 1: Quality indicators with detailed description

Indicator (brief description)	Indicator of appropriate (A) or inappropriate (I) care	Numerator (Number of people who died with dementia who*)	Denominator (*Number of people who died with dementia)
<b>Domain: aggressiveness of care</b>			
Tube feeding or intravenous feeding <sup>§</sup>	I	*received tube feeding or intravenous feeding in the last month prior to death	*
Diagnostic testing <sup>§</sup>	I	*had diagnostic testing (spirometry OR radiography OR blood drawn OR electrocardiogram) in the last month prior to death	*
Statins <sup>§</sup>	I	*received statins and did not have declining statin use in the last [12,6,1] months prior to death	* and received statins
Port-a-cath installment <sup>§</sup>	I	*had a port-a-cath installed in the last 2 weeks prior to death	*
Neurologist visit <sup>¶\</sup>	I	*received treatment from a neurologist in the last month prior to death	*
Gastric protectors <sup>¶\</sup>	I	*received two or more prescriptions of gastric protectors in the last 6 months prior to death (ie prescription until death)	*
Anti-hypertensives <sup>§</sup>	I	*received antihypertensives in the last [6,3,1] months prior to death	*
Calcium vitamin D <sup>§</sup>	I	*received calcium or vitamin D in the last [6,3,1] months prior to death	*
NOACs or vitamin K antagonists <sup>¶\</sup>	I	*received a prescriptions for novel oral anticoagulants OR vitamin K antagonists in the last 3 months prior to death (i.e. prescription until death)	*

Prophylactic medication <sup>†\</sup>	gout I	*received a prescriptions for prophylactic gout medication in the last 3 months prior to death	*
Cardiopulmonary resuscitation <sup>†§</sup>	I	*were reanimated in the last 2 weeks prior to death	*
Chemotherapy <sup>†\</sup>	I	* had a cancer diagnosis and received chemotherapy in the [12, 6] months prior to death	* and had a cancer diagnosis
Serotonin reuptake inhibitors <sup>†\</sup>	I	*received serotonin reuptake inhibitors in the last 3 months prior to death	*
Surgery <sup>†§</sup>	I	*received surgery in the last [6,3, 1] months prior to death	*
Blood transfusion <sup>†§</sup>	I	*received blood transfusion in the last month prior to death	*
Domain: Pain and symptom treatment			
Morphine neuropathic medication <sup>†§</sup>	and A	*received neuropathic medication when receiving morphine in the last 2 years prior to death	*
Domain: Palliative care			
Specialized palliative care <sup>†§</sup>	A	*received specialized palliative care (hospital palliative unit OR palliative daycare centre OR multidisciplinary home care) in the last 2 years prior to death	*
Official palliative care status <sup>†§</sup>	A	* received official palliative care status, enabling financial government support for palliative care at any point prior to death	*
Late initiation of palliative care <sup>†§</sup>	I	* had a first referral to specialized palliative care OR received official palliative status during the last week before death	*
Domain: Place of treatment and place of death			
Home death <sup>†§</sup>	A	*died at home	*
Hospital admissions <sup>†§</sup>	I	* had one or more hospital admission/s in the last [6, 3, 1 ]months prior to death	*
ED admissions <sup>†\</sup>	I	* had one or more emergency hospital visits in the last [6, 3, 1 ]months prior to death	*
Home death or death in nursing home of residence <sup>†§</sup>	A	*lived and died in a nursing home	*and lived in a nursing home
Hospital death <sup>†§</sup>	I	*died in hospital	*
ICU admission <sup>†§</sup>	I	*had one or more admissions to the intensive care unit in the last month prior to death	*

Domain: Coordination and continuity of care

Family physician A contact <sup>†§</sup>	*had an increase in average number of contacts with a family physician in the last month prior to death compared to the previous 23 months	*
Primary caregiver A contact <sup>†§</sup>	Sum of number of contacts with a family physician or other primary care professional in the last 3 months prior to death	*
ICU admissions from nursing home <sup>†§</sup>	*lived in a nursing home and had 1 or more ICU visits in the last month prior to death	*and lived in a nursing home

<sup>†</sup>Indicator from literature, <sup>‡</sup>Indicator from expert interviews, <sup>§</sup>Accepted in phase 3a scoring round, <sup>¶</sup>Accepted in phase 3b plenary discussion, <sup>||</sup>Adapted and accepted in phase 3b plenary discussion.

*Risk factors for comparison across health care regions and relative benchmarks*

For the comparison of QIs across health care regions, we performed risk adjustment procedures. The northern part of Belgium has 14 major health care regions, based on natural patient flow towards major hospitals in each region.<sup>20</sup> These regions cover the administrative regions of Flanders and Brussels; no equivalent exists in the Walloon region. We therefore limited this analysis to Flanders and Brussels. To obtain a fair comparison across health care regions, we performed risk adjustment procedures. We started from a comprehensive list of possible risk factors<sup>21</sup> and made a selection based on availability of data in the current dataset. The following risk factors were identified as relevant and measurable with the current dataset: age, gender, living situation (e.g. alone, with children, in a nursing home), being entitled to a higher degree of reimbursement due to lower degree of self-reliance, being officially recognized by the physician as having heavy care needs, frequent (more than 5 in the same year) or extended (at least 120 days in one year) hospital stays, highest level of education, household composition, degree of urbanization of the municipality of residence and net taxable income.

### *Statistical analyses*

The characteristics of the decedents with dementia and the quality indicators were calculated using descriptive statistics.

Risk adjusted comparison and the establishment of relative benchmarks consisted of four steps:

1) We evaluated the effects of the potential risk factors on individuals' outcomes for each of the quality indicators (coded binary as present [1] or absent [0]) using logistic regression. 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.

2) We used stepwise model building, with a significance level of 0.3 for entry and significance level of 0.05 to stay in the model. Based on the logistic regression, predicted scores (between 0 and 1) were calculated for each individual. For example: age and being entitled to a higher degree of reimbursement due to lower degree of self-reliance were associated with higher ICU admission, while living in a nursing home was associated with lower ICU admission. No other socio-demographic variables were withheld by the stepwise model-building process for ICU admission.

3) For each health care region, an average risk adjusted score was calculated by dividing the average predicted score by the average observed score for that health care region, multiplied by the average observed score across all regions. In the example of ICU admission, this score was calculated using the age, lower degree of self-reliance and living in a nursing home for all people who died of dementia living in this each region.

4) To establish relative benchmarks, quartiles across health care regions were calculated for each quality indicator. For indicators of appropriate care, the relative benchmark was established at the third quartile (or above), while for indicators of inappropriate care, the relative benchmark was established at the first quartile (or below).

All analyses were conducted with SAS Enterprise Guide, version 7.1.

## Ethics

The study was approved by a university hospital committee for medical ethics (B.U.N. 143201627075). The administrative data linking process was approved by the national Belgian Data Protection Authority (project SA1/STAT/MA-2015-026-020-MAV) and by the Statistical Monitoring Committee (project STAT-MA-2015-026).

## Results

### Study Population Characteristics

The study population consisted of 10,629 people who died with dementia in Belgium in 2015 (10.6 percent of all deceased), of whom 65.8 percent were women. The mean age at death was 85 (data not shown). 46.5 percent lived in a collective household (most likely a nursing home). 7.8 percent completed higher education and 8.6 percent did not complete primary education. 59.7 percent lived in a highly or very highly urbanized region. (Table 2)

Table 2: Characteristics of all deaths from or with dementia, Belgium, 2015.

		People who died with dementia	
		Number*	Percent
<b>All deaths</b>		10,629	100.0
<b>Gender</b>	Male	3,633	34.2
	Female	6,996	65.8
<b>Age</b>	0-64	87	0.8
	65-74	411	3.9
	75-84	3,642	34.3
	85 and older	6,489	61.1
<b>Nationality</b>	Belgian	10,162	95.6
	Other	467	4.4
<b>Underlying cause of death</b>	Dementia	7,005	65.9
	Cancer	369	3.47
	Ischemic heart disease	323	3.04
	Heart failure	261	2.46
	Other	2671	25.13
<b>Household type†</b>	Single person	1,994	18.77

	Couple with no children living at home	2,647	24.9
	Couple with children living at home	417	3.9
	Single parent family	388	3.6
	Collective household	4,944	46.5
	Other	235	2.2
<b>Housing comfort<sup>‡</sup></b>	High	3,842	40.0
	Average	2,247	23.4
	Low	3,521	34.6
<b>Level of education</b>	Higher education	829	7.8
	Upper secondary education	1,272	12.0
	Lower secondary education	2,254	21.2
	Primary education	3,979	37.4
	No completed education	916	8.6
	Unknown	1,379	12.9
<b>Level of urbanization of residence<sup>§</sup></b>	Very high	3,287	30.9
	High	3,059	28.8
	Average	2,702	25.4
	Low	1,403	13.2
<b>Net Taxable Income</b>	Decile 1	44	0.4
	Decile 2	44	0.4
	Decile 3	78	0.7
	Decile 4	1,119	10.5
	Decile 5	2,165	20.4
	Decile 6	3,469	32.7
	Decile 7	2,078	19.6
	Decile 8	803	7.6
	Decile 9	519	4.9
	Decile 10	306	2.9

\*May not always add up to 10,629 because of missing values, which were always lower than 1.0%, except for housing comfort (9,6%) and education level (13.0%).

<sup>‡</sup>Married and unmarried couples living together were taken together in one group. People living in a nursing home are registered as 'collective household' if (1) they officially live in the nursing home for more than a year OR (2) they were admitted to a nursing home at least 180 days before death.

<sup>‡</sup>Defined by the number of rooms and facilities (e.g. bathroom) available in the persons home, as provided in the 2001 census.

<sup>§</sup>Degree of urbanization of the official residence, as categorized by Eurostat (<http://ec.europa.eu/eurostat>) and OECD (<http://www.oecd.org/>)



*Quality Indicators of Appropriate End-Of-Life Care*

Of all people who died with dementia in Belgium in 2015, 9.8 percent received specialist palliative care, and 68.4 percent died at home or in the nursing home where they lived. Of all people living in a nursing home at least 180 days before death, 79.2 percent died in the nursing home. (data not shown) 60.2 percent had an increase in family physician contacts during the last week of life compared with the period before, with an average of 1.83 reimbursed contacts per week during the last week of life. (Table 3)

Table 3: Quality indicators indicating appropriate end-of-life care, within the total population dying with dementia (N=10,629), Belgium, 2015

Indicator	Time period (number of days before death until death)							
	No time specification	7d	14d	30d	90d	180d	360d	720d
Dispensing of morphine and neuropathic medication	-	1.3	1.8	2.2	2.8	3.2	3.7	4.5
Specialist palliative care	9.8	-	-	-	-	-	-	-
Official palliative care status	5.8	-	-	-	-	-	-	-
Home death*†	10.9	-	-	-	-	-	-	-
Death at home or in nursing home of residence**	68.4	-	-	-	-	-	-	-
Family physician contact increase	-	60.2	74.0	74.1	-	-	-	-
(average number of family physician contacts per week)§	-	1.83	1.25	0.85	-	-	-	-
Average number of primary caregiver contact per week§	-	2.32	1.79	1.47	1.34	-	-	-

\*This indicator is only measured at the moment of death. Therefore, time periods are irrelevant.

†The denominator of this indicator is people who did not stay in a nursing home at least 180 days before death, being 32.6 percent of the population.

\*\*The denominator of this indicator is people who lived in a nursing home at least 180 days before death, being 67.4 percent of the population.

§This indicator is not presented by percentages. It depicts the average number of contacts per week across the population during the indicated time period.

### Quality Indicators of Inappropriate End-Of-Life Care

Of all people who died with dementia, 25.6 percent were admitted to an emergency department, 32.4 to hospital and 2.2 to ICU during the last 30 days of life. 25.1 percent of people died in the hospital.

In the last two weeks prior to death, 25.8 percent of people who died with dementia was submitted to diagnostic testing (medical imaging, ECG or pulmonary function testing). 0.8 percent received surgery during the last 30 days.

Of those who died with dementia and had a cancer diagnosis, 1.7 percent received chemotherapy during the last 30 days prior to death.

Regarding drug dispensing in the last 30 days prior to death, 43.8 percent received anti-hypertensives, 38.5 percent received NOACs or vitamin K antagonists, 26.5 percent received gastric protectors and 6.5 percent received statins.

Of those who received specialist palliative care 38.3 percent received it only in the last week, which corresponds to 3.7 percent of the total population who died with dementia. (Table 4)

*Table 4: Quality indicators indicating inappropriate end-of-life care, within the total population dying with dementia (N=10,629), Belgium, 2015.*

Indicator	Time period (number of days before death until death)							
	No time specification	7d	14d	30d	90d	180d	360d	720d
Diagnostic testing	-	16.7	25.8	36.3	-	-	-	-
Diagnostic testing - medical imaging*	-	16.1	24.3	35.1	-	-	-	-
Diagnostic testing - ECG or pulmonary function testing	-	8.4	13.5	22.1	-	-	-	-
Chemotherapy†	-	0.3	0.8	1.7	2.9	8.1	10.8	-
Surgery	-	0.2	0.4	0.8	1.6	-	-	-
Blood transfusion	-	0.2	0.4	0.7	1.2	-	-	-
Late palliative care	-	3.7 <sup>‡</sup>	4.7 <sup>§</sup>	-	-	-	-	-
Hospital admission	-	17.7	24.0	32.4	43.0	56.9	-	-
ED admission	-	9.5	15.3	25.6	39.5	50.8	-	-
Hospital death	25.1	-	-	-	-	-	-	-
ICU admission	-	1.0	1.5	2.2	3.2	-	-	-
ICU admission from nursing home	-	0.4	0.7	1.0	1.3	2.7	-	-

Dispensing of:

Statins	-	2.5	3.9	6.5	13.4	18.7	30.2	-
Gastric protectors	-	13.3	18.8	26.5	39.6	44.1	-	-
Anti-hypertensives <sup>\</sup>	-	22.4	31.5	43.8	61.4	68.3	-	-
Calcium vitamin D <sup>¶</sup>	-	2.3	4.3	8.6	16.1	21.5	-	-
NOACs or vitamin K antagonists	-	19.0	27.4	38.5	-	-	-	-
Prophylactic gout medication	-	0.7	1.0	1.8	3.6	-	-	-
Serotonin reuptake inhibitors	-	4.2	6.4	10.2	17.9	-	-	-

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\*This indicator measures the occurrence of radiography or echography

<sup>†</sup>This indicator was measured only for people who also had a cancer diagnosis. (N=1.194)

<sup>‡</sup>This is 38.3 percent of those who received specialized palliative care.

<sup>§</sup>This is 47.7 percent of those who received specialized palliative care.

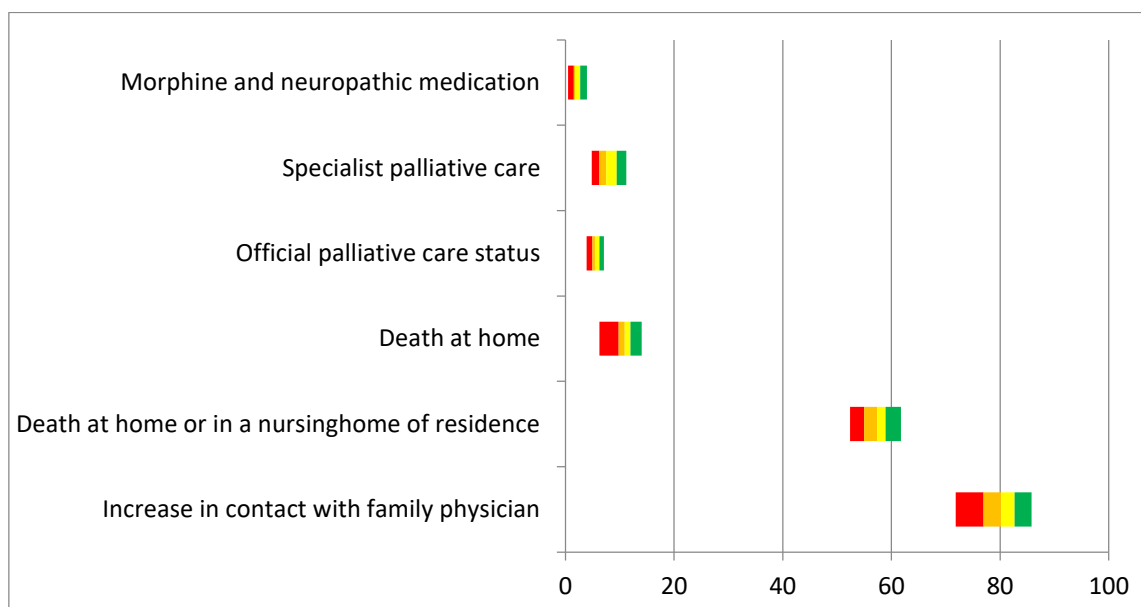
<sup>\</sup>Anti-hypertensives: this includes all antihypertensives (C02), diuretics (C03), beta blocking agents (C07), Calcium channel blockers (C08) and renin-angiotensin systemic agents(C09)

<sup>¶</sup>Not all forms of Calcium or vitamin K antagonists are reimbursed in Belgium, some variants can be bought over the counter and as such are not included in this measurement.

### *Comparison of quality indicator scores of end-of-life dementia care between health care regions*

Variation of scores between different health care regions in Flanders and Brussels (N = 7,581) is found for the indicators of appropriate end-of-life-care (Figure 1): dying at home or in a nursing home of residence varies between 52 and 62 percent, with the best scoring quartile scoring above 59 percent. Having an increase in contacts with the family physician in the last 30 days compared to the period before varies between 72 and 86 percent, with the best scoring quartile above 83 percent. The use of specialist palliative care varies between 5 and 11 percent between regions, with the best scoring quartile scoring above 9 percent.

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 with dementia (N=10,629), Belgium, 2015

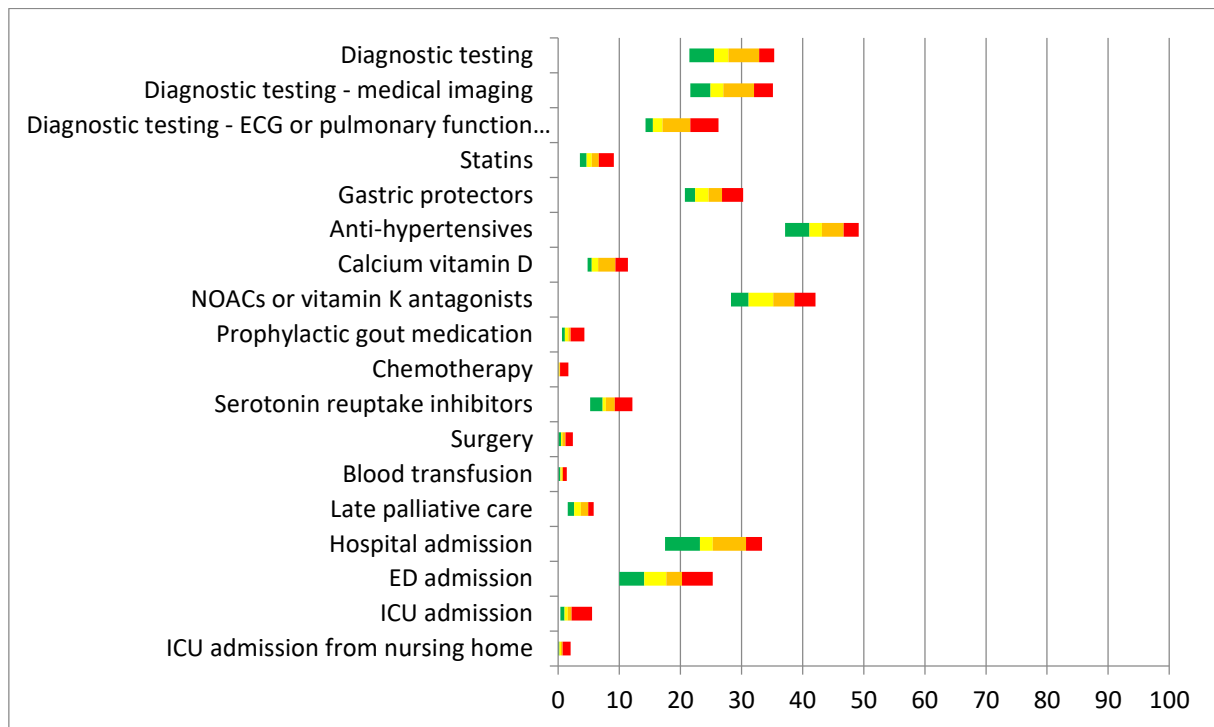


We used the period of 30 days before death for all indicators, or closer to death if the indicator was validated only for a shorter period before death.

- Worst scoring quartile
- Q1-median
- Median-Q3
- Best scoring quartile and suggested relative standard to be achieved

The use of diagnostic testing in the last 30 days varies from 21 to 35 percent between regions, with the best scoring quartile scoring below 26 percent (Figure 2). ED admission in that period varies between 10 and 25 percent, with the best scoring quartile scoring below 14 percent. Dispension of gastric protectors in the last 30 days varies between 21 and 30 percent, with the best scoring quartile below 22 percent, while anti-hypertensives in the last 30 days varies between 37 and 49 percent, with the best scoring quartile below 41 percent. The quality indicator measuring port-a-cath installment was not included in this comparison, since variation was low.

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 with dementia (N=10,629), Belgium, 2015



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.

- Worst scoring quartile
- Q1-median
- Median-Q3
- Best scoring quartile and suggested relative standard to be achieved

Based on these results, we suggest a relative benchmark for each indicator, set at the best scoring quartile. (Table 5)

Table 5: Suggestions of relative benchmarks for indicators, set at the best scoring quartile of regional comparison in Flanders, as a goal to be pursued on a national level in Belgium. (all measured at 30 days before death where time is relevant)

<b>Quality indicator</b>	<b>Suggested benchmark</b>	
<b>Morphine and neuropathic medication</b>	<b>Above</b>	2.7
<b>Specialist palliative care</b>		9.5
<b>Official palliative care status</b>		6.2
<b>Death at home</b>		12.0
<b>Death at home or in a nursing home of residence</b>		58.9
<b>Increase in contact with family physician</b>		82.6
<b>Diagnostic testing</b>		<b>Below</b>
<b>Diagnostic testing – Medical imaging</b>	24.9	
<b>Diagnostic testing – ECG or pulmonary function testing</b>	15.5	
<b>Statins</b>	4.7	
<b>Gastric protectors</b>	22.4	
<b>Anti-hypertensives</b>	41.1	
<b>Calcium Vitamin D</b>	5.5	
<b>NOACs or vitamin K antagonists</b>	31.1	
<b>Prophylactic gout medication</b>	1.1	
<b>Chemotherapy</b>	0.0	
<b>Serotonin reuptake inhibitors</b>	7.2	
<b>Surgery</b>	0.5	
<b>Bloodtransfusion</b>	0.3	
<b>Late palliative care</b>	2.6	
<b>Hospital admission</b>	23.2	
<b>ED admission</b>	14.1	
<b>ICU admission</b>	1.0	
<b>ICU admission from nursing home</b>	0.2	

## **Discussion**

### *Summary of main findings*

Using a validated set of quality indicators to describe the quality of end-of-life care in people who died with dementia, we found remarkable percentages for several indicators of appropriate care. The majority died at home or in a nursing home of residence (68.4 percent), with large variation across health care regions. Specialized palliative care was not used very often. We also found large percentages for several indicators of inappropriate care, including the percentage of people with dementia dying in the hospital (25.0 percent), which is comparable to previous research<sup>12</sup>. Many people with dementia receive gastric protectors (26.5 percent), antihypertensives (43.8 percent), NOACs or vitamin K antagonists (38.5 percent) in the last month before death, with large variation across health care regions.

### *Strengths and limitations*

Our study provides an insightful overview of end-of-life care provision for people who died with dementia. The use of routinely collected administrative data is a main strength of this study. In contrast to studies using sample data, the use of administrative data precludes sampling, nonresponse and recall bias.<sup>22,23</sup> Studying end-of-life care in a vulnerable population like people with dementia is otherwise ethically and methodologically challenging. Additionally, administrative data are relatively inexpensive,<sup>24</sup> as they are routinely collected by health insurance companies (for example, in the United States, Japan and Belgium) or by governments (for example, in the United Kingdom).

A second main strength of this study is the linking and use of socio-demographic and death certificate databases, which provide background variables to make a fair comparison between health care regions, taking into account socio-demographic and economic differences between regions.

The third main strength of this study is that the results are directly comparable to those in other countries, such as the US, Canada or the



UK. This goes for the quality indicator results, as well as the relative benchmarks. The methodology we use to measure quality indicators and to establish relative benchmarks is novel and can also be replicated in other countries.

A limitation of this study is that the linked administrative data do not include diagnostic information. We therefore must rely on death certificate data to select the dementia population. Literature suggests death certificate data tend to underestimate the prevalence of dementia.<sup>25-27</sup> To identify comorbidities that might influence treatment, we used death certificate data as a proxy, where diagnostics data would be more accurate.

Furthermore, the linked administrative databases do not contain data on non-reimbursed care. As such, palliative care included in regular nursing home care and generalist palliative care by the family physician or other carers are not measured in quality indicators measuring specialist palliative care. They do not contain data on non-reimbursed medication, except for laxatives, calcium combinations and several analgesics that are registered, although not reimbursed. This affects the results for the gastric protectors and calcium with vitamin D quality indicators. In practice, they are dispensed to a higher percentage of people with dementia than calculated in these indicators.

Data on non-reimbursed care and diagnostic information would increase the robustness of the risk adjustment method and reduce the possibility that some of the variation between regions is due to unmeasured confounders at the individual level.

### *Interpretation*

Several indicators of inappropriate end-of-life care are highly prevalent, especially hospital death, diagnostic testing and ED admission. Similar results were found in previous research in the US and the UK.<sup>28,29</sup> This suggests a high number of people who died with dementia underwent an aggressive curative trajectory with one or more care transitions. This occurs in people who lived in a nursing home as well as people who lived at home. We also found large variations across health care regions on these indicators, even when taking into

account a number of relevant confounding variables. This indicates there are opportunities for improvement, at least in several regions. Especially for these indicators, ambitious and realistic standards should be established to decrease the number of hospital deaths, ED admissions and diagnostic tests, and thus increase the quality of end-of-life care for people dying with dementia.

Specialized palliative care is remarkably rare in people who died with dementia, taking into account the progressive and terminal nature of the disease, especially compared to people dying with cancer<sup>30</sup>. A large percentage of those who receive it, do so only in the last week before death (47.7 percent). There are three plausible causes for this: first, palliative care included in regular nursing home care is not measured in this indicator, which might occur often in people who died with dementia.<sup>4,31</sup> Secondly, during the dementia disease trajectory, prognosis of functional decline more than several months ahead is often difficult.<sup>3,9</sup> This makes the decision to initiate palliative care especially difficult.<sup>7,10</sup>

Thirdly, health care providers are not always aware that palliative care is appropriate for people suffering with dementia, or that dementia is a life-limiting condition.<sup>32</sup>

We found high percentages of people using antihypertensives, gastric protectors and NOACs or vitamin K antagonists. These medications mainly have a prophylactic rather than an aggressive curative function. They can and should be discontinued when patients near the end of life, to avoid adverse effects and costs when no benefits are present.<sup>33,34</sup> Our findings are corroborated by recent research on polypharmacy.<sup>35,36</sup> The indicators on antihypertensives, gastric protectors and NOACs or vitamin K antagonists mark an area where we have the opportunity and necessity to enhance the quality of end-of-life care for people with Dementia.

#### *Towards quality improvement*

We indicated three main opportunities for quality improvement: reducing care transitions and aggressive care (e.g. diagnostic testing, ED admissions, hospital death), earlier initiation of palliative care and discontinuation of prophylactic medication (e.g.

antihypertensives, gastric protectors and NOACs or vitamin K antagonists) near the end of life. As we controlled for the most impactful population differences across regions, such as differences in degree of urbanization, income, age, or education level, variation across regions is likely to be determined by real differences in health care practice across regions. The suggested standards for these indicators, based on the fair comparison between regions, are a starting point for quality improvement.<sup>15</sup> These standards are both ambitious and attainable, as currently 25% of regions achieve them.

To improve practice, policy makers can use the suggested benchmarks to further analyze the reasons for the inconsistencies between regions, and develop and test interventions that can improve practice within a region.<sup>37,38</sup> For instance, the implementation of advance care planning can support the decision making process when treating people with dementia.<sup>39</sup> This might in turn lead to earlier initiation of palliative care, fewer care transitions and discontinuation of ineffective medication near the end of life.

### **Conclusions and implications**

The evidence in this study suggests the occurrence of potentially inappropriate end-of-life care in people who died with dementia in Belgium, especially diagnostic testing, hospital and ED admissions, lack of discontinuation of potentially inappropriate medication and late initiation of specialized palliative care. We found substantial risk-adjusted variation between regions for multiple QIs, suggesting opportunities for quality improvement in dementia end-of-life care. A first step towards quality improvement could be using evidence-based relative standards, as developed in this study.

### **Conflict of interest**

The authors have no conflicts of interest to declare. All individuals who merit authorship are included as authors.

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**Chapter 7:** Trends in appropriateness of end-of-life care in people dying from cancer, COPD or with dementia: applying quality indicators on administrative databases.

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## **Abstract**

### **Background**

Recent efforts from governments and practitioners aimed to increase appropriateness of end-of-life care of patients with advanced illness, such as cancer, COPD or dementia. An assessment of a possible shift in appropriateness of end-of-life care across the population is lacking.

### **Aim**

Measuring quality indicators with routinely collected population-level data, this study aims to evaluate the appropriateness of end-of-life care for people with cancer, COPD or dementia between 2010 and 2015 in Belgium.

### **Design**

We conducted a population-level decedent cohort study, using data from eight population-level databases, including death certificate and health claims data. We measured validated sets of quality indicators for appropriateness of end-of-life care.

### **Setting/participants**

We included all people who died from cancer or COPD or with dementia between 1st January 2010 and 1st January 2016 in Belgium.

### **Results**

We observed three trends common across cancer, COPD and dementia decedents: an increase in the percentage of people (1) with an increased contact with a family physician, (2) who received specialized palliative care (mostly initiated in the last 14 days), and (3) admitted to an emergency department, all in the last 30 days. We found additional trends specifically for each disease group.

### **Conclusion**

Although we found an increase of specialized palliative care and generalist palliative care use, we also found an increase in indicators of inappropriate care, including emergency department and intensive

care unit admissions. To increase the appropriateness of end-of-life care, palliative care should be initiated earlier and unnecessary care transitions and medication should be avoided.

## **Background**

In people with advanced serious diseases such as cancer, chronic obstructive pulmonary disease (COPD) or dementia, when death is imminent in the foreseeable future, the emphasis of care ideally gradually shifts to comfort care. Continuing disease-modifying treatment when the benefits no longer outweigh possible negative impacts in terms of quality of life, comfort or dignity, could be considered inappropriate end-of-life care.<sup>1,2</sup> In contrast, appropriate care near the end of life, such as the timely initiation of palliative care, could increase well-being considerably in people suffering from advanced life-threatening conditions.<sup>3-6</sup>

In the last decades, measuring the appropriateness of end-of-life care and changing care practices at the end of life towards more appropriate end-of-life care has been on the agenda of many researchers and policy makers.<sup>3,5,7-9</sup> In contrast, research shows there has mainly been an increase in indicators of aggressive treatment near the end of life in western countries. Earle et al., for instance, found an increase in chemotherapy use and continuation of chemotherapy closer to death in Medicare patients with cancer in the US between 1993 and 1996.<sup>10</sup> Teno et al. found an increase between 2000 and 2009 in the USA in intensive care unit (ICU) admission and healthcare transition in the final 30 days of life, despite an increase in out-of-hospital death and hospice use.<sup>11</sup> Similar research in the US, Canada and Korea shows an increasing occurrence of multiple emergency department (ED) visits, ICU admissions and hospital admissions in the last weeks of life.<sup>12-</sup>

Recent efforts from governments and practitioners have aimed to increase the appropriateness of end-of-life care and the quality of life of patients with advanced illness, for instance by promoting the timely introduction of palliative care and advance care planning.<sup>4,17-19</sup> While traditionally, these efforts focus on people with cancer, efforts have also been made to increase access to palliative care and promote advance care planning for people with dementia and COPD.<sup>20,21</sup> Appropriateness of end-of-life care received increasing attention from policy makers in countries such as the US, Canada, Germany and Belgium, among others.<sup>22-25</sup> When comparing Belgian government advisory documents of 2009 to those of 2017, the increasing emphasis on appropriateness of end-of-life care is evident, moving from providing definitions of palliative care in 2009<sup>26</sup>, to reporting on the appropriateness of end-of-life care and providing advice to promote palliative care use in 2017<sup>25</sup>. These efforts in research and policy might be a reflection of a broader societal evolution towards more attention for appropriateness of end-of-life care and positive attitudes towards palliative care. If that is the case, a shift towards more appropriate end-of-life care could be expected.

However, a comprehensive assessment of the appropriateness of end-of-life care across the population, measuring a wide range of indicators of both appropriate and inappropriate end-of-life care is currently lacking. Using a previously developed quality indicators set based on administrative data<sup>9</sup>, this study aims to evaluate the appropriateness and inappropriateness of end-of-life care for people with cancer, COPD or dementia between 2010 and 2015 in Belgium. The specific research questions are:

1. Did people dying from cancer or COPD or with dementia in Belgium receive more appropriate end-of-life care in 2015 than they did in 2010? And If so, what changes can be observed?

2. What indicators of appropriate or inappropriate end-of-life care present the largest changes in this time period?

## **Methods**

### *Study design and data sources*

We conducted a population-level decedent cohort study of all deceased from cancer, from COPD or with dementia between 31th December 2009 and 1<sup>st</sup> January 2016 in Belgium. Data from eight administratively managed population-level databases was linked<sup>27</sup>. At the moment of the linking procedure, data from 2015 were the most recent data fully available in all linked databases. As healthcare insurance is legally mandatory in Belgium, the central health care claims databases contain data on almost the entire Belgian population.<sup>28</sup>

(1) The health care claims database containing all health care use data of reimbursed home, nursing home and hospital care, except medication dispensed in public pharmacies;

(2) The database with socio-demographic data on all people with healthcare insurance;

(3) The pharmaceutical database containing data on all reimbursed medication dispensed in public pharmacies;

(4) The Cancer Registry database with data on all incidences of cancer including the type of cancer and date of diagnosis of each incidence;

(5) The national death certificate database containing all registered causes of death;

(6) The population registry database with data on household composition;

(7) The census database, containing data from national censuses held in 2011 and 2001, including housing characteristics and educational level;

(8) The fiscal database, including the net taxable income of each Belgian citizen;

After acquiring approval from all relevant data protection agencies, all databases were linked in a secure and ethically responsible manner, guaranteeing anonymity of the deceased.<sup>27</sup> The database linking procedure is described in detail in a previous publication.<sup>27</sup> Unfortunately, the data are not publicly available and due to privacy regulations, cannot be shared by the authors.

### *Population*

We included all people who died from cancer or COPD or with dementia between 31st December 2009 and 1st January 2016 in Belgium. People dying from cancer (ICD10 codes C00-C99) or COPD (ICD10 codes J41-J44) were identified using the underlying cause of death on the death certificate only. People who died with dementia were identified using the underlying, intermediate, external and associated causes of death reported on the death certificate (ICD-10 codes F00, F01, F02, F03 or G30). We used this broader selection because dementia is often underreported as a primary cause of death and people with advanced dementia often die from other causes, most commonly pneumonia.<sup>29,30</sup> That

is why, in contrast to cancer and COPD, we report on people dying 'with' and not necessarily 'from' dementia.

#### *Data*

In the Belgian health care system, health care costs for a wide range of treatments and medication are reimbursed to the patient. Every reimbursement is registered by health insurers, while a central agency collects data from all health insurance registries.<sup>28</sup> The resulting central health and pharmacy databases were part of the linking procedure mentioned in the methods section.<sup>27</sup> From these databases, we used all available data on health care use including treatment, medication use, dates of treatment and prescription and admission to hospitals, emergency departments, intensive care units and nursing homes. We also selected multiple socio-economic, demographic and clinical variables from other administrative databases that might influence health care use including age, gender, net taxable income, dependence on care, highest attained level of education, household composition and degree of urbanization of the municipality of residence.

#### *Quality indicators*

We used three validated sets of quality indicators for appropriateness of end-of-life care: one for people dying with dementia (28 indicators), one for people dying from COPD (28 indicators) and one for people dying from cancer (26 indicators). They were developed and validated using a RAND/UCLA Appropriateness method.<sup>9,31</sup> The expert panels for this validation consisted of general practitioners, pharmacologists and palliative care specialists, adding neurologists,



nursing home coordinating and advisory physicians and geriatrists for indicators for people with dementia, oncologists, pneumologists and radiotherapists for indicators for people with cancer and pneumologists for indicators for people with COPD.<sup>9</sup>

The quality indicators in all three sets measure the prevalence of specific healthcare interventions in a specified period before death (e.g. 7 days, 14 days, 30 days, 180 days), within the specific population they were developed for. For the purpose of this trend study all indicators were measured for the period of 30 days before death, except when specific indicators were not validated by the expert panel for that time period, or time before death was irrelevant for the quality indicator. One indicator measuring tube feeding or intravenous feeding could not be measured with the available data, as these are not reimbursed as individual interventions, but as a package in the hospital context.

#### *Risk adjustment and trend analysis*

To obtain a trend analysis portraying real evolutions in appropriateness of end-of-life care rather than changes in the risk profile of the population (i.e. attributional validity<sup>32</sup>), we controlled for variables that changed across years and might influence health care use. We used a comprehensive list of possible confounders and made a selection based on availability in the linked dataset<sup>27</sup>. The following risk factors were identified as relevant and measurable with the current dataset: age, gender, highest attained level of education, net taxable income, household composition (e.g. married, single, with or without children, in a nursing home), being officially recognized as having high care needs, being entitled to a higher degree

of reimbursement due to lower degree of self-reliance, and degree of urbanization of the municipality of residence. These variables were used to calculate risk adjusted quality indicator scores for each of the years.

#### *Statistical analyses*

We calculated the population characteristics using descriptive statistics. To perform the risk adjusted trend analysis, we used stepwise logistic regression model building (with a significance level of 0.3 for entry and 0.05 to stay in the model), to identify what variables were associated with each quality indicator (coded binary as present [1] or absent [0]) across years. Using the results from this predictive model, we calculated a predicted quality indicator score for each quality indicator per year. A risk-adjusted score was then calculated by dividing the average predicted score by the average observed score for each year, multiplied by the average observed score across all years. This way, a trend analysis was performed, taking into account relevant population differences across years.

We also calculated all risk adjusted indicator score differences between 2010 and 2015. We subtracted the indicator scores in 2015 with the indicator scores of 2010 and divided this by the score in 2010, to obtain a relative (percentage) increase. We then inverted all results of indicators of inappropriateness of care (multiplied by -1) and joined all indicators for each disease (cancer, COPD, dementia) in a ranking from most positive to most negative evolutions.

All analyses were conducted with SAS Enterprise Guide, version 7.1. Programming codes are available from the authors on request.

### *Reporting, ethics and funding*

We report our results following the RECORD guidelines for observational routinely-collected health data.<sup>33</sup>

The study was approved by the Brussels university hospital committee for medical ethics (B.U.N. 143201627075).

The administrative data linking process was approved by the national Data Protection Authority (project SA1/STAT/MA-2015-026-020-MAV) and by the Statistical Monitoring Committee (project STAT-MA-2015-026).

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## **Results**

### *Cohort characteristics*

A total of 634,445 people who died between 1<sup>st</sup> January 2010 and 1<sup>st</sup> January 2016 in Belgium were included in the analysis, of which 25.2% (159,590) died from cancer, 6.0% (37,930) died from COPD and 9.5% (59,967) with dementia (table 1). The mean age at death across all years was 74, with 72 in people with cancer, 76 in people with COPD and 84 in people with dementia. (data not shown)

Table 1: Summarized\* population description of all people who died from cancer, with COPD or with dementia in Belgium from 2010 until 2015.

		Dying from Cancer (N = 159,590)		Dying with COPD (N = 37,930)		Dying with Dementia (N =59,967)	
		2010 (N = 26,768)	2015 (N = 26,493)	2010 (N = 6,878)	2015 (N = 6,185)	2010 (N = 10,017)	2015 (N = 10,629)
<b>Average age</b>		68.2	73.8	72.0	78.2	79.5	86.6
<b>Agecategory</b>	<65	24.6	22.9	11.7	11.6	1.3	0.8
	65-74	23.6	24.3	19.4	21.2	5.1	3.9
	75-84	35.6	34.4	44.5	40.6	41.5	34.3
	>84	16.2	18.4	24.4	26.6	52.1	61.1
<b>Sex</b>	Female	43.6	44.1	32.7	36.7	65.4	65.8
<b>Householdtype</b>	Single	29.3	29.9	31.6	31.3	20.4	18.8
	Single parent	5.0	5.3	5.2	4.7	3.8	3.7
	Couple with children	12.1	11.5	7.6	7.1	4.4	3.9
	Couple without children	44.7	44.4	37.2	36.5	27.2	24.9
	Collective (i.e. nursing home)	7.1	7.2	15.9	18.1	41.9	46.5
	Other	1.9	1.7	2.5	2.2	2.4	2.2
<b>Housing Comfort</b>	High	47.2	51.6	35.8	39.8	34.5	40.0
	Average	17.1	14.9	20.6	18.7	27.4	23.4
	Low	26.9	26.3	30.5	31.3	25.8	26.5
	None	8.8	7.2	13.1	10.2	12.3	10.2
<b>Degree of urbanization of residence</b>	Very high	31.5	30.0	32.6	30.9	33.9	30.9
	High	28.2	28.8	26.3	27.5	28.6	28.8
	Average	26.7	26.2	25.7	24.3	24.9	25.4
	Low	13.6	13.9	15.3	16.2	12.6	13.2

<b>Region</b>	Flanders	58.9	58.3	49.6	48.1	57.9	57.0
	Wallonia	33.1	34.0	41.7	44.5	32.3	35.3
	Brussels	8.0	7.7	8.7	7.4	9.8	7.7
<b>Cancertype</b>	Respiratory	27.8	25.2				
	Digestive tract	28.9	28.4				
	Urinary tract	6.4	6.5				
	Head and neck	3.2	3.4				
	Melanoma	2.6	3.4				
	Breast	6.9	7.6				
	Female genital organs	5.2	4.9				
	Male genital organs	4.9	5.9				
	Other	13.9	14.7				

\*A detailed description of all population variables across all years can be found in the appendix as supplementary tables 8, 9 and 10.

*Risk adjusted differences in quality indicators scores between 2010 and 2015 (table 2)*

Across the study populations, for all three disease groups, we found a large increase between 2010 and 2015 in the percentage of people who had an increased contact with a family physician towards the end of life, i.e. more contacts with the GP in the final 30 days than in the period before (+21.7% in cancer, +33.7% in COPD and +89.4% in dementia). We also found an overall increase in people who received specialized palliative care, (+5.4% in cancer, +25.6% in COPD, +8.8% in dementia) with particularly a late initiation of palliative care (in last 14 days only) increasing, (+4.6% in cancer, +36.9% in COPD, +17.8% in dementia). Another major trend across all three disease groups is the increase in percentage of people who are admitted to an

emergency department in the last 30 days (+7.0% in cancer, +4.4% in COPD and +8.2% in people dying with dementia). (table 2, figures 1, 2 and 3)

Table 2: Trends overview, containing all risk adjusted differences between 2010 and 2015, ranking all indicators\* from most positive to most negative evolution in relative percentage increase.†

Cancer indicators	Improvement score†		COPD indicators	Improvement score†		Dementia indicators	Improvement score†	
	Relative increase in indicator score between 2010 and 2015	Absolute increase in indicator score between 2010 and 2015		Relative increase in indicator score between 2010 and 2015	Absolute increase in indicator score between 2010 and 2015		Relative increase in indicator score between 2010 and 2015	Absolute increase in indicator score between 2010 and 2015
Increased number of contact with family physician	+21.7%	+9.8	Increased number of contact with family physician	+33.7%	+13.7	Increased number of contact with family physician	+89.4%	+32.5
Multidisciplinary oncology consult	+14.7%	+1.8	Specialist palliative care	+25.6%	+2.6	Blood transfusion (last 14 days before death)	-26.2%	-0.1
ICU admissions from a nursing home	-9.3%	-0.2	Official palliative care status	+23.7%	+1.9	Opioids and neuropathic medication	+24.5%	+0.4
Chemotherapy	-5.8	-1.0	Start taking an antidepressant	-20.4%	-1.1	ICU admissions from nursing home	-19.1%	-0.2
Specialist palliative care	+5.4%	+2.5	Continuous endotracheal intubation	-20.2%	-1.4	ICU admissions	-17.1%	-0.5

Official palliative care status	+3.8%	+1.4	Reanimation after intubation	-17.0%	-0.3	Dispension of serotonin reuptake inhibitors	-11.4%	-1.3
Opioids and neuropathic medication	+2.6%	+0.2	Coronary or abdominal surgery	-16.7%	-0.2	Official palliative care status	+10.7%	+0.6
Opioids	+1.0%	+0.8	Blood transfusion (last 14 days before death)	-16.2%	-0.2	Specialist palliative care	+8.8%	+0.8
Diagnostic testing - ECG or pulmonary function testing	-0.5%	-0.2	Repeated endotracheal intubation	-8.0%	-1.2	Diagnostic testing - ECG or pulmonary function testing	-3.9%	-0.9
Diagnostic testing (all)	-0.2%	-0.1	Endotracheal intubation or tracheotomy	-7.1%	-1.2	Hospital death	-3.2%	-0.8%
Death at home or in nursing home where resided for at least 180 days	+0.1%	+0.1	Opioids	+6.0%	+2.3	Death at home or in nursing home where resided for at least 180 days	+1.6%	+1.1
Diagnostic testing - medical imaging	+0.1%	+0.0	Diagnostic testing - ECG or pulmonary function testing	-4.8%	-2.1	Hospital admissions	-0.1%	-0.0
Start taking an antidepressant	+0.1%	+0.0	Death at home or in nursing home where	+4.5%	+2.0	Diagnostic testing (all)	+0.1%	+0.0

			resided for at least 180 days					
Blood transfusion (last 14 days before death)	+0.7%	+0.0	Hospital death	-3.9%	-2.1	Diagnostic testing - medical imaging	+0.7%	+0.2
Hospital admissions	+0.8%	+0.5	ICU admissions from nursing home	-1.7%	-0.0	Dispension of anti-hypertensives	+4.5%	+1.9
Surgery	+1.0%	+0.0	Death at home	+1.0%	+0.3	ED admissions	+8.2%	+1.9
Death at home	-1.9%	-0.6	Diagnostic testing (all)	-0.3%	+0.2	Dispension of NOAC's or vitamin K antagonists	+9.0%	+3.2
Feeding tube or intravenous feeding	+3.7%	+0.1	Inhalation therapy	-0.2%	-0.2	Dispension of prophylactic gout medication	+13.4%	+0.2
Late initiation of palliative care	+4.6%	+1.6	Diagnostic testing - medical imaging	+0.1%	+0.0	Dispension of statins	+14.5%	+0.8
ED admissions	+7.0%	+2.3	Hospital admissions	+1.7%	+1.0	Death at home	-16.1%	-2.0
			Late initiation of physiotherapy	+3.1%	+0.2	Late initiation of palliative care	+17.8%	+0.7
			Surgery	+8.3%	+0.1	Chemotherapy	+23.5%	+0.1



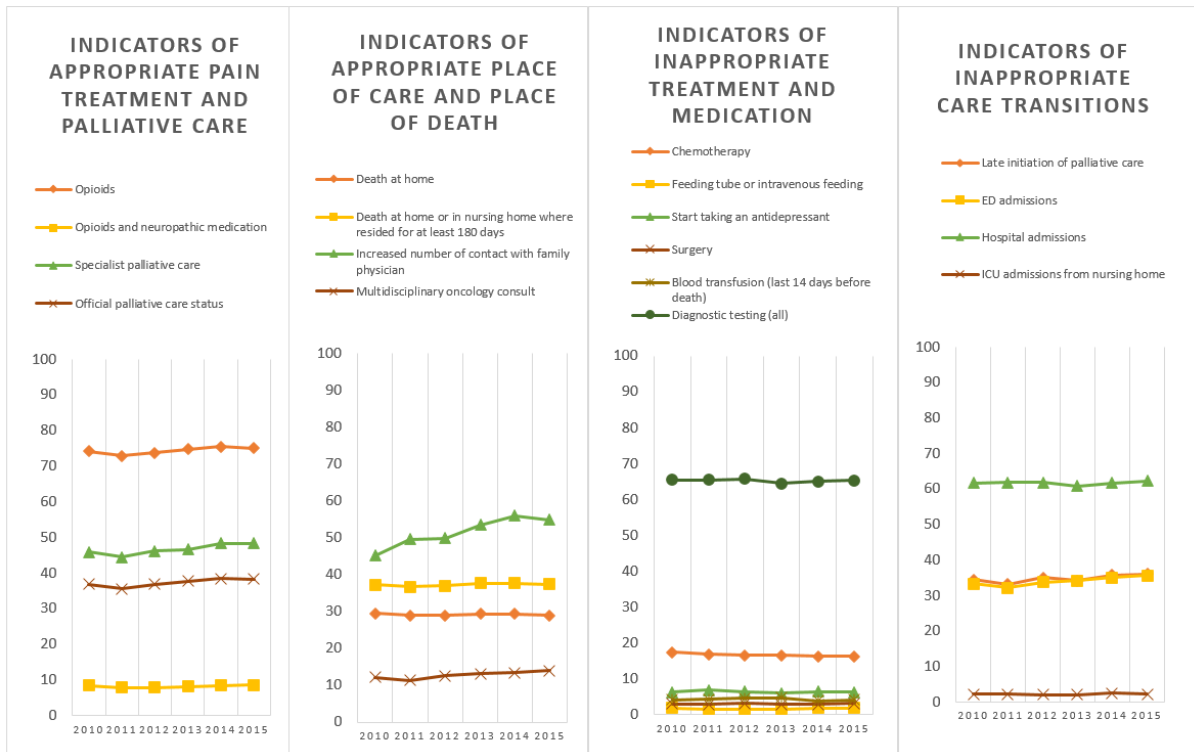
ED admissions	+10.9%	+4.4	Dispension of gastric protectors	+23.7%	+5.0
ICU admissions	+12.3%	+1.6	Surgery	+32.5%	+0.2
Late initiation of palliative care	+36.9%	+1.3	Dispension of calcium vitamin D	+36.0%	+2.3

\*Only indicators measured as a percentage are included in this table, to enable comparability.

†For the ranking order, all results of indicators of inappropriateness of care were inverted (multiplied by -1), so a higher ranking means a decrease of these indicators

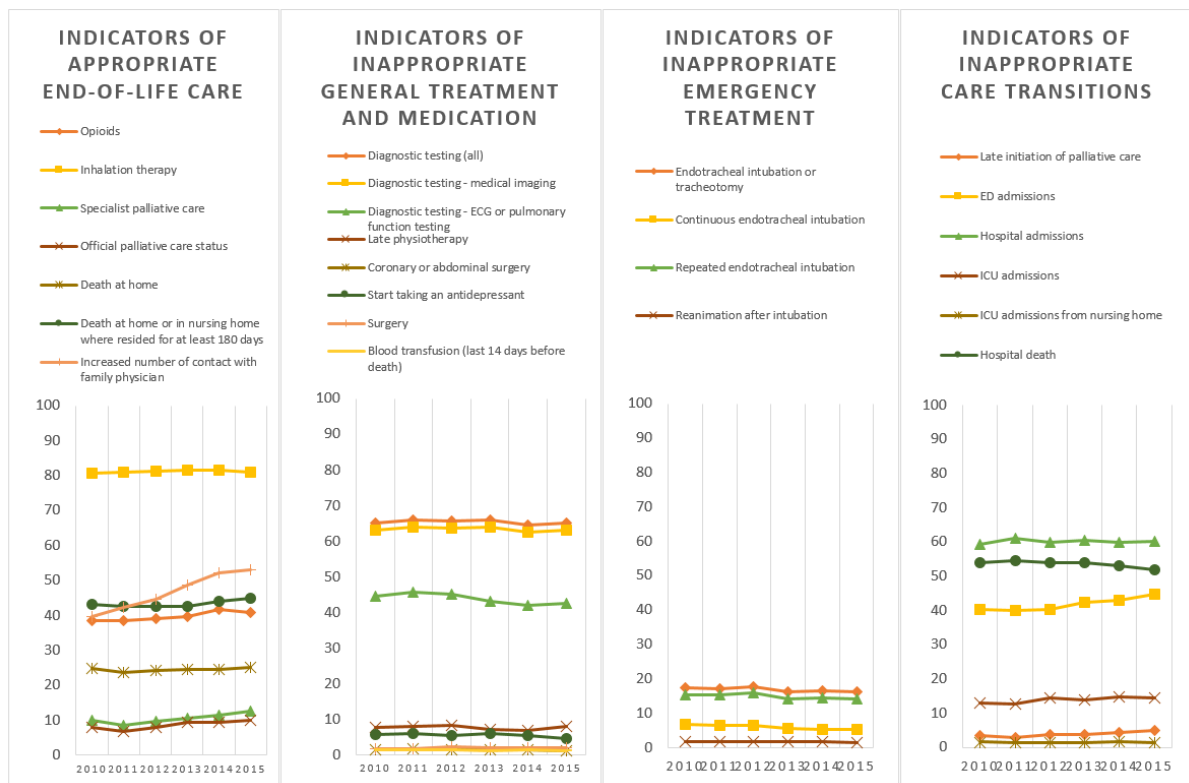
For those who died from cancer, we additionally found an increasing percentage receiving a multidisciplinary oncology consult from 12.3% to 14.1% and a decrease of those receiving chemotherapy in the last 30 days of life from 17.5% to 16.5%. (table 2, figure 1)

Figure 1: Trends in indicators of appropriate or inappropriate care in the last 30 days of life for people dying from cancer, thematically grouped.



For COPD, we found an increase in the percentage of people receiving the official palliative care status (+23.7%) and the percentage of people who received opioids (+6.0%). We also found a decrease in the percentage of people receiving endotracheal intubation or tracheotomy (-7.12%), continuous (-20.18%) and repeated endotracheal intubation (-7.95%). However, the percentage of people admitted to the ICU increased (+12.29%). (table 2, figure 2)

Figure 2: Trends in indicators of appropriate or inappropriate care in the last 30 days of life for people for people dying from COPD, thematically grouped.



In people who died with dementia, in addition to the changes described above, we found an increase in the percentage of people with dispensation of NOAC's or vitamin K antagonists (+8.98%), gastric protectors (+23.67%), and calcium and vitamin D (+36.04%). The percentage receiving serotonin reuptake inhibitors decreased (11.44%). (table 2, figure 3)

Figure 3: Trends in indicators of appropriate or inappropriate care in the last 30 days of life for people for people dying with dementia, thematically grouped.



## **Discussion**

### *Main findings*

Using full-population data we observed three trends in the appropriateness of end-of-life care that were common across cancer, COPD and dementia decedents: (1) a large increase in the percentage of people who had an increased contact with a family physician in the last 30 days, (2) an increase in the proportion who received specialized palliative care (mostly an increased late initiation of palliative care, i.e. in the last 14 days), and (3) a large increase in the percentage of people admitted to an emergency department in the last 30 days. Additionally, we found several trends specifically for people dying from cancer, from COPD or with dementia.

### *Strengths and limitations*

A first strength of this study is that the use of routinely collected administrative data allows us to study diverse and hard-to-reach populations, such as cognitively impaired and vulnerable participants, without discrimination. Other research suffers from issues adapting data collection methods for these populations (e.g. translating or adapting questionnaires) or selection bias, where our data collection method includes (almost) the entire Belgian population.<sup>33-35</sup> Including people with COPD and dementia is a second strength of this study, as end-of-life care research has traditionally mainly focused on people with cancer.<sup>36,37</sup> Linking administrative databases including socio-demographic and death certificate databases also provides information on possible confounding variables, so we can observe trends in health care provision, unaffected by possible demographic and diagnostic evolutions.

A first limitation of this study is that we rely on death certificate data to select the COPD and dementia population. Literature suggests death certificate data tend to underestimate the prevalence of dementia.<sup>38,39</sup> A second limitation is that the selected routinely collected databases do not contain data on non-reimbursed care. Some important aspects of care, such as patient-carer communication, patients' preferences, or health care that is not specifically reimbursed, such as palliative care included in regular nursing home care, cannot be measured. This implies that important aspects of appropriateness of end-of-life care are not measured in this study, but also that there might be residual confounding in comparing quality indicator scores across years. However, we assume to have captured the most impactful population-level changes between years with available routinely collected data.

### *Interpretation*

We found an overall increase in the percentage of people receiving specialized palliative care, with the largest growth for people dying from COPD. This increase, however, seems mostly due to specialized palliative care initiated in the last two weeks of life. A remaining challenge would, therefore, be to match increased access to palliative care service with their increased timely initiation. The percentage of people with increasing contacts with a general practitioner (GP) near the end of life has also risen. This might entail that so-called generalist palliative care, in which the GP usually plays a large role<sup>40</sup>, is also increasing.

Despite the increase in palliative care, we found an increase in several indicators of possible inappropriate end-of-life care, most notably emergency department (ED) visits rising in all disease groups and ICU admissions in people dying from COPD or with dementia. These seemingly contradictory findings are in line with the results of Teno et al.<sup>15</sup>, who found an increased use over time in the USA of hospice and hospital-based palliative care near the end of life, but at the same time a reduced average length of stay in the hospice, alongside an increase in ICU admissions and multiple hospital visits near the end of life. With Teno et al. we can argue that increased use of palliative care does not reduce resource use in general. It may even be that palliative care is sometimes combined with aggressive treatment rather than replacing it.<sup>15</sup>

For people dying with dementia, we found an alarming trend in medication provision: only the percentage of people receiving serotonin reuptake inhibitors in the last month of life is decreasing, while rates for all other indicators on possibly inappropriate medication are rising. It has been argued that polypharmacy and the continued intake of long-term preventive medication has adverse effects on the health and quality of life of frail older adults, including those with dementia.<sup>8,41</sup> People with dementia near the end of life in Belgium often live in a nursing home. Studies report a number of barriers to discontinuing medication in this context, including perceived opposition of the patient's family or the patient him/herself.<sup>42,43</sup> It has been argued that the initiation of some of the medications mentioned might benefit patients in a palliative care context, to treat symptoms.<sup>43</sup> This, coupled with a lack of discontinuation, would lead to a rise in medication use. However, the

use of standardized medication reviews with tools such as the STOPPFrail<sup>41</sup> criteria, which have been circulated from 2015 onwards, could facilitate the discontinuation of inappropriate medication prescription in people with dementia.

### *Implications*

Overall, our findings suggest there is an increase in several indicators of appropriate end-of-life care, but little reduction in indicators of inappropriateness of end-of-life care. The increased use of specialized palliative care does not come with a reduction in inappropriate end-of-life care.

We suggest that, to increase appropriateness of end-of-life care, an effort should be made to reduce the number of ED and ICU admissions of people with serious and chronic illness near the end of life. Palliative care should be initiated earlier and, especially for people with dementia, medication policies should focus on deprescribing and discontinuation of inappropriate medication. Systematic monitoring of quality indicator scores and reestablishing relative standards, could help define goals for future improvement of the quality of end-of-life care.



## **Conclusion**

We present a trend analysis of a large set of validated indicators of appropriate and inappropriate end-of-life care in people dying from cancer, from COPD or with dementia. Although we found indications of an increase of both specialized palliative care use and generalist palliative care use, we also found an increase in several indicators of inappropriate care in the last month of life, including ED and ICU admissions. To increase the appropriateness of end-of-life care, palliative care should be initiated earlier, unnecessary care transitions should be avoided and unnecessary medication should be discontinued.

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## **PART III: General Discussion**





## **Chapter 8: Main findings and discussion**

As the final part of this dissertation, part three discusses the meaning of our findings. We summarize the main results, we discuss the main strengths and limitations of our research and the consequences of our findings, and we conclude with implications for practice, research and policy.

## 1. Quality indicator development

We developed three sets of quality indicators (QI's) for appropriateness and inappropriateness of end-of-life care: one set for people with cancer (26 indicators), one for people with COPD (28 indicators) and one for people with dementia (28 indicators). All indicators were validated in consensus by multidisciplinary expert panels. 14 indicators were valid for all three disease groups. All developed indicators are measurable with available health care data, routinely collected by Belgian health insurance organizations. The developed indicator sets enable us to evaluate the appropriateness of end-of-life care in the Belgian health care system and to compare countries, regions and health care providers in terms of appropriateness of end-of-life care.

We substantially expanded on the existing literature with new indicators for people with cancer to be measured with administrative data, such as diagnostic testing, tube feeding and the use of specialist palliative care, while corroborating several existing quality indicators (QI's) measured previously in the United States and Canada.<sup>1-4</sup> Our development of quality indicator sets for COPD and

Alzheimer dementia is a novel contribution in quality indicators for end-of-life care measurable with administrative data. In accordance with efforts of policy makers and researchers from international organizations<sup>5,6</sup> to extend palliative care and end-of-life care to non-cancer populations in need of appropriate end-of-life care, these indicators may facilitate monitoring and improving end-of-life care for people dying with COPD and Alzheimer dementia.

## 2. Using linked administrative databases to study end-of-life care

We identified several available administrative databases containing routinely collected data useful for end-of-life care research, including for quality indicator measurement: health care claims data from the InterMutualistic Agency (IMA)<sup>7</sup>, cancer incidence data from the Belgian Cancer Registry (BCR)<sup>8</sup> and death certificate and socio-economic data from Statistics Belgium (StatBel)<sup>9</sup>. We obtained approval to link and use the selected data from two national privacy committees. Two trusted third parties linked the data on an individual patient level.<sup>10,11</sup> The linking process was not done before in Belgium. Our study proves it is feasible and expands the possible research use of the data. This suggests this methodology might be replicated in future health care research to study health care use on a population level.

### 3. Appropriateness of end-of-life care

#### 3.1 Dying from cancer

We measured all indicators developed for people dying from cancer in the population of 26,464 people who died from cancer in 2012 in Belgium. To investigate possible associations between the quality indicators and various socio-demographic and economic variables, we reduced the large set of quality indicators to a small selection of thematically linked principal components. We first selected quality indicators that we deemed theoretically consistent health care practices, (for example: tube feeding, surgery, hospital admission and diagnostic testing, representing a possible dimension of aggressive hospital care), then performed principal component analysis to determine their common variance and backwards selected indicators based on their score on the component. This reduced the set of 26 indicators to four components "curative cancer treatments", "potentially inappropriate hospital transitions and hospital care", "potentially appropriate comfort and palliative care" and "potentially appropriate pain and symptom treatment". We then investigated associations between various socio-demographic and economic variables with the resulting components.

Compared with international literature<sup>3,4</sup>, we found relatively low percentages of people dying at home (29.5%) or receiving specialist palliative care (47.1%). Our results also suggest an overuse of chemotherapy near the end of life (17.2% in the last 30 days). As for associations between appropriateness of care and population characteristics, we found people younger than 65 and younger than 84 dying from cancer receiving more curative cancer treatment and more

potentially inappropriate hospital transitions and hospital care, as well as more potentially appropriate pain and symptom treatment. People dying from cancer in Wallonia and Brussels received more possibly inappropriate transitions to hospital and hospital care and less possibly appropriate comfort and palliative care.

### 3.2 Dying from COPD

We measured all indicators developed for people dying from COPD with the 4,231 people who died from COPD in 2015 in Belgium. We additionally examined variation between 14 health care regions, covering Flanders and Brussels, using a selection of socio-economic and demographic variables to establish a fair comparison between regions. Based on this variation, we suggested the best scoring 25% of regions as performance standards for each indicator.

We found that of those dying from COPD in 2015 in Belgium, 60.0% was admitted to hospital at least once during the last 30 days of life and 11.8% received specialized palliative care at least once during the last 2 years of life. Controlling for differences in relevant socio-economic and demographic variables available in our linked administrative database, we found large risk-adjusted regional variation in provision of specialized palliative care (4.0% to 32.0%) and in being submitted to diagnostic testing at least once within the last 30 days of life (44.0% to 69.7%). This suggests there is room for improvement to increase the use of specialized palliative care and reduce the use of diagnostic testing (among others) in people with COPD in Flanders and Brussels. As an example, we suggest the relative

standard for diagnostic testing at this moment to be at maximum 54.9 percent for all health care regions in Flanders and Brussels. We also suggest at least 23.3 percent of all people dying from COPD receive specialist palliative care. These standards are currently achieved by 25% of health care regions and can therefore be regarded as realistic and attainable performance standards. As practice evolves and indicators are remeasured, the suggested standards can evolve accordingly.

### 3.3 Dying with dementia

We measured all indicators developed for people with dementia in all 10,629 people who died with dementia in Belgium in 2015. On average, they had 1.83 contacts with a family physician in the last week before death and 68.4 percent died at home or in the nursing home where they lived for at least 6 months.

Relatively high percentages of people with dementia underwent diagnostic testing (36.3 percent) or emergency department (ED) admissions (25.6 percent) in the last 30 days before they died. 32.4 percent were admitted to hospital at least once in the last 30 days of their life and 25.1 percent died in the hospital. As with the indicators for people with COPD, we compared risk adjusted regional differences between 14 health regions in Flanders and Brussels and found substantial variation: emergency department visits varied between 19 and 31 percent, dispensing of gastric protectors between 18 and 42 percent, and anti-hypertensives between 40 and 53 percent across health care regions. This led us to suggest there are major opportunities to increase the appropriateness of end-of-life care in people with dementia, especially by reducing possibly harmful or

unnecessary medication use and hospital transitions. For example, we suggest the percentage of people to receive anti-hypertensives to be reduced to be below 46 percent of all people with dementia.

#### 4. Trends

We also measured trends in all developed indicators for appropriate or inappropriate end-of-life care, across all three populations (people dying from cancer, from COPD or with dementia) from 2010 until 2015. We measured all indicators at 30 days before death, unless they were only validated for the last 14 days or when timing was irrelevant. Although six years is a relatively short period to study trends, we found more fluctuation in indicator scores than expected.

We first compared the difference in all indicators between 2015 and 2010. Four trends occur across all three pathology groups indicating both trends towards more appropriateness and more inappropriateness: 1) a major increase in the percentage of people who had an increased contact with a family physician closer towards the end of life, (+32.51 percent in people with dementia), 2) an increase in people who received specialist palliative care, coupled with 3) a larger proportion of palliative care initiated only in the last 14 days, and 4) an increase in the percentage of people who were admitted to an emergency department in the last 30 days before they died. Several other important indicators of inappropriate end-of-life care, such as diagnostic testing, surgery, hospital admission, and hospital death remained largely unchanged between 2010 and 2015.

In addition, for people with cancer specifically, the percentage of people who in the last 30 days of life had a multidisciplinary oncology consult (+1.80 percent) and people who received specialist palliative care (+2.47 percent) increased, while the percentage receiving chemotherapy decreased (-1.02 percent). Some indicators, especially those within the hospital setting, suggest appropriateness of end-of-life care is increasing, however possibly inappropriate care transitions increased as well.

For people who died from COPD, in addition to the general trends, the percentage of people receiving continuous (-1.36) or repeated intubation (-1.23 percent) decreased. More people received opioids (+2.31 percent), but at the same time a higher percentage of people with COPD was admitted to the intensive care unit (+1.60 percent). This suggests that, as in people dying from cancer, appropriateness of end-of-life COPD care within hospital settings is increasing, but possibly avoidable transitions towards hospitals are also becoming more prevalent.

Lastly, in people with dementia specifically, a higher percentage received possibly inappropriate medication in 2015 than in 2010, such as Novel Oral Anticoagulants or vitamin-K antagonists, (+3.16 percent), gastric protectors (+5.01 percent) or calcium with vitamin D (+2.27 percent).



## 5. Methodological strengths and limitations

### 5.1 Strengths

#### 5.1.1 Using the RAND/UCLA appropriateness method<sup>12</sup> to develop new indicators

To develop the three sets of quality indicators, we supplemented existing indicators from literature with interviews with relevant experts and validated these using a RAND/UCLA appropriateness method of expert consultation. This increases the scope of the quality indicators developed beyond what is currently known in the literature. End-of-life care research and palliative care have mainly been focused on people with cancer so far.<sup>13-15</sup> This leaves scientific research and knowledge on care for other populations, such as people with COPD or dementia, underdeveloped. However in practice, pulmonologists, geriatricians, neurologists, palliative care specialists, family physicians and nurses in all settings, including nursing homes, provide end-of-life care for these patients groups on a daily basis and thus have practical knowledge. The interviews and expert panels with experts from all of the above disciplines, including doctors and nurses, served to include this practical knowledge. It is a strength of our study that we tapped into this potential, to fill a gap in the current state of end-of-life care literature.

#### 5.1.2 Routinely collected data to study vulnerable populations

Linking a selection of administrative databases resulted in a population-level database with detailed data on end-of-life health

care use, as well as necessary demographic, socio-economic and diagnostic information.<sup>16</sup> Using routinely collected data is a non-invasive method of data collection. We obtained detailed health care information, without overburdening patients, which is especially relevant near the end of life.<sup>17-19</sup>

Using routinely collected data also means we have a dataset covering (almost) the full Belgian population of decedents in specific years. Our dataset therefore also includes populations that may be difficult to reach with other methods, such as people with cognitive impairment (e.g. people with dementia) or people with a socio-economic and ethnic background different than the researchers.<sup>20-22</sup> Other research might often suffer from issues adapting data collection methods for these populations (e.g. translations and cognitive testing of questionnaires) or selection bias, where our data collection method includes the Belgian population without discrimination.

## 5.2 Limitations

### 5.2.1 Developing indicators with input from current practice

One of the main goals of developing and measuring quality indicators is that they may reveal discrepancies between health care practice on a population level and government policy goals.<sup>23</sup> They can also uncover possible inequities in provision of appropriate end-of-life care and pinpoint underlying factors explaining unwanted differences between subpopulations.<sup>24</sup> However, in our research, the quality indicator development process relies heavily on the input of experts in interviews, because literature search yields limited quality indicator

results. Evidence on possibly unfavorable effects on patients quality of life in an end-of-life care context is missing for most treatments. Expert knowledge is regarded as the lowest level of evidence.<sup>25</sup> We performed no validation of the quality indicator sets outside the health system, for example by including patients receiving end-of-life care or their families in the expert panels. One could argue that the experts can be biased towards a positive evaluation of current end-of-life care practice. It would not be unthinkable that experts, when asked to identify indicators for appropriate care, might stay close to their current standard practice. Their expertise might hinder them in identifying what could be more appropriate than what is currently occurring. We partly mitigated this by including experts from a wide range of specialties, with different perspectives on current practice, from oncologists and pulmonologists to family physicians and palliative care specialists.<sup>12</sup>

We argue that identifying current best and worst practices as indicators of appropriateness end-of-life care is the best place to start to move towards more appropriate end-of-life care. As such, it is essential that the quality indicator sets developed in this research project are regularly updated to reflect the current state of appropriateness of end-of-life care.

One could also comment that patient and relative perspectives on appropriateness of care should be included in the indicator development process. We opted not to include them for one main reason: developing indicators to be measured on a population level requires a broad perspective on appropriateness of end-of-life care. The indicators do not take patient preferences into account. Treatment

measured in a population-level indicator of inappropriate end-of-life care might be appropriate end-of-life care in a specific patient's situation and corresponding to patient preferences. Identifying and evaluating population-level indicators requires making abstraction of the individual patient's situation and knowledge of current standard health care. Therefore, we did not include patients or relatives in the quality indicator development process.

#### 5.2.2 Limitations specific to the selected administrative databases

Administrative data are routinely collected and the databases are structured to cater to administrative needs, not research purposes. Additionally, they may lack essential information to answer specific research questions, e.g. certain socio-demographic or diagnostic data that may be most relevant in end-of-life care research. In our specific situation, healthcare data, socio-demographic data and clinical data are stored in separate databases, owned by different organizations. Selecting, linking, processing and interpreting available data correctly to answer research questions they were not designed to answer can prove a challenge. It is key to identify the strengths and weaknesses of each database and use them accordingly.

We partly compensate for these individual limitations by linking the databases and thereby increasing the different types of data available. Still, some of the database characteristics limited our research. The Belgian Cancer Registry provides us with excellent data on every cancer incidence in Belgium, including diagnostic and patient details otherwise unavailable.<sup>8</sup> Its main limitation is that it contains

data on people with cancer only, leaving us to other methods to identify those dying from COPD or with dementia. The Statistics Belgium databases contain a host of valuable socio-demographic and economic variables.<sup>9</sup> However, some of them date back to 2001 and might therefore fail to capture upward social mobility of individuals since that time and some variables, such as net taxable income, are less relevant in an elderly population and therefore less relevant in the end-of-life care context. The death certificate data allow us to identify people who died from cancer, COPD or with dementia. Some causes of death, such as dementia, are on average underreported, especially in people suffering from multiple life-limiting diseases or general frailty.<sup>26</sup> The IMA health claims data form the core dataset to measure the quality indicators developed in this research project and provide a detailed description of reimbursed health care practice in Belgium.<sup>7</sup> However, it does not contain non-reimbursed health care: experimental studies, such as immunotherapy for people with cancer, other health care not (yet) reimbursed, such as advance care planning (ACP) consultations, over the counter medication, which is provided without prescription, or health care that is not individually reimbursed, such as palliative care in nursing homes. This has repercussions on the measurements of several quality indicators or the interpretation of their results. For example, nursing home palliative care and support by a mobile hospital palliative care team are not included in the indicator on specialist palliative care because they are not reimbursed healthcare actions with a separate registration. This is especially important in people dying with dementia, as many of them reside in nursing homes.<sup>27</sup> Likewise, blood tests are not included in diagnostic testing, because

they are not reimbursed separately and therefore not detectable with IMA health claims data.

Some administrative databases suffer from issues with completeness or accuracy of the data.<sup>28</sup> Long and complicated data collection procedures, multiple data transfers and insufficient use of feedback mechanisms may lead to missing data and errors. However, the Belgian Cancer Registry and the IMA databases have been reported to contain relatively complete and correct data, due to multiple validation processes and internal consistency tests, as well as comparison with databases with different data collection methods.<sup>29,30</sup>

### 5.2.3 Data unavailable in the available administrative databases

An important limitation of our studies is that we did not include data on patient-related outcomes of healthcare services, such as patient's preferences of care, psycho-social information, patient or family reported outcomes<sup>31</sup> and experiences or information about pain and symptom management or communication aspects. In Belgium, a common coding system for PROMs is lacking, so they are not available as administrative data.<sup>32</sup> If they would be available, the patient's preferences could be taken into account when measuring appropriateness and inappropriateness of care. Another limitation of using routinely collected population-level data is that medication, treatment and services not covered by insurers are not included in the datasets. In Belgium, compared to other countries, data are relatively complete, including data on health care in hospital, nursing homes, public pharmacies and home settings. In other countries, this is rarely the case.<sup>3,33,34</sup> Nevertheless the occurrence some services cannot be measured because they are not reimbursed as such (e.g. advance care planning

consultations, palliative care in a nursing home) or are not reimbursed on an individual level (e.g. in-hospital mobile palliative care teams). This limits our scope of quality indicator measurement.

#### 5.2.4 Limitations of a decedent cohort study design

A possible limitation is related to the decedent cohort design of our studies and the population selection. The target population of our studies is all people suffering from cancer, COPD or dementia who approach the end of life and therefore might have shifting care goals, towards comfort and palliative care. A decedent cohort study does not necessarily select this population correctly. We look back from the time of death to include those who died from cancer, from COPD or with dementia. This means we did not include all patients with cancer, COPD or dementia: we excluded those who survived. It has been argued that this is a group that possibly benefited from life-prolonging treatments.<sup>35</sup> Additionally, we included people for whom it may not have been clear they were approaching the end of life. Caregivers do not always recognize imminent death, and accurate prognosis might be difficult to perform.<sup>36-38</sup> A prospective design, including all people at the time of diagnosis of cancer, dementia or COPD and evaluating the appropriateness of care they received prospectively in a specific time period after diagnosis, might provide a more correct study population to evaluate the appropriateness of end-of-life care provided.<sup>35</sup>

However, we argue that at time of diagnosis of cancer, COPD or dementia, the selected population would probably be heterogeneous in functional status. People with dementia are diagnosed in varying

stages of the disease and are often not diagnosed at all.<sup>39,40</sup> In people with cancer, functional status and time between diagnosis and death vary with cancer type.<sup>37,41</sup> A population of deceased sharing the same cause of death is likely to be more functionally homogenous in the weeks prior to death than people who receive the same diagnosis. As such, due to functional homogeneity of the population, indicators of appropriateness of care would be more generalizable and reliable. We also argue that efforts made to identify imminent death and communicating this prognosis to the patient, are signs of appropriate care. Not identifying or communicating imminent death in a timely manner, could be an indicator of inappropriate end-of-life care. As such, when measuring the appropriateness of end-of-life care, we do not want accurate prognosis to be a selection criterion for the population, as this would exclude people who are possibly receiving inappropriate end-of-life care. For these reasons, we believe the decedent cohort population selection to be appropriate to answer our current research questions.

#### 5.2.5 Evaluating the health system from within

We used data generated by the health system itself to evaluate its performance. With these data, it was impossible to measure aspects of health care that are not registered by the system, but are nonetheless essential to evaluate appropriateness of end-of-life care. For example, when measuring the percentage of people receiving specialist palliative care, we include hospital based palliative care, palliative day-care centers and palliative home care. Palliative care provided by a family physician or by nursing home staff are not registered, as



they are not reimbursed. This limitation of our study also pinpoints limitations of the health system itself. Currently family physicians, nursing homes staff, psychologists and physiotherapists, among others, have no reimbursement options specifically for palliative care. However, such reimbursement could be an opportunity for policy to direct practice. We will discuss this in further detail below.

## 6. Discussion of the findings

### 6.1 Scientific relevance of the indicators

Our developed indicator set for people with cancer has recently been included in a systematic review, performing an assessment of acceptability, evidence base, definition, feasibility, reliability and validity of population-based indicators for end-of-life care in people with cancer.<sup>42</sup> The authors of the systematic review selected a total of 15 indicators recommended for use, 13 of which were also included in this dissertation, (QI of inappropriate care: chemotherapy use, hospitalization, emergency department admission, intensive care unit admission, diagnostic testing, tube or intravenous feeding (excluding people with gastro-intestinal cancer), port-a-cath installment or surgery close to death; QI of appropriate care: palliative care provision, GP contact, neuropathic medication provision or opioid use close to death, dying at home). Some of the selected QIs were with different wording or other measurement specifics. Several of these indicators for people with cancer were also measured in other studies prior to our research, for instance, in the US and Canada.<sup>3,4</sup> We also developed several indicators that are probably not measurable with data available in most other countries at the moment. (e.g. multidisciplinary oncological consultations, or government support for palliative care)

The indicator sets for people with COPD or dementia are entirely new developments. To our knowledge, similar quality indicator sets have not been developed up to this point. Research on appropriateness of end-of-life care in people with dementia or COPD is lacking in general. However, a Swedish study recently compared end-of-life care in people

with dementia with people with cancer, using indicators not measurable with our current dataset.<sup>43</sup> They used an existing questionnaire developed by the Swedish Register of Palliative Care<sup>44</sup>, based on the principles of a good death, proposed by the British Geriatrics Society<sup>45</sup>. As such, our development process combining literature review, expert interviews and expert evaluation is novel and scientifically rigorous. Further validation of the developed indicator sets in a national and international context is recommended, through repeated measurement and testing of acceptance of indicators with relevant experts.

Based on our own measurements, a few indicators have proven to be less relevant for future assessments of appropriateness of end-of-life care, either because they are not measurable with currently available data or they occur in very low percentages of the population. The indicator sets were developed with administrative data to measure them in mind. However, since we had little a priori experience with the available administrative data at the time of the indicator development, we misjudged the availability of or possibilities with the specific data. Therefore, these could not be measured with the linked dataset: blood tests as part of diagnostic testing, starting a new chemotherapy treatment line, receiving anti-emetics with chemotherapy, receiving radiotherapy for patients with bone metastases and receiving radiotherapy for patients with small cell lung cancer.

Several indicators did not have enough discriminative power: their results were close to 0 across the population, so they are not meaningful indicators of appropriateness or inappropriateness of end-of-life care<sup>46,47</sup>: receiving tube feeding or intravenous feeding,

receiving cisplatin in people age 80 and older, installment of a port-a-cath, reanimation in people with dementia and a neurologist consultation.

All other developed indicators were measurable with available data and had sufficient variation in results. According to literature, quality indicators should also be clinically relevant, manageable and based on existing evidence or consensus.<sup>47,48</sup> The rigorous indicator development process, based on evidence when possible, complemented and validated by relevant clinical expert knowledge, demonstrates our quality indicator sets meet these requirements.

## 6.2 Determining standards and setting goals for quality improvement

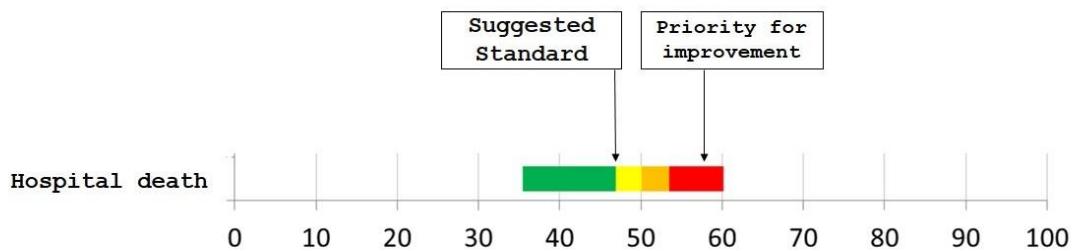
The quality indicators developed and measured in this research project aim to assess the performance of the Belgian health care system in terms of appropriateness of end-of-life care. They can be used to answer policy questions and to be a first step towards improvement of the quality of end-of-life care.<sup>49</sup> The second step would be comparing the results to a standard and setting goals. As explained in the introduction of this dissertation, interpreting quality indicator results correctly can only be done through comparison with standards.<sup>3,49,50</sup> Standards represent the preferred value for each indicator and can be derived from a variety of sources. We have suggested data-driven relative standards based on the measurement results. Through comparison between health care regions in Flanders and Brussels we have determined data-based standards.

When comparing regions, or other subpopulations, (e.g. people dying in different years, as we did in chapter 7) it is important that differences found between these subpopulations can be attributed to actual differences in quality or appropriateness of end-of-life care.<sup>51,52</sup> Possible confounding factors might influence the end-of-life care provided and can vary between subpopulations, but are not indicators of the appropriateness of care provided.<sup>51,53,54</sup> To ensure correct attribution, we controlled for a number of confounding variables. We selected age, gender, highest attained level of education, net taxable income, household composition (e.g. married, single, with or without children, in a nursing home), being officially recognized as having high care needs, being entitled to a higher degree of reimbursement due to lower degree of self-reliance, and degree of urbanization of the municipality of residence. Supplementary tables S.11 and S.12 show the logistic regression model used for each quality indicator, with odds ratios and area under the curve. Other relevant confounders might be patient preferences, cultural background of the patient, the involvement of informal caregivers, or others. However, those are not currently measurable with available administrative data. Based on previous research<sup>16,52,53</sup>, we assume the confounders we were able to use cover the majority of individual differences that may have an influence on end-of-life care provision. However, in future research other possible confounders may be added, when available.

When comparing subpopulations on quality indicators scores, controlling for confounding variables, the population can be divided into best and worst performers and standards can be set. In our example, we divided the population in four groups defined by quartiles, from worst performers (worst 25%: improvement should be a priority),

to sub-median (improvement is necessary and feasible), to above the median (improvement is possible) and best performers (top 25%), who score above the standard. This could be indicated by colors or otherwise. (Figure 1)

**Figure 1: Suggested relative standards for hospital death in people dying from COPD**

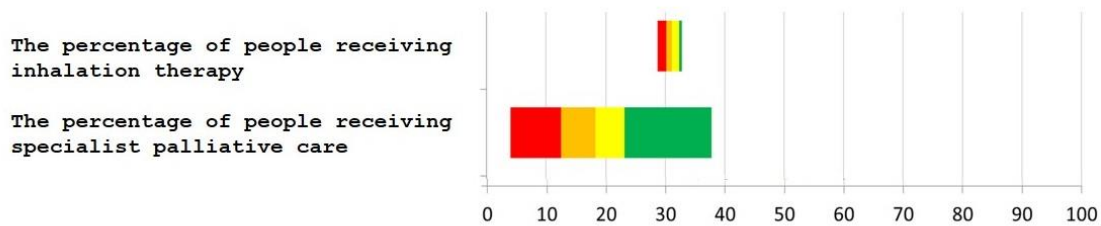


We compared health care regions to suggest standards, which are based on natural health care flow towards major hospitals. We could also compare primary care regions, nursing homes, administrative regions ('arrondissementen') or specific communities, such as towns or cities, depending on what is the relevant level to evaluate. In each of these examples, relative standards can be set, e.g. at the best scoring quartile, to guide quality improvement.

Variation between regions or other subpopulations can also be used to identify indicators that present the most opportunities for improvement. Some quality indicators will have more variation between regions than others, indicating there is a larger gap between better and worse performing regions. These indicators can be a priority for improvement, since some regions are clearly underperforming to what is possible in the current health care context. As an example, (figure 2) for people dying from COPD, there is more variation in people receiving specialist palliative care than in people receiving

inhalation therapy between regions. Therefore, specialist palliative care could be a priority target for improving appropriateness of end-of-life care for people with COPD.

**Figure 2: Using variation between subpopulations to identify indicators that present the most opportunities for improvement**



Another way to use quality indicators for quality improvement, apart from setting relative standards, is to evaluate the effect of interventions or policy.<sup>55,56</sup> For example, we could perform an intervention in 7 out of 14 health regions and perform pre- and post-measurements of an indicator set. Improving indicators scores in intervention regions more than in non-intervention regions, could mean, after risk adjustment, that the intervention is successful. Also, a selection of indicators can be focused on instead of using the full quality indicator sets.

### 6.2.1 Goals for improvement of end-of-life care for people dying from cancer

Earle et al. developed a standard for chemotherapy use in the last fourteen days of life at 10.0 percent or less of the population dying from cancer.<sup>3</sup> We found percentages lower than this in Belgium (8.6 percent), but we found a higher use of chemotherapy in the last thirty days compared to results from a study in seven other countries.<sup>15</sup> The

percentage of people with cancer who had an admission to the emergency department (ED) in the last thirty days (33.8 percent) is lower than the percentages reported in Canada (58 percent), the United States (46 percent) and England (48 percent).<sup>57</sup> Our results for specialist palliative care provision in Belgium (47.1 percent) are comparable to the percentage of people receiving palliative home care in Canada (47.3 percent)<sup>58</sup>. In Belgium, 30 percent of people with cancer die at home. This is comparable to Spain (31.6 percent) and England (26.1 percent), but lower than the Netherlands (46.3 percent) and higher than France (19.1 percent) and Canada (16.1 percent).<sup>59</sup> Our trend analysis with data from 2010 until 2015 in Belgium suggests the use of specialist palliative care is rising, as well as GP contacts. However, the percentage of people being admitted to an emergency department is also rising, and the rise of specialist palliative care is mainly limited to the last 14 days of life.

Assessment of the variation of indicators for people dying from cancer across regions would provide us with valuable information to identify priorities for improvement. However, based on the information currently available, we would argue the main challenges for appropriateness of end-of-life care in Belgium for people with cancer would be the consolidation of continuity of care, reducing the percentages of people being admitted to ED, ICU or hospital in the last weeks of their life, and to prevent hospital death whenever this is congruent with the patients' wishes.



### 6.2.2 Goals for improvement of end-of-life care for people dying from COPD

For people with COPD, we found large variations between health care regions for a large number of indicators, even after controlling for various possible confounders. This leads us to the assumption that appropriate end-of-life care for people dying from COPD is far from established as standard practice in Belgium. It also means that in some regions, end-of-life care for people with COPD is better developed, as they are ahead of what is considered standard practice in other regions.

The main areas of possible improvement identified by the COPD quality indicator results are<sup>1</sup>: increasing the use of specialized palliative care (variation between 4 to 38 percent) and death at home (between 7 and 33 percent), while decreasing diagnostic testing (between 44 and 70 percent), ED admission (between 18 and 42 percent) and hospital death (between 35 and 60 percent). The main domains represented in these quality indicators are the provision of palliative care and continuity of care. In some regions, provision of specialist palliative care is considerably lower and in some regions transitions to emergency departments and death at the hospital are much more frequent. We suggest these to be the main targets for those who seek to improve appropriateness of end-of-life care for people with COPD. This is reinforced by the results of our trend analysis, that suggest that transitions towards hospitals were increasingly prevalent between 2010 and 2015. As some regions are performing better than others, we

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<sup>1</sup> All indicator percentages mentioned here are measured in the last 30 days before death, when timing is relevant.

suggest strengthening inter-region consultation to share best practices. This would be a nationwide effort, whereby the regional Belgian governments take the initiative to include all relevant stakeholders for each region, including palliative care networks, home care services, general practitioners, hospital wards treating people with COPD and universities, to discuss how appropriateness of end-of-life care for people with COPD can be improved and what can be learned from practices and improvement initiatives in other regions.<sup>60</sup>

### 6.2.3 Goals for improvement of end-of-life care for people dying with dementia

For people with dementia, we found less variation than for people with COPD in general and especially little variation in quality indicators of appropriateness of end-of-life care. This could mean that, based on our results, there is a well-established standard practice for end-of-life care for people with dementia in Belgium. Whether this standard practice is at a desired level of quality of care, requires other non-data driven standards to evaluate.

The main areas of possible improvement based on variation in the quality indicator results are<sup>2</sup>: decreasing diagnostic testing (between 21 and 35 percent), ED admission (between 10 and 25 percent), dispensation of gastric protectors (between 21 and 30 percent), and anti-hypertensives (between 37 and 49 percent). High variation in ED admissions can be linked to continuity of care, increased use of gastric protectors and anti-hypertensives has been associated with the

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<sup>2</sup>All indicator percentages mentioned here are measured in the last 30 days before death, when timing is relevant.

occurrence of poly medication.<sup>61</sup> Our results therefore suggest improving continuity of care and reducing poly medication in people with dementia. This is reinforced by the results of the trend analysis that suggest an increasingly high percentage of people dying with dementia received possibly inappropriate medication, such as gastric protectors or Novel Oral Anticoagulants or vitamin-K antagonists.

Possible interventions to improve the continuity in end-of-life care for people with dementia could focus on enhancing palliative care capabilities of nursing homes (staff training<sup>62-64</sup> and equipment<sup>65</sup>), as well as increasing advance care planning and the execution of those plans in cases of emergency<sup>66,67</sup>. (e.g. discussing with residents whether they want to be taken to the intensive care unit in case of severe pneumonia and making sure all caregivers are aware of their preferences)

## 7. Implications and recommendations

### 7.1 Implications and recommendations for practice

#### *Using quality indicators*

Our indicators identify what is generally considered appropriate or inappropriate end-of-life care in people dying from cancer, from COPD or with dementia. As we worked closely together with end-of-life care practitioners from a variety of medical specialties to develop and validate the quality indicators in a consensus procedure<sup>12</sup>, we hope they find the results both acceptable and inspiring to improve appropriateness of end-of-life care. As we discussed in the limitations section, this probably introduced a bias towards current practice as appropriate care. However, when our quality indicator results are used to improve practice, they might be more recognizable and acceptable by health care professionals. For any quality improvement effort, acceptance and relevance of measurement results are prerequisites for effective quality improvement.

With repeated quality measurements, goal setting and improvement efforts, practitioners can integrate the quality indicator sets in a plan-do-check-act (PDCA) cycle for quality improvement. The PDCA cycle is a commonly used instrument to work towards organizational development.<sup>68</sup> As the title suggests, it consists of four steps: (1) Plan, identifying change goals and what is necessary to achieve them, (2) Do, executing the plan from the first step, (3) Check, to compare the results with the original goals and lastly, (4) Act, readjustment of the execution to achieve the goals. The main goals of employing a PDCA cycle in organizational change is to ensure the continuous

engagement of all those involved in the improvement process.<sup>69</sup> Quality indicators can be used to identify improvement priorities in the Plan-step, as well as evaluate the results in the Check-step. This requires repeated measurements of the quality indicators. When the cycle is repeated, new goals can be selected over time, when improvement is satisfying. As such, the developed indicator sets can directly be used as a tool for quality improvement on a health care provider level. Locally available data can be used to measure the quality indicator sets, or a selection of indicators. For example: a group of nursing homes could measure several indicators for people with dementia, e.g. hospital admissions from their nursing home or provision of specific medication such as gastric protectors. The indicator scores can then be compared between nursing homes of the same group, to give them feedback on the appropriateness of end-of-life care provided in their institution.

#### *Suggestions to improve appropriateness of end-of-life care*

Based on our findings, we can also make some specific suggestions for end-of-life care practitioners.

First, we suggest to make extra efforts to initiate advance care planning with all patients who approach the end of life. This is relevant for all practitioners: general practitioners could initiate care planning conversations with their patients<sup>70,71</sup>, nursing homes could have clear procedures to initiate advance care planning with every resident<sup>66</sup>, specialists (oncologists, pneumologists, geriatricians,...) could initiate advance care planning conversations, or they could take the initiative to inform the general practitioner when they suspect the end of life is approaching for one of their

patients. An increasing number of patients reflecting on and discussing their preferences for end-of-life care might lower the percentage of several indicators of inappropriate end-of-life care, such as admissions to the ED or ICU or diagnostic testing near the end of life, towards the percentage of people who actually want to be admitted or submitted to tests. Linked to this recommendation about more ACP, nursing homes might want to evaluate the training of their staff and the available equipment they have at their disposal to treat residents near the end of life. Limited staff knowledge and experience and lack of equipment (e.g. for adequate in-house pain treatment) have been reported to be among the greatest barriers to installing advance care planning in nursing homes.<sup>65</sup> Additionally, they might evaluate their procedures on advance care planning and the execution of their residents care plans in case of emergency.

Secondly, practitioners caring for people with COPD might consider referring their patients to palliative care more often and earlier.<sup>72</sup> Previous research identified effective triggers for initiating referral to palliative care to be a clear functional decline, such as when the patient becomes oxygen-dependent or housebound, or shortly after recovery from an acute exacerbation.<sup>73,74</sup> However, although the fresh experience of the life-threatening consequences of their disease and the invasive treatment required to deal with them may lead to more patients waiving future aggressive treatment, experts interviewed in our studies reported that exacerbations are extremely distressing, to the extent that many patients request emergency hospital admission, despite earlier expressed wishes to avoid it.

Lastly, general practitioners might need to become better at deprescribing unnecessary medication for their patients with dementia, especially long-term prophylactic medication such as anti-hypertensives, to avoid polymedication.<sup>61,75</sup> We suggest to do this in consultation with the patient and any involved relatives, to avoid resistance.

## 7.2 Implications and recommendations for research

The indicator sets we developed and measured provide several new research opportunities.

First, we suggest to measure them in other countries. Local researchers can use them to evaluate their health care system in term of appropriateness of end-of-life care, as well as set their own relative standards by comparing care regions or other subpopulations. Measurement of the indicators in other countries requires a thorough evaluation of what data are available in the measuring country, as well as what quality indicators can be measured and how they can be assessed. Furthermore, parallel national or regional measurements enable international comparison of health care systems in terms of appropriateness of end-of-life care. Of course, these efforts may be coordinated by an international consortium, to facilitate the construction of common data models, transferability of results and even direct comparison of data. At the moment, administrative databases are structured differently in different countries and data available in one country, might not be available in others. For example, claims data in Belgium include data from all health insurers

and from public pharmacies and hospitals<sup>7</sup>, while in other European countries, there is no central agency (like IMA in Belgium) that collects data from different health insurers. In some countries, public pharmacy data or hospital data are not routinely collected, or not linked to other health data. However currently in many countries, independent researchers and those employed by database administrators have access to routinely collected health data and are using it to evaluate end-of-life.<sup>76</sup>

Secondly, we suggest the indicator sets to be used to evaluate expected changes in the health system, i.e. policy changes or major socio-demographic or economic evolutions. If a government anticipates a change in the health system that may have a direct or indirect effect on the appropriateness of end-of-life care provided, the developed indicator sets can be a tool to evaluate the effects. This requires a thorough investigation of all relevant confounding variables that may play a role, to single out the effect.<sup>53</sup> Controlling for possible confounders can be completed with a difference-in-difference methodology<sup>77</sup>, taking normal changes in the population into account when studying an expected effect. Similarly, the quality indicator sets could be used to evaluate the effectiveness of specific interventions in a trial. If researchers develop an intervention that is expected to improve the appropriateness of end-of-life care, or specific quality indicators, measuring the relevant indicators with routinely collected administrative data can be a cost-effective, non-invasive and less-biased method<sup>17</sup> to perform an experimental (pretest posttest control group) or quasi-experimental (e.g. nonequivalent control group, controlled interrupted time series) design to establish the effect of the intervention. An advantage is that pre-intervention



measurements can even be performed after the trial, with administrative data being routinely collected.

Thirdly, we suggest researchers further validate the developed indicator sets. Currently some of the developed indicators have not been measured elsewhere, especially the indicators for people with COPD or dementia. Some of them are based on expert opinion, validated by expert consensus.<sup>78</sup> We suggest researchers further evaluate the validity of the indicators, investigating whether they are connected to other measurements of appropriateness of end-of-life care or to quality of life related outcomes. This requires experiments or methodologically sound observational studies that clearly show the impact of specific types of care (i.e. the individual outcomes on which the quality indicators are based ) on the quality of care and quality of life near the end of life. For example: does (a higher percentage of people being submitted to) diagnostic testing have a negative impact on patient reported outcome measures<sup>31</sup>?

Lastly, more research effort should be invested in establishing non-relative standards for indicators of appropriate or inappropriate end-of-life care. For some indicators, absolute standards can be developed. For example: we could use knowledge on preferences in the general population to develop standards. The percentage of people who prefer to die at home across the population could be a starting point for an absolute standard for an indicator measuring the percentage of people dying at home. Many indicators are directly related to patient preferences and/or patient reported outcome measures. As such, mapping these preferences across the population could provide us with an indication for absolute standards. As end-of-life care practice

evolves, so should the indicators of appropriate and inappropriate care, as well as the standards for these indicators. The method of relative data-driven standards lends itself to this, as with each measurement of the quality indicators, new standards can be suggested, but we suggest these relative standards to be supplemented with information on patient preferences and patient-reported outcome measures.

### 7.3 Implications and recommendations for policy

We believe the methodological groundwork in this study, as well as the results, could be informative to international and Belgian national and regional policy makers. The developed quality indicator sets can be used to evaluate the appropriateness of end-of-life care, or to describe long term trends in Belgium or any other population, guiding policy decisions, or to develop and help enforce standards for appropriateness of end-of-life care. The results can be used to steer end-of-life care policy, on a disease-specific basis to reduce or increase certain types of care, but also across the population. Based on our limited results and tying in with our recommendations for practice, we suggest investing more in continuity of care and communication near the end of life, to increase advance care planning and avoid possibly inappropriate care transitions. We also suggest supporting nursing homes in training their staff and purchasing the equipment they need in house to treat residents near the end of life. This support can be financial, but also informational by connecting existing meeting platforms (e.g. Zorgnet/Icuro<sup>79</sup>, VVSG<sup>80</sup>, Vlozo<sup>81</sup>) and stimulating them to spread knowledge, training and best practices in

appropriate end-of-life care. Additionally, we suggest to bring together practitioners caring for people with COPD and palliative care specialists, to discuss how palliative care can be initiated sooner and become integrated into standard end-of-life COPD care.<sup>73,82</sup> National and regional governments can play a crucial part in bringing health care providers together to share best end-of-life care practices. Lastly, we suggest policy makers to encourage general practitioners to consider discontinuing unnecessary medication for their patients with dementia. This can be done by raising awareness about polymedication and its negative effects, through existing platforms for general practitioners, such as university faculties for family medicine, Domus Medica<sup>83</sup> or Société Scientifique de Médecine Générale<sup>84</sup>.

#### *Continued evaluation of the health system*

Currently, the website Healthybelgium.be (supported by the Belgian Federal government) publishes a selection of 4 indicators on end-of-life care, with regular updates and trend analyses.<sup>23</sup> They are limited to people with cancer and include the provision of palliative care, timely initiation of palliative care, chemotherapy use near the end of life and dying in the place of usual residence. The website presents these results in a comprehensible way, with adequate information to facilitate interpretation for a broader public. By presenting these results, the website succeeds in both reporting on the performance of the health care system and informing on what is currently deemed appropriate end-of-life care. We recommend to expand these four indicators with the indicators that we developed, not only for people with cancer, but also with indicators for people with COPD or dementia. The indicators could be measured on a yearly basis, with the most

recent available administrative data. These results could be presented on the Healthy Belgium website to inform the public and could be a starting point for discussions on health care priorities for the coming years. Presenting the results on the website would also serve to enhance the public visibility of appropriateness of end-of-life care.

*Targeted reimbursement to improve appropriateness of end-of-life care*

In most previous efforts to improve appropriateness of end-of-life care, the focus has been on the provision and improvement of specific health services, such as developing care pathways, new procedures or innovative treatments to be implemented.<sup>67,85-87</sup> Fortunately, research on how to improve quality of care on a service level increasing a specific metric, such as advance care planning, the use of communication tools or more appropriate pain treatment, is abundant. However, in Belgium and other countries, where citizens are obliged to have health insurance, the government has an enormous impact on what health care is used, through reimbursement.<sup>88,89</sup> While ideally patients and caregivers together decide what care is appropriate in their specific situation, the government creates the financial framework for their decisions. The cost of non-reimbursed medication and treatments is often too high for a majority of patients.<sup>89-91</sup> Reimbursements have a large impact on that cost and thereby determine what care is available and what is considered standard care. Through reimbursement, the government can promote any type of health care by making it affordable. When seeking to reduce possibly inappropriate end-of-life care, (e.g. hospital transitions) policy makers should analyze what options the health care system offers as alternatives to possibly inappropriate end-of-life care. Strategic reimbursement, e.g.

for advance care planning or nursing home palliative care, can be employed to improve the appropriateness of end-of-life care.

The 2017 KCE report on palliative care and end-of-life care mentions a list of determinants and contributing factors that might be directly or indirectly influencing the occurrence of inappropriate end-of-life care.<sup>92</sup> The report divides these into factors related to the health care professionals involved, the patients, the patients' relatives and societal and health care organizational factors. The long list of determinants and contributing factors suggests that no single factor causes appropriate or inappropriate end-of-life care to occur. The end-of-life care context creates a complex situation that health care professionals might not be trained for and where they might feel inexperienced. Patients, relatives and care professionals often suffer from cultural barriers and taboos to talk about death and dying, or their wishes and expectations.<sup>92-95</sup> In this complex situation, the health care system determines what care is available and what care is affordable, and as such defines the boundaries of individuals actions. If we want to improve the appropriateness of end-of-life care, are there any feasible alternatives for possibly inappropriate treatment? For example, if we are to reduce hospital admissions near the end of life, are home care and nursing home care sufficiently developed to guarantee high quality end-of-life care? In cases of emergency, do we have a clear plan of action that avoids unnecessary care transitions? Who is aware of this plan and can it be enforced by the patient or a decision maker in emergency situations? These are not questions for individual patients to solve. Rather, it is the health care system that defines the options from which patients and all care practitioners involved can choose.<sup>96</sup>

When developing our quality indicators and performing the subsequent measurements, we found several important aspects of appropriate end-of-life care that are not measurable using health claims data, because they are not individually reimbursed, or not reimbursed at all. The most impactful examples are palliative care provided in nursing homes and advance care planning consultations. Specific reimbursement for advance care planning would be relevant for nearly all patients near the end of life and their relatives. It would make advance care planning an official part of standard end-of-life care, as proposed by many researches and practitioners.<sup>66,67,97</sup> Through reimbursement, the government could directly influence the quality of care provided and create opportunities for care providers and patients to choose the more appropriate options.

As a general conclusion, we believe the government has the obligation to provide a well-performing health care system, providing high quality and appropriate care for its most vulnerable citizens, especially those at the end of life.

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# **Samenvatting van de belangrijkste bevindingen**

## **1. Context**

### **1.1 Het belang van gepaste levenseindezorg**

De laatste tientallen jaren stijgt de levensverwachting wereldwijd. Er worden ook relatief minder kinderen geboren, waardoor de gemiddelde leeftijd van de bevolking stijgt. Dankzij toegenomen medische kennis en nieuwe medische technologie kunnen veel dodelijke ziekten succesvol worden behandeld. Hedendaagse hygiënemaatregelen bevorderen het succes van medische ingrepen en medische noodingrepen zijn erg effectief. Met die toegenomen effectiviteit, is ook het vertrouwen in de medische wetenschap gegroeid. Nochtans zijn er nog steeds ziekten die niet effectief behandeld kunnen worden, zoals kanker, Chronic Obstructive Pulmonary Disease (COPD) en dementie. Het percentage mensen met een dergelijke levensverkortende aandoening stijgt, naarmate de gemiddelde leeftijd stijgt. Daarom wordt het steeds belangrijker onze gezondheidszorg af te stemmen op mensen met dergelijke levensbedreigende en ongeneeslijke aandoeningen, zodat ook zij gepaste zorg krijgen.

### **1.2 Wat is gepaste levenseindezorg?**

Maar wat is gepaste zorg voor mensen met een levensverkortende aandoening? Om dat te weten, moeten we verwachte voordelen en nadelen van een behandeling tegen elkaar afwegen. Het gezondheidsvoordeel van een behandeling kan bijvoorbeeld toegenomen levensverwachting zijn, of preventie van pijn, of het verhogen van comfort of zelfredzaamheid.

Mogelijke negatieve uitkomsten zijn onder andere de kans op sterven, afname van levenskwaliteit, toegenomen pijn of symptoomlast.

Bij mensen met kanker, COPD of dementie kan in de laatste weken, maanden of jaren van hun leven gepaste zorg verschuiven van louter levensverlengende zorg naar meer aandacht voor comfortzorg en palliatieve zorg. Palliatieve zorg is vooral gericht op levenskwaliteit, symptoombestrijding en existentiële zorg, in combinatie met levensverlengende behandelingen. Ook rouwzorg en zorg voor mantelzorgers maken er deel van uit. Agressieve levensverlengende behandelingen die de levenskwaliteit sterk verlagen (bijvoorbeeld plotse ziekenhuisopname, chemotherapie of chirurgie kort voor het overlijden) kunnen in dat geval ongepast zijn. Om gepaste zorg te verlenen is het bovendien belangrijk dat palliatieve zorg op tijd gestart wordt en dat de zorg gepland wordt volgens de wensen van de patiënt.

Gepaste en ongepaste zorg bij het levenseinde wordt een steeds belangrijker onderwerp in de Belgische en internationale gezondheidsliteratuur. In 2017 publiceerde het Federaal Kenniscentrum voor de Gezondheidszorg een rapport dat een grote bezorgdheid uitdrukt voor ongepaste levenseindezorg in België. Uit dit rapport bleek dat mensen met levensverkortende aandoeningen in België vaak behandelingen en medicatie krijgen waarvan de positieve effecten de negatieve effecten niet overstijgen. Dit is een bezorgdheid die ook internationaal weerklank vindt. Meer en meer groeit de consensus dat er te vaak agressieve of futiele zorg wordt geboden en te weinig palliatieve zorg aan mensen met levensverkortende aandoeningen.

### **1.3 Gepaste zorg en het gezondheidszorgsysteem**

Als we de gepastheid van zorg aan het levenseinde willen bestuderen, kijken we eerst en vooral naar het gezondheidszorgsysteem in België en welke zorg door dat systeem wordt aangeboden. De context van het gezondheidszorgsysteem bepaalt immers welke behandelingen beschikbaar zijn. In België is een ziekteverzekering verplicht. Terugbetaling door de ziekteverzekering dekt een groot deel van de medische kosten van alle Belgen. Op die manier bepaalt het Rijksinstituut voor Ziekte en Invaliditeitsuitkering (RIZIV) in sterke mate welke zorg aangeboden wordt door die zorg betaalbaar te maken.

Bovendien registreren de ziekenfondsen alle terugbetalingen die ze doen en geven ze deze informatie door aan een centraal agentschap: het Intermutualistisch Agentschap (IMA). Bij elke terugbetaling wordt bijgehouden door wie ze werd voorgeschreven, wie de patiënt was, hoe oud de patiënt was, waar die woonde en nog een heel aantal andere gegevens over de patiënt en de voorschrijver. Als we toegang kunnen krijgen tot deze data, krijgen we een scherp beeld van welke levenseindezorg wordt geleverd in België op niveau van de volledige populatie.

### **1.4 Kwaliteitsindicatoren**

Hoe weten we welke levenseindezorg gepast is voor mensen met kanker, COPD of dementie? Daarvoor kunnen we gebruik maken van kwaliteitsindicatoren. Kwaliteitsindicatoren zijn 'goed gedefinieerde en meetbare aspecten van de zorg'. Ze worden in veel contexten gebruikt om kwaliteit te meten. Een voorbeeld in onze context is: "Het



percentage van de mensen met kanker, die chirurgie ondergingen in de laatste 30 dagen voor hun overlijden". Zoals blijkt uit het voorbeeld bestaat een goede kwaliteitsindicator uit **(1) een teller:** 'het aantal mensen die chirurgie ondergingen', **(2) een noemer:** 'alle mensen die stierven aan kanker' en **(3) een specificatie over wanneer te meten,** in dit geval: de laatste 30 dagen voor overlijden. Dit laatste is niet bij alle indicatoren van toepassing.

Het gaat hier om indicatoren op populatieniveau (bijvoorbeeld geldig voor alle mensen die stierven aan kanker in België), eerder dan een indicator van kwaliteitsvolle zorg op individueel niveau (van één patiënt). Dit betekent ook dat een behandeling voor een individuele patiënt gepast kan zijn (bijvoorbeeld chirurgie in de laatste 30 dagen als pijnbestrijding); maar tegelijk een teken van ongepaste levenseindezorg wanneer het bij te veel mensen voorkomt. Dat werpt onmiddellijk de volgende vraag op: wat is 'te veel voorkomen'? Hoe hoog mag een indicator van ongepaste zorg maximum zijn? Het doel is immers niet 0 procent, want bij sommige mensen is de behandeling nog steeds gepast.

Om die afweging te maken hebben we een vergelijkingsbasis of standaard nodig. Een dergelijke standaard kan op verschillende manieren bepaald worden, bijvoorbeeld vastgelegd door experts en/of beleidsmakers, of gebaseerd zijn op huidige metingen van de praktijk. In dit onderzoek kiezen we ervoor om de vastgestelde indicatorscores te vergelijken tussen verschillende regio's en op basis van die vergelijking een standaard op te stellen. Dit doen we bijvoorbeeld op het niveau van de best scorende regio's. Zo komen we uiteindelijk tot een evaluatie van gepastheid van levenseindezorg in België.

## **1.5 Doelstellingen en onderzoeksvragen**

**Het hoofddoel van dit onderzoek** is het evalueren van het Belgische gezondheidszorgsysteem in termen van gepastheid van levenseindezorg bij mensen met dementie, COPD of kanker. Om dat te bereiken hebben we vier doelen:

1. Indicatoren van gepaste en ongepaste levenseindezorg ontwikkelen voor mensen met kanker, COPD of dementie.
2. Gegevens identificeren en gebruiken die deze indicatoren kunnen meten voor de volledige Belgische bevolking.
3. De ontwikkelde indicatoren meten met de beschikbare gegevens. Daarbij proberen we ook te kijken welke factoren de indicatorscores beïnvloeden, om daarmee rekening houdend standaarden te ontwikkelen.
4. Trends beschrijven in de gepastheid van levenseindezorg tussen 2010 en 2015 in België.

## **2. Ontwikkeling van de kwaliteitsindicatoren**

We ontwikkelden drie sets kwaliteitsindicatoren: één voor mensen met kanker, één voor mensen met COPD en één voor mensen met dementie. Het ontwikkelingsproces kende drie stappen:

1. Bestaande indicatoren identificeren in de literatuur;
2. Interviews met relevante experts om bijkomende indicatoren te identificeren;

3. Expertpanels om alle kandidaat-indicatoren te evalueren en de finale sets indicatoren samen te stellen.

We betrokken relevante experts van uiteenlopende disciplines, o.a. huisartsen, pneumologen, neurologen, radiologen, oncologen en palliatieve zorgspecialisten. Zowel verpleegkundigen als artsen zetelden in de panels.

De finale beslissing tot het selecteren van een indicator gebeurde steeds in consensus, volgens de RAND-UCLA Appropriateness Method. We selecteerden enkel indicatoren die gemeten kunnen worden op populatieniveau in België met ziekteverzekeringsgegevens, dit betekent dat we beperkt zijn tot terugbetaalde behandelingen en medicatie. Dit betekent dat een aantal belangrijke aspecten niet worden opgenomen als indicator, waaronder communicatie tussen arts en patiënt, palliatieve zorg door de huisarts of in een woonzorgcentrum en zorgplanning, aangezien deze niet expliciet worden terugbetaald door de ziekteverzekering.

Uiteindelijk werden 26 indicatoren geselecteerd voor mensen met kanker, 28 voor mensen met COPD en 28 voor mensen met dementie. De indicatoren werden ingedeeld in vijf inhoudelijke domeinen: agressieve zorg, pijn en symptoom behandeling, palliatieve zorg, plaats van verzorging en overlijden, en coördinatie en continuïteit van zorg. Volgende tabel bevat van elke indicatorenset twee voorbeelden.

	Indicator van <b>gepaste</b> levenseindezorg	Indicator van <b>ongepaste</b> levenseindezorg
Voor mensen met <b>kanker</b>	Het percentage mensen met een toename in huisartscontact de laatste maand voor overlijden	Het percentage mensen die chemotherapie kregen in de laatste week voor overlijden
Voor mensen met <b>COPD</b>	Het percentage mensen die opioïden kregen toegediend in de laatste 3 maanden voor overlijden	Het percentage mensen die gereanimeerd werden na een intubatie tijdens de laatste week voor overlijden
Voor mensen met <b>dementie</b>	Het percentage mensen die thuis overleden of in het woonzorgcentrum waar ze voordien woonden	Het percentage mensen die diagnostische testen onderging de laatste week voor overlijden

De details van alle indicatoren, met een uitleg waarom ze een teken zijn van gepaste of ongepaste levenseindezorg, vindt u in de appendix, Supplementary material S.1 (voor kanker), Supplementary material S.2 (voor COPD) en Supplementary material S.3 (voor dementie).

### **3. Selectie van administratieve gegevens**

Gegevens over gezondheidszorg op populatieniveau zijn in België beschikbaar via het Intermutualistisch Agentschap (IMA). Deze gegevens laten ons toe behandelingen en medicatie in kaart te brengen en zo de kwaliteitsindicatoren te meten.

Bovendien kunnen we de gegevens van het IMA linken aan gegevens van het Kankerregister en van Statistics Belgium, die beide ook op nationaal niveau gegevens verzamelen. In ons onderzoek hebben we dit gedaan en zo beschikken we niet alleen over gegevens over alle terugbetaalde behandelingen en medicatie, met informatie over waar en door wie ze verstrekt werden, maar ook over ziekenhuisbezoeken, kankerdiagnoses, doodsoorzaken en een groot aantal socio-demografische variabelen, zoals leeftijd, geslacht, gezinssamenstelling, woonsituatie, opleidingsniveau en belastbaar inkomen; die door het Kankerregister en Statistics Belgium verzameld worden. Voor het verbinden van de databanken en het gebruik van de gegevens werd goedkeuring verkregen van het Nationale Comité ter bescherming van de Persoonlijke Levenssfeer.

Niettemin ontbreken er nog een aantal soorten gegevens die relevant kunnen zijn voor gepastheid van levenseindezorg, onder andere gegevens over voorkeuren van patiënten, informatie over arts-patiënt communicatie en zorgplanning. We moeten er bij de interpretatie van onze resultaten rekening mee houden dat we niet over die informatie beschikken.

## **4. Indicator metingen**

### **4.1 Gepaste zorg voor mensen met kanker**

We maten de kwaliteitsindicatoren voor mensen met kanker bij alle mensen overleden aan kanker in België in 2012, in totaal 26.464 mensen. In vergelijking met andere landen vonden we in België minder mensen die thuis sterven (29.5 procent van alle overledenen met kanker), of

gespecialiseerde palliatieve zorg krijgen, (47.1 procent van alle overledenen met kanker) beide indicatoren van gepaste levenseindezorg. De resultaten suggereren ook dat relatief veel mensen chemotherapie wordt gegeven (17.2 procent in de laatste 30 dagen voor overlijden), een teken van agressieve levenseindezorg. We merken dat leeftijd een belangrijke rol speelt: jongere mensen scoren hoger op indicatoren van zowel gepaste als ongepaste zorg: ze krijgen meer zorg in het algemeen. Het gewest blijkt ook een rol te spelen: mensen in Wallonië en Brussel krijgen vaker ziekenhuiszorg en minder vaak gepaste comfortzorg en palliatieve zorg.

#### **4.2 Gepaste zorg voor mensen met COPD**

We maten alle indicatoren voor mensen met COPD bij alle mensen overleden met COPD in België in 2015, in totaal 4.231 mensen. Van hen werden relatief veel mensen gehospitaliseerd in de laatste 30 dagen voor overlijden (60.0 procent) en relatief weinig mensen overleden met COPD kregen gespecialiseerde palliatieve zorg (11.8 procent). Dit duidt op relatief ongepaste levenseindezorg. We onderzochten ook de verschillen tussen 14 gezondheidsregio's in Vlaanderen en Brussel en vonden grote variatie tussen regio's, vooral op vlak van gespecialiseerde palliatieve zorg (4.0 - 32.0 procent) en het ondergaan van diagnostische testen (44.0 - 69.7 procent) Dit suggereert dat er veel ruimte is voor verbetering voor gepaste levenseindezorg voor mensen met COPD. Op basis van onze resultaten stellen we voor als doelstelling dat minstens 23.3 procent van de mensen met COPD gespecialiseerde palliatieve zorg zouden moeten krijgen.

### **4.3 Gepaste zorg voor mensen met dementie**

We maten alle indicatoren voor mensen met dementie bij alle mensen overleden met dementie in België in 2015, in totaal 10.629 mensen. 68.4 procent van hen stierf thuis of in het woonzorgcentrum waar ze woonden. Dit wordt gezien als een teken van gepaste levenseindezorg. Relatief veel mensen werden naar spoed gebracht in de laatste 30 dagen voor overlijden (25.6 procent). Dat is een teken van ongepaste levenseindezorg. Er is ook veel variatie in gebruik van mogelijk ongepaste of futiele medicatie in de laatste maand voor overlijden, met name maagbeschermers (18 - 42 procent) en bloeddrukverlagende middelen (40 - 53 procent). Ook hier berekenden we standaarden als suggestie op basis van deze resultaten.

### **4.4 Trends 2010-2015**

Ook al is 6 jaar een relatief korte periode, toch vonden we enkele duidelijke evoluties in gepastheid van zorg bij alle drie de ziektegroepen: (1) een duidelijke toename in huisartsencontact, een teken van gepaste levenseindezorg, (2) een toename in het gebruik van gespecialiseerde palliatieve zorg, een teken van gepaste levenseindezorg. Dit vond evenwel bijna uitsluitend plaats in de laatste 14 dagen voor overlijden; wat een teken is dat palliatieve zorg vaak te laat wordt ingezet, en (3) een toename in spoedopnames in de laatste 30 dagen voor overlijden, wat een teken is van ongepaste levenseindezorg.

Voor mensen met COPD zagen we een toename van voorgeschreven opioïden en een afname van het percentage mensen met herhaalde of langdurige intubatie; beide indicatoren van gepaste levenseindezorg. We zagen ook een toename van mensen opgenomen op een intensive care unit, wat een teken is van ongepaste levenseindezorg.

Voor mensen met dementie nam het gebruik van een aantal typen medicatie nog toe: bijvoorbeeld maagbeschermers, die vaak een teken zijn dat mensen een grote hoeveelheid medicatie gebruiken, waarvan een aantal mogelijk nutteloos zijn of zelfs gevaarlijke neveneffecten hebben.

## **5. Interpretatie en bedenkingen**

We hebben de bestaande literatuur over gepastheid van levenseindezorg sterk uitgebreid met de drie ontwikkelde sets kwaliteitsindicatoren. Voor mensen met kanker waren al enkele kwaliteitsindicatoren beschikbaar uit voorgaand onderzoek, waarop we ons ook gebaseerd hebben. Vooral voor mensen met COPD of dementie deden we baanbrekend werk door het identificeren van indicatoren van gepaste en ongepaste levenseindezorg die op populatieniveau kunnen worden gemeten. Dit kan levenseindezorg in het algemeen in België helpen verbeteren. Bij de ontwikkeling van de indicatoren hebben we praktijk-experten ingezet. Dat zorgt ervoor dat onze indicatorensets dicht aansluiten bij het werkveld en in grote mate herkenbaar zijn voor zorgverleners en beleidsmakers. Bovendien is uit recent onderzoek gebleken dat onze indicatoren wetenschappelijk relevant zijn en ook in andere contexten (bijvoorbeeld in andere landen) opnieuw gemeten kunnen worden.



Ook op vlak van het linken en gebruiken van administratieve data (van IMA, Statistics Belgium en het Kankerregister) deden we baanbrekend werk. We hebben aangetoond dat het linken van databanken mogelijk is en dat de resulterende data kunnen gebruikt worden om gezondheidszorggebruik te meten op populatieniveau in België. Een groot voordeel van het gebruiken van gegevens van de ziekteverzekering is dat deze dataverzameling bijzonder effectief is: het is niet nodig kwetsbare mensen aan het levenseinde actief te bevragen. Ook levert ze gedetailleerde gegevens op over alle mensen, inclusief moeilijk bereikbare of bevroagbare groepen, bijvoorbeeld door taal- of culturele barrières. Het gebruik van dergelijke gegevens is uiterst geschikt voor het onderzoeken van kwetsbare groepen, zoals mensen aan het levenseinde.

Werken met experts voor de ontwikkeling van indicatoren heeft echter ook het nadeel dat de experts vertrekken van de huidige praktijk en dus mogelijk ook minder kritisch staan tegenover hun eigen praktijk en minder mogelijkheden zien die ze zelf momenteel niet toepassen.

Bovendien werden bij de ontwikkeling van de kwaliteitsindicatoren geen patiënten en naasten van patiënten betrokken. In vergelijking met medische experts kennen zij waarschijnlijk het gezondheidszorgsysteem minder goed en kunnen ze minder op populatieniveau inschatten wat gepaste of ongepaste levenseindezorg is. Het is echter waarschijnlijk dat patiënten vanuit hun perspectief interessante nieuwe inzichten zouden kunnen bieden op gepastheid van levenseindezorg.

Werken met ziekteverzekeringsgegevens en gegevens van Statistics Belgium en het Kankerregister heeft ook nadelen: elke organisatie verzamelt gegevens voor de eigen doelstellingen van de organisatie.

Welke gegevens verzameld worden en welke niet wordt vooraf bepaald. We kunnen als onderzoekers niet de dataverzameling mee vormgeven en de verzamelde gegevens afstemmen op onze onderzoeksvragen. In plaats daarvan moeten we de te meten kwaliteitsindicatoren selecteren die meetbaar zijn met de beschikbare data. We hebben a priori geen gegevens over niet-terugbetaalde zorg.

## **6. Aanbevelingen voor praktijk, onderzoek en beleid**

Wat zijn op basis van onze bevindingen de belangrijkste concrete aanbevelingen om de kwaliteit van levenseindezorg in België voor mensen met kanker, COPD of dementie te verbeteren?

### **6.1 Voor de zorgpraktijk**

De hier ontwikkelde indicatoren kunnen worden gebruikt als deel van een verbetercyclus, waar op basis van de resultaten prioriteiten voor verandering en verandertrajecten worden gekozen. Daarna kunnen de indicatoren opnieuw worden gemeten om vooruitgang te meten en nieuwe prioriteiten te bepalen. We stellen bovendien voor dat zorginstellingen samenwerken om hun resultaten samen te meten, te vergelijken en zo verbeterdoelen te stellen. Onze tweede aanbeveling voor de praktijk luidt: geef meer aandacht aan zorgplanning. Overleg over de wensen van de patiënt kan helpen onnodige zorgtransities te vermijden, als alle betrokken zorgverleners op de hoogte zijn van de planning.

Voor hulpverleners die zorgen voor mensen met COPD is op basis van onze resultaten een toename van gebruik van en tijdige opstart van

palliatieve zorg de belangrijkste aanbeveling. Voor hulpverleners die zorg verlenen aan mensen met dementie raden we aan te werken aan het afbouwen van medicatie die niet meer nuttig is. Dit gebeurt natuurlijk in overleg met de patiënt, zodat voor iedereen duidelijk is waarom het medicatiegebruik wordt afgebouwd.

## **6.2 Voor onderzoek**

Onderzoekers bevelen we sterk aan onze indicatorensets opnieuw te meten in andere contexten, internationaal, in andere gezondheidszorgsystemen en andere populaties. Dit kan onze indicatorensets alleen meer valide maken en bijsturen waar nodig.

We bevelen ook aan de indicatoren prospectief te gebruiken, om verwachte veranderingen in het gezondheidszorgsysteem te evalueren. Sinds kort wordt bijvoorbeeld raadpleging van een psycholoog terugbetaald in België. Heeft die terugbetaling een effect op de gepastheid van levenseindezorg?

Ten slotte bevelen we onderzoekers aan om verder standaarden te ontwikkelen voor onze indicatorensets, op basis van andere bronnen dan de vergelijking tussen zorgregio's. Voorkeuren van patiënten over hun plaats van overlijden zou bijvoorbeeld een sterke basis kunnen zijn voor standaarden voor indicatoren die de plaats van overlijden meten. (bijvoorbeeld: het percentage mensen die thuis overlijden: hoeveel procent van de mensen willen effectief zelf thuis overlijden?)

## **6.3 Voor het beleid**

Ook voor Belgische beleidsmakers hebben we enkele aanbevelingen op basis van onze resultaten:

Ten eerste: investeer in continuïteit van zorg. Dit kan op een aantal manieren, bijvoorbeeld door woonzorgcentra te ondersteunen in het uitbouwen van een palliatieve zorg beleid en expertise.

Ten tweede: ondersteun meer palliatieve zorg voor mensen met COPD. Dit kan bijvoorbeeld door overleg op te zetten tussen experts die zorgen voor mensen met COPD en palliatieve zorg specialisten.

Ten derde: ondersteun huisartsen in het afbouwen van medicatie aan het levenseinde. Geef aan dat polymedicatie een probleem is, in onze resultaten bleek dit vooral bij mensen met dementie, en hoe het kan teruggebracht worden.

We bevelen beleidsmakers ook ten zeerste aan om het gezondheidszorgsysteem te blijven evalueren met behulp van kwaliteitsindicatoren en gezondheidszorggegevens, zoals we hier demonstreerden. Dit gebeurt nu reeds door de onderzoekers van [healthybelgium.be](http://healthybelgium.be) over uiteenlopende thema's en het is een belangrijk initiatief dat zeker nog kan uitgebreid worden.

Onze laatste aanbeveling aan beleidsmakers is mogelijk de belangrijkste: gebruik terugbetaling van behandeling en medicatie om gepaste levenseindezorg aan te moedigen. Momenteel wordt palliatieve zorg door huisartsen of in woonzorgcentra bijvoorbeeld niet expliciet terugbetaald. Wanneer dit wel zo zou zijn, zouden beleidsmakers een meer rechtstreekse positieve impact kunnen hebben op de kwaliteit van levenseindezorg in België. Het gezondheidszorgsysteem is immers de context waarbinnen alle zorg plaats vindt en het definieert de mogelijkheden waaruit artsen en patiënten kiezen voor hun optimale behandeling. We geloven dat de overheid een verantwoordelijkheid heeft

om een performant systeem op te zetten dat gepaste zorg terugbetaalt en aanmoedigt, en dit vooral voor de meest kwetsbare mensen in de bevolking, zoals mensen aan het levenseinde.

Curriculum vitae and list of  
publications

## **Curriculum vitae**

Robrecht De Schreye was born on May 9th 1984. He graduated in 2010 as Master in Philosophy and Master of Science in Psychology at KULeuven. In 2014 he joined the End-of-Life Care Research Group at VUB, where he worked as a doctoral researcher on the FWO-project *A population-level evaluation of the quality and cost-effectiveness of end-of-life care*. He was supervised by Prof dr. Joachim Cohen, Prof. dr. Tinne Smets, Prof. dr. Luc Deliens and Prof. dr. Dirk Houttekier. From 2018 until 2020, he was involved in the research project "Het Vlaams indicatoren project woonzorgcentra", developing quality indicators for Flemish nursing homes and collaborated on several other projects within the End-of-Life Care research group involving the use of administrative data and quality indicators. He also collaborated as researcher in an international working group on the use of big data in end-of-life care research. He presented his research at several national and international conferences, including the 2017 Health affairs conference in Washington DC. He is currently working for Sciensano, at the Health Services research department.

## List of publications

- 1) Maetens A, **De Schreye R**, Faes K, Houttekier D, Deliens L, Gielen B, et al. Using linked administrative and disease-specific databases to study end-of-life care on a population level. BMC Palliat Care. 2016;15:86. IF<sub>2018</sub>:3.12, **Q1**
- 2) **De Schreye R**, Houttekier D, Deliens L, Cohen J. Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study. Palliat Med. 2017;31:932-45. IF<sub>2017</sub>:3.29, **Q1**
- 3) **De Schreye R**, Smets T, Deliens L, Annemans L, Gielen B, Cohen J. Appropriateness of End-of-Life Care in People Dying From COPD. Applying Quality Indicators on Linked Administrative Databases. J Pain Symptom Manage. 2018;56:541-550.e6. IF<sub>2018</sub>:1.626, **Q1**
- 4) **De Schreye R**, Smets T, Annemans L, Deliens L, Gielen B, De Gendt C, et al. Applying Quality Indicators For Administrative Databases To Evaluate End-Of-Life Care For Cancer Patients In Belgium. Health Aff Proj Hope. 2017;36:1234-43. IF<sub>2018</sub>: 4.381, **Q1**
- 5) **De Schreye R**, Smets T, Deliens L, Annemans L, Gielen B, Cohen J. Appropriateness of End-of-Life Care in People Dying With Dementia: Applying Quality Indicators on Linked Administrative Databases. J Am Med Dir Assoc. 2020; IF<sub>2018</sub>:4.899, **Q1**
- 6) **De Schreye R**, Deliens L, Annemans L, Gielen B, Smets T, Cohen J. Trends in appropriateness of end-of-life care in people with cancer, COPD or with dementia measured with population-level administrative data: do quality indicators improve over time? Palliative Medicine, Submitted



- 7) Maetens A, Beernaert K, **De Schreye R**, Faes K, Annemans L, Pardon K, et al. Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study. *BMJ Open*. 2019;9:e025180. IF<sub>2018</sub>:2.42, **Q1**
  
- 8) Paque K, **De Schreye R**, Elseviers M, Vander Stichele R, Pardon K, Dilles T, et al. Discontinuation of medications at the end of life: A population study in Belgium, based on linked administrative databases. *Br J Clin Pharmacol*. 2019;85:827-37. IF<sub>2018</sub>:3.867, **Q1**

## Appendix

**Supplementary material S.1:** Indicatoren voor (on)gepaste zorg aan het levenseinde bij mensen met kanker via administratieve data

Volgende kenmerken vindt men bij elke indicator terug:

- Een inhoudelijke beschrijving van de indicator in de titel
- De bron van de indicator, uit literatuur of uit expertinterview
- De reden waarom de indicator een teken is van gepaste of ongepaste zorg
- De teller en noemer om de indicator te berekenen
- Exclusie van subpopulaties waarvoor de indicator niet geldt
- De operationalisering van de indicator in de IMA-databank
- Een norm/richtcijfer voor de score op deze indicator (waar mogelijk)

## Terminologie

Een aantal begrippen worden regelmatig herhaald en zijn geen standaard taalgebruik. Van deze termen geven we hier een korte verklaring. Het is nuttig om deze vooraf door te nemen.

1. *Reden*: Wanneer we bij 'reden' spreken over de motivatie om een bepaalde indicator op te nemen als teken van gepaste of ongepaste zorg, is dat steeds bedoeld op geaggregeerd niveau. Een indicator geldt dus niet voor elke mens (persoon/patiënt) in elke situatie. De indicatoren worden op populatieniveau gemeten en zeggen dus iets over het voorkomen van bepaalde zorgpraktijken in België.

2. *De variabele 'nomenclatuurcode'* is een variabele in de IMA-databank "gezondheidszorgen", die alle nomenclatuurcodes van terugbetaalde medische handelingen bevat. Als zodanig wordt hij vaak gebruikt in de operationalisering van indicatoren voor gepaste of ongepaste zorg.

3. *De variabele 'productcode'* is een variabele uit de IMA-databank "farmanet", die alle productcodes van terugbetaalde medicijnen (op voorschrift) bevat. Als zodanig wordt hij vaak gebruikt in de operationalisering van indicatoren voor gepaste of ongepaste zorg.

6. Norm/richtcijfer is veelal niet vastgelegd. Ze kan echter worden vastgelegd op basis van de waargenomen verdelingen (bijvoorbeeld op basis van best practice examples, bijvoorbeeld de beste 10%). In de lijst is dit aangegeven met "nog te bepalen".

## **A. Thema: Afwezigheid van agressieve zorg voor het levenseinde**

### A.1. Indicator "Aantal mensen die één of meerdere chemotherapie-behandelingen ontvingen binnen een vastgelegde periode kort voor het levenseinde."

- Bron: (Earle et al., 2003; Grunfeld et al., 2006); (Prigerson et al., 2015)

- Reden: Een hoog percentage mensen met een kort interval tussen de laatste chemotherapie-behandeling en het overlijden is een indicator voor therapeutische hardnekkigheid en dus voor een lage zorg- en levenskwaliteit aan het levenseinde. Chemotherapie heeft ernstige bijwerkingen en is geassocieerd met een gemiddeld lagere levenskwaliteit. Bovendien duidt dergelijke behandeling kort voor het overlijden op een tekort aan fysieke en psychologische begeleiding voor het levenseinde. Dit geldt voor alle vormen van chemotherapie die momenteel gebruikt worden.

- Teller: Het aantal mensen die een chemotherapiebehandeling krijgen in de laatste x dagen voor het overlijden. Meetmomenten zullen zijn: 14 dagen, 30 dagen, 90 dagen en 180 dagen voor overlijden.

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA data:

1. Voor intraveneuze chemotherapie: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de verschillende behandelingen chemotherapie (cytostatica). De variabele 'nomenclatuurcode' wordt geordend volgens de variabele 'datum'. Het verschil in aantal dagen tussen de laatste behandeling met chemo en het overlijden vormt een nieuwe variabele. We creëren een nieuwe binaire variabele, die 1 scoort als het aantal dagen  $\leq x$  en 0 als het aantal dagen  $> x$ . (waarbij x volgende waarden kan aannemen: 14, 30, 90 en 180)

2. Voor orale chemotherapie: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de verschillende behandelingen chemotherapie (cytostatica). De variabele 'nomenclatuurcode' wordt geordend volgens de variabele 'datum'. Het verschil in aantal dagen tussen de meest recente datum van behandeling en de datum voor overlijden vormt een nieuwe variabele. We creëren een nieuwe binaire variabele, die 1 scoort als het aantal dagen  $\leq (x+30)$  en 0 als het aantal dagen  $> (x+30)$ . (waarbij x volgende waarden kan aannemen: 14, 30, 90 en 180) We tellen 30 dagen bij om het verschil tussen de datum van overschrijving en de laatste orale behandeling in rekening te brengen.

- Norm/richtcijfer: Nog te bepalen. Earle et al. (2005) leggen het richtcijfer (in de VS) op <10% die nog chemo krijgt in de laatste 14 dagen.

A.1b. Indicator "Het gemiddelde interval tussen de laatste chemotherapie-behandeling en het levenseinde (uitgedrukt in aantal dagen)"

- Bron: (Earle et al., 2003; Grunfeld et al., 2006);

- Reden: Een hoog percentage van mensen met een kort interval tussen de laatste chemotherapie-behandeling en het overlijden is een indicator voor therapeutische hardnekkigheid en dus voor een lage zorg- en levenskwaliteit aan het levenseinde. Chemotherapie heeft ernstige bijwerkingen en is geassocieerd met een gemiddeld lagere levenskwaliteit. Bovendien duidt dergelijke behandeling kort voor het overlijden op een tekort aan fysieke en psychologische begeleiding voor het levenseinde. Dit geldt voor alle vormen van chemotherapie die momenteel gebruikt worden.

- Teller: Het aantal dagen tussen de laatste chemotherapiebehandeling en het overlijden van de mens.

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA data:

1. Voor intraveneuze chemotherapie: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de behandeling chemotherapie (cytostatica). De variabele 'nomenclatuurcode' wordt geordend volgens de variabele 'datum'. Het verschil in aantal dagen tussen de meest recente datum van behandeling en de datum van overlijden vormt een nieuwe variabele. We delen de waarde van deze variabele door Het totaal aantal mensen overleden met kanker.

2. Voor orale chemotherapie: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de verschillende behandelingen chemotherapie (cytostatica). De variabele 'nomenclatuurcode' wordt geordend volgens de variabele 'datum'. De meest recente datum van behandeling wordt afgetrokken van de datum van overlijden. Daarna worden nog 30 dagen extra afgetrokken, om het verschil tussen de datum van overschrijving en de laatste orale behandeling in rekening te brengen. De uitkomst vormt een nieuwe variabele. We delen de waarde van deze variabele door Het totaal aantal mensen overleden met kanker.

- Norm/richtcijfer: Karim et al.: 35,6% van patiënten heeft 60 dagen of minder in Saudi-Arabië

A. 2. Indicator "Het aantal mensen die een nieuwe chemotherapie-lijn opgestart krijgen kort voor het levenseinde"

- Bron: (Earle et al., 2003; Grunfeld et al., 2006);

- Reden: Een hoog percentage van mensen met een kort interval tussen het beginnen van een nieuwe chemotherapie-lijn en het overlijden is een indicator voor therapeutische hardnekkigheid en dus voor een lage zorg- en levenskwaliteit aan het levenseinde. Chemotherapie heeft ernstige bijwerkingen en is geassocieerd met een gemiddeld lagere levenskwaliteit. Bovendien duidt dergelijke behandeling kort voor het overlijden op een tekort aan fysieke en psychologische begeleiding voor het levenseinde.

- Teller: Aantal mensen die een nieuwe chemotherapie-lijn starten, x dagen of minder voor het overlijden. Meetmomenten zullen zijn: 14 dagen, 30 dagen, 90 dagen en 180 dagen voor overlijden.

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA data: Binnen de variabelen 'nomenclatuurcode' identificeren we de codes die overeenkomen met de behandeling chemotherapie (cytostatica). We identificeren op basis van nomenclatuurcode de opstart van een nieuwe behandeling: dezelfde code komt in de voorbije twee weken niet voor. Vervolgens vergelijken we de datum van het eerste voorkomen van die code met de datum van overlijden. We berekenen het verschil tussen beide en vergelijken dat met de vastgelegde grens (14 dagen, 30 dagen, 90 dagen en 180 dagen voor overlijden). Er wordt voor elke vastgelegde grens een nieuwe binaire variabele aangemaakt. Als het verschil in aantal dagen gelijk aan of minder is dan x (variërend van 14, 30, 90 tot 180), scoort deze variabele 1, anders 0.

- Norm/richtcijfer: Earle et al. (2005) leggen het richtcijfer (in de VS) op <2% die een nieuwe chemotherapie-lijn opgestart krijgt in de laatste 30 dagen.

A.3. Indicator "Het aantal mensen die sondevoeding of intraveneuze (parenterale) voeding kregen in de laatste 30 dagen voor overlijden"

- Bron: (Sampson et al., 2009; Teno et al., 2011)

- Reden: Sondevoeding en intraveneus voeden zijn ineffectief in het verlengen van de levensduur bij mensen zonder kanker in het spijsverteringsstelsel. Bovendien hebben ze een negatief effect op de levenskwaliteit van de mens, vanwege een aantal complicaties. (verhoogd risico op longontsteking, bewegingsbelemmering, misselijkheid, diarree, ...) Handmatig voeden is een alternatief dat leidt tot een hogere levenskwaliteit, maar is niet altijd mogelijk. Daarom is een relatief hoog percentage mensen die sondevoeding of intraveneuze voeding krijgen kort voor het overlijden een indicator van ongepaste zorg aan het levenseinde.

- Teller: (3 verschillende tellers, die elk een variatie van de indicator zijn)

1. Het aantal mensen dat sondevoeding kreeg in de laatste 30 dagen voor het overlijden, behalve mensen met kanker in het spijsverteringsstelsel.

2. Het aantal mensen dat intraveneuze voeding kreeg in de laatste 30 dagen voor het overlijden, behalve mensen met kanker in het spijsverteringsstelsel.

3. Het aantal mensen dat intraveneuze voeding of sondevoeding kreeg in de laatste 30 dagen voor het overlijden, behalve mensen met kanker in het spijsverteringsstelsel.

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de behandeling sondevoeding en intraveneuze voeding. Er worden twee nieuwe variabelen gecreëerd die binair aangeven of we de respectievelijke nomenclatuurcodes terugvinden. Een derde variabele geeft weer of een van beide behandelingen voorkwamen. We delen de waarde van deze variabelen door het totaal aantal mensen overleden met kanker.

- Norm/richtcijfer: Nog te bepalen.

#### A.4. Indicator "Het aantal mensen waarbij een derde lijn chemotherapie werd ingezet"

- Bron: (Earle et al., 2003)

- Reden: Het opstarten van nieuwe lijnen chemotherapie na het niet aanslaan van voorafgaande behandelingen kan een manier zijn om het bespreken van een slechte prognose en het plannen van levenseindezorg te vermijden. Wanneer het in een subpopulatie bij een relatief groot

aantal mensen voorkomt, is het dus een teken van ongepaste zorg aan het levenseinde.

- Teller: Het aantal mensen met kanker dat minstens 3 chemotherapie-lijnen ondergaat in de laatste 2 jaar voor overlijden (dat is de maximumperiode met de beschikbare data).

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de behandeling chemotherapie. We tellen het aantal episoden waarin regelmatig wordt behandeld. Wanneer er een niet-behandelingsperiode is van een maand of langer, veronderstellen we dat een nieuwe lijn werd gestart. We identificeren alle mensen met 3 of meer afzonderlijke lijnen chemotherapie.

- Norm/richtcijfer: Het percentage mensen met 3 of meer lijnen mag maximum 20% bedragen. (Earle, 2003)

#### A.5. Indicator "Het aantal mensen dat Cisplatine kreeg bij mensen ouder dan 80 jaar"

- Bron: expertinterview

- Reden: Cisplatine is een chemotherapieproduct dat niet geschikt is voor personen ouder dan 80+ of voor sterk zorgafhankelijke personen, omdat het gegeven wordt met 8 liter vocht. Wanneer het in die subpopulatie toch gegeven wordt is het een sterke indicator van ongepaste zorg aan het levenseinde.

- Teller: het aantal mensen van 80 jaar of ouder met kanker die behandeld werden met cisplatine in de laatste 2 jaar voor overlijden. (dat is de maximumperiode met de beschikbare data)

- Noemer: het totaal aantal mensen van 80 jaar of ouder overleden met kanker.

- Exclusie: alle mensen zonder kanker, of mensen met kanker jonger dan 80 jaar.

- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we cisplatine. De leeftijd van overledenen is beschikbaar in het demografische luik van de IMA-databank.

- Norm/richtcijfer: Nog te bepalen.

A.6. Indicator "Het aantal mensen waarbij diagnostische testen (bloedafname, spirometrie, EKG, dialyse of radiografie) werden afgenomen tijdens de laatste 30 dagen voor het overlijden"

- Bron: expertinterview
- Reden: Diagnostische testen zijn vaak belastend voor de patiënt. Bovendien beïnvloeden ze de behandeling of de prognose niet meer, voorbij een bepaald stadium. Daarom zijn ze een teken van futiele en ongepaste zorg aan het levenseinde, wanneer ze bij een relatief groot aantal mensen voorkomen kort voor het overlijden.
- Teller: het aantal mensen die onderworpen werden aan bloedafname, spirometrie, EKG, dialyse of radiografie in de laatste 30 dagen voor het overlijden.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: alle mensen zonder kanker.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de verschillende diagnostische testen. We splitsen dit op in een aantal variabelen, een per test. Voor elke test kan de variabele verschillende waarden hebben: 0 bij geen diagnostische testen, 1 bij 1 of 2 diagnostische testen, 2 bij 3 of meer diagnostische testen.
- Norm/richtcijfer: Nog te bepalen.

A.7. Indicator "Het aantal mensen waarbij een port-a-cath wordt geïnstalleerd in de laatste twee weken voor overlijden"

- Bron: expertinterview
- Reden: Het plaatsen van een port-a-cath is een belastende ingreep. Wanneer hij kort voor het levenseinde wordt geïnstalleerd, is dat bovendien een futiele ingreep, want de voordelen van een port-a-cath tonen zich op langere termijn. Daarom stellen we dat het een teken is van ongepaste zorg voor het levenseinde, als het kort voor het overlijden bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met een port-a-cath installatie in de laatste twee weken voor het overlijden.
- Noemer: Het totaal aantal mensen overleden met kanker. (per groep afzonderlijk te berekenen)
- Exclusie: alle mensen zonder kanker.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de installatie van een port-a-cath tijdens de twee weken voor



overlijden. We creëren een nieuwe binaire variabele die weergeeft of de installatie al dan niet heeft plaatsgevonden.

- Norm/richtcijfer: Nog te bepalen.

A.8. Indicator "Het aantal mensen met langdurig per-oraal gebruik van corticoïden tijdens het laatste jaar, 6 maanden, 30 dagen en laatste 7 dagen voor overlijden"

- Bron: expertinterview

- Reden: Permanent gebruik van corticoïden geeft een aantal bijwerkingen, waaronder spierafbraak en suikerziekte. Op korte termijn is het een effectief middel voor symptoombestrijding. Als corticoïden gedurende lange tijd worden voorgeschreven en niet worden afgebouwd kort voor het overlijden, is dat een indicator van ongepaste zorg voor het levenseinde, als het bij een voldoende groot aantal mensen voorkomt. We vergelijken dus het gebruik van corticoïden op lange termijn met dat op korte termijn.

- Teller: het aantal mensen met een voorschrift voor per-oraal gebruik van corticoïden. We stellen meetmomenten in op 2 jaar, 1 jaar, 6 maanden en 1 week voor het levenseinde.

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: alle mensen zonder kanker.

- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we hoeveel perorale corticoïden werden voorgeschreven op verschillende tijdstippen. Per subpopulatie vergelijken we de verschillende meetmomenten.

- Norm/richtcijfer: Nog te bepalen.

A.9. Indicator "Het aantal mensen met longmetastasen die een zuurstofbehandeling krijgen tijdens de laatste 2 jaar voor overlijden"

- Bron: expertinterview

- Reden: Bij mensen met longmetastasen heeft het toedienen van zuurstof geen effect op levensduur of levenskwaliteit. We kunnen het dus beschouwen als een indicator van ongepaste zorg, als het bij een voldoende groot aantal mensen voorkomt.

- Teller: het aantal mensen overleden met longmetastasen die zuurstofbehandeling krijgen toegediend.

- Noemer: het totaal aantal mensen overleden met longmetastasen.

- Exclusie: alle mensen overleden zonder longmetastasen.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling zuurstoftoediening. Uit de data van de Stichting Kankerregister identificeren we kankerpatiënten met longmetastasen. We creëren een binaire variabele die van elke mens vaststelt of hij/zij al dan niet zuurstofbehandeling krijgt toegediend.
- Norm/richtcijfer: Nog te bepalen.

A.10. Indicator "Het gemiddeld aantal voorschriften van anxiolytica en antidepressiva tijdens het laatste jaar voor overlijden"

- Bron: expertinterview
- Reden: Antidepressiva en anxiolytica worden veel voorgeschreven in België, vermoedelijk te veel. Hoe veel te veel is weten we niet exact, maar een hoog percentage is een teken van ongepaste zorg. We kunnen relatief vergelijken tussen zorgverstrekkers of regio's.
- Teller: Het totaal aantal voorgeschreven antidepressiva en anxiolytica bij mensen met kanker in een bepaalde zorgregio of bij een bepaalde instelling tijdens het laatste jaar voor overlijden (dat is de maximumperiode met de beschikbare data).
- Noemer: Het totaal aantal mensen in die onderzochte regio of instelling met kanker.
- Exclusie: mensen overleden zonder kanker.
- Operationalisering in IMA data: We zoeken in de farmacologische gegevens naar antidepressiva en anxiolytica en creëren twee nieuwe variabelen die per mens weergeven of hij/zij er toegediend kreeg.
- Norm/richtcijfer: Nog te bepalen.

A.11. Indicator "Het aantal mensen dat chirurgie ondergaat 6, 2 of 1 maand(en) voor het overlijden"

- Bron: expertinterview
- Reden: chirurgie is erg belastend en dient indien nodig te worden vermeden. Veel ingrepen zijn overmatig bij terminale mensen. Daarom nemen we chirurgie ondergaan kort voor het overlijden als indicator voor ongepaste zorg, als het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal mensen met kanker die nog chirurgie ondergingen in de laatste 6 maanden/2 maanden/1 maand voor overlijden.

- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: We zoeken in de gezondheidszorgdata naar codes voor chirurgie en maken een nieuwe variabele die binair aangeeft of iemand wel of niet chirurgie ondergaan heeft binnen de vastgelegde periode voor overlijden. Meer dan 1 chirurgische ingreep wordt niet expliciet geteld.
- Norm/richtcijfer: Nog te bepalen.

#### A.12. Indicator "Het aantal mensen met een bloedtransfusie tijdens de laatste 2 maanden/1maand/2 weken voor overlijden"

- Bron: expertinterview
- Reden: Bloedtransfusie is erg belastend en dient indien nodig te worden vermeden. Bovendien is het futiel bij mensen die zich in het terminale stadium van een ziekte bevinden. Daarom nemen we bloedtransfusie ondergaan kort voor het overlijden als indicator voor ongepaste zorg, als het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal mensen met kanker die nog bloedtransfusie ontvingen in de laatste 2, 1 maand(en) of 2 weken voor overlijden en niet lijden aan een hematologische aandoening.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: We zoeken in de gezondheidszorgdata naar codes voor bloedtransfusie en maken een nieuwe variabele die binair aangeeft of iemand het wel of niet ontvangen heeft 2 maanden voor overlijden.
- Norm/richtcijfer: Nog te bepalen.

## **B. Thema: Behandelen van pijn en fysieke symptomen**

### B.1. Indicator "Het aantal mensen die opioïden kregen voor pijnbestrijding"

- Bron: (Bruera et al., 2004)
- Reden: Bij mensen met kanker vormt pijn het belangrijkste symptoom dat de levenskwaliteit verlaagt. Opioïden vormen een hoofdbestanddeel van pijnbestrijders. Daarom is een relatief groot percentage mensen

waarbij opioïden gebruikt wordt een teken van gepaste zorg aan het levenseinde.

- Teller: Het aantal mensen met kanker met een voorschrift voor opioïden in de laatste 3 maanden, 1 maand en 2 weken voor het levenseinde.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA-data: Binnen de farmanet-databank identificeren we de codes die overeenkomen met geneesmiddelen uit de opioïdengroep. Voorbeelden zijn: morfine, codeïne, oxycodone hydrochloride, fentanyl citraat.
- Norm/richtcijfer: Nog te bepalen.

### B.2. Indicator "Het aantal mensen die radiotherapie kregen tegen botmetastasen kort voor het levenseinde"

- Bron: (Di Staso et al., 2015; Grunfeld et al., 2006)
- Reden: Botmetastasen zijn erg pijnlijk en veel voorkomend bij kankerpatiënten die het levenseinde naderen. Radiotherapie is een effectieve methode om ze te bestrijden. Wanneer radiotherapie gebruikt wordt bij een relatief groot aantal mensen is dat een indicator van gepaste zorg bij het levenseinde.
- Teller: Het aantal mensen met kanker en botmetastasen dat radiotherapie krijgt toegediend in de laatste 2 jaar voor overlijden.
- Noemer: Het aantal mensen met kanker en botmetastasen.
- Exclusie: mensen zonder kanker en botmetastasen.
- Operationalisering in IMA data: We creëren een nieuwe variabele die het al dan niet voorgeschreven zijn van radiotherapie weergeeft, gebaseerd op de nomenclatuurcodes. De diagnose botmetastasen wordt geëxtraheerd uit de gekoppelde databank van het Belgisch Kankerregister.

Norm/richtcijfer: Nog te bepalen.

### B.3. Indicator "Het aantal mensen die sterke anti-emetica kregen tegen misselijkheid en braken, ten gevolge van chemotherapie"

- Bron: (Grunfeld et al., 2006)

- Reden: Misselijkheid en braken zijn belangrijke nevenverschijnselen bij nagenoeg alle vormen van chemotherapie. De bestrijding ervan is standaard nodig, vooral bij mensen nabij het levenseinde. Wanneer anti-emetica gebruikt worden bij een relatief groot aantal mensen is dat een indicator van gepaste zorg bij het levenseinde.
- Teller: Het aantal mensen met kanker dat chemotherapie krijgt dat anti-emetica krijgt toegediend in de laatste 2 jaar voor overlijden. (de maximumperiode met de beschikbare gegevens)
- Noemer: Het aantal mensen die chemotherapiebehandelingen krijgen.
- Exclusie: mensen zonder kanker of die geen chemotherapie krijgen.
- Operationalisering in IMA data: We creëren een nieuwe variabele die binair het al dan niet voorgeschreven zijn van anti-emetica weergeeft, gebaseerd op de nomenclatuurcodes. Die bekijken we binnen de subpopulatie die chemotherapie krijgt, gebaseerd op de nomenclatuur- en productcodes die overeenstemmen met chemotherapie.

Norm/richtcijfer: Nog te bepalen.

#### B.4 Indicator "Het aantal mensen die behandeld werden met cytostatica waarbij anti-emetica werden voorgeschreven in de laatste 2 jaar voor overlijden"

- Bron: expertinterview
- Reden: Cytostatica worden bij een groot aantal mensen gebruikt en zijn emetogene producten. Ze dienen dan ook standaard bestreden te worden met anti-emetica om de levenskwaliteit van de betrokken mensen zo hoog mogelijk te houden. Daarom is het gebruik van anti-emetica een teken van gepaste zorg voor het levenseinde.
- Teller: Het aantal mensen met kanker die behandeld worden met cytostatica en een voorschrift voor anti-emetica krijgen in de laatste 2 jaar voor overlijden.
- Noemer: Het totaal aantal mensen die behandeld worden met cytostatica in de laatste 2 jaar voor overlijden.
- Exclusie: mensen zonder kanker of met kanker, die niet behandeld worden met cytostatica.
- Operationalisering in IMA-data: eerst identificeren we mensen die behandeld werden met cytostatica, dankzij de nomenclatuurcodes. Binnen deze groep onderzoeken we dan wie van hen ook behandeld werd in de opgegeven periode voor overlijden met anti-emetica.
- Norm/richtcijfer: Nog te bepalen.

B.5 Indicator "Het aantal mensen dat antalgische (of palliatieve) radiotherapie kreeg als pijnstiller" als teken van gepaste zorg voor mensen met kleincellige longkanker

- Bron: expertinterview
- Reden: Bij mensen met klein-cellige longtumoren wordt preventief antalgische radiotherapie toegepast, ook palliatieve radiotherapie genoemd, ter bestrijding van pijn. Daarom nemen we deze behandeling aan als een teken van gepaste zorg kort voor het levenseinde, indien ze bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal behandelingen van antalgische radiotherapie bij mensen met kleincellige longkanker.
- Noemer: Het totaal aantal mensen met kleincellige longkanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA-data: Terug te vinden in databank: éénmalige bestraling of hersenbestraling is altijd pijnbestrijdend. We vinden het terug in de variabele 'nomenclatuurcode' van de IMA databank.
- Norm/richtcijfer: Nog te bepalen.

B.6 Indicator "Het aantal mensen dat neuropathische middelen in combinatie met morfine krijgt als pijnstiller"

- Bron: expertinterview
- Reden: Bij een hoge dosis morfine horen altijd neuropathische middelen om een combinatie te vormen. Als er enkel een hoge dosis morfine gegeven wordt, is dat een teken van ongepaste zorg. Co-drugs kunnen eenvoudig zijn, bijvoorbeeld paracetamol. We onderzoeken dus het aantal mensen dat een combinatie krijgt aangeboden als teken van gepaste zorg aan het levenseinde voor mensen met kanker.
- Teller: Het aantal mensen met kanker die een combinatie van neuropathische middelen en morfine krijgt toegediend in de laatste 2 jaar voor overlijden.
- Noemer: Het aantal mensen met kanker die morfine krijgen toegediend.
- Exclusie: mensen zonder kanker en mensen met kanker die geen morfine krijgen.
- Operationalisering in IMA-data: We creëren twee nieuwe variabelen: een die binair aangeeft of iemand al dan niet morfine heeft gekregen

en een tweede die binair aangeeft of iemand neuropathische middelen en morfine heeft gekregen.

- Norm/richtcijfer: Nog te bepalen.

### B.7 Indicator "het aantal mensen die contact hadden met een psycholoog in de laatste 2 maanden voor overlijden"

- Bron: expertinterview

- Reden: Psychologische ondersteuning is belangrijk voor mensen met terminale aandoeningen. Professionele ondersteuning wordt sinds 2013 in sommige vormen terugbetaald. We vergelijken het gebruik 2 jaar voor overlijden met dat korter voor het overlijden (2 maanden). Contact met een psycholoog wordt gehanteerd als een teken van gepaste zorg voor het levenseinde, indien het bij een voldoende groot aantal mensen voorkomt.

- Teller: Het aantal mensen die contact hadden met een psycholoog in de laatste 2 maanden voor overlijden en in de laatste 2 jaar voor overlijden.

- Noemer: Het aantal mensen met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA-data: (enkel in data vanaf 2013) We creëren twee nieuwe variabelen: eentje die binair aangeeft of iemand al dan niet contact heeft gehad met een psycholoog de laatste 2 maanden voor overlijden en eentje die hetzelfde aangeeft 2 jaar voor overlijden. Vervolgens kijken we naar het verschil tussen beiden.

- Norm/richtcijfer: Nog te bepalen.

## **C. Thema: Het (tijdig) opstarten van palliatieve zorg**

### C.1 Indicator "Het aantal mensen die gespecialiseerde palliatieve zorg ontvangen"

- Bron: (Bakitas et al., 2015; Earle et al., 2003)

- Reden: Palliatieve zorg is er expliciet op gericht gepaste zorg rond het levenseinde te stimuleren. Het ontvangen van gespecialiseerde palliatieve zorg valt samen met een verminderde kans op het ontvangen van agressieve zorg kort voor het levenseinde. Wanneer palliatieve zorg toegepast wordt bij een relatief groot aantal mensen is dat een indicator van gepaste zorg bij het levenseinde.

- Teller: Het aantal mensen dat opgenomen werd op een palliatieve eenheid van een ziekenhuis of gebruik maakt van een multidisciplinaire thusequipe of opgenomen werd in een palliatief dagcentrum (afzonderlijk te berekenen) in de laatste 2 jaar voor overlijden.
- Noemer: Het totaal aantal mensen in de onderzochte populatie met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA-data: We maken een binaire variabele die aangeeft of iemand opgenomen werd op een palliatieve eenheid. Daarnaast wordt een binaire variabele multidisciplinaire thusequipe en een binaire variabele palliatief dagcentrum aangemaakt via de variabele 'nomenclatuurcode'.
- Norm/richtcijfer: Nog te bepalen.

### C.2 Indicator "Het aantal mensen dat gebruik maakt van de ondersteuningsmaatregel 'palliatief statuut'"

- Bron: (Earle et al., 2003)
- Reden: Het aanvragen van het palliatieve statuut is vaak een teken van gepaste zorg aan het levenseinde. Mensen die dit aanvragen krijgen vaak kwaliteitsvolle ondersteuning door palliatieve experts en huisarts. Daarom nemen we het toegekend krijgen van het palliatief statuut op als een teken van gepaste zorg voor het levenseinde, indien het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal mensen die het palliatief statuut krijgen toegekend met kanker in de laatste 2 jaar voor overlijden.
- Noemer: Alle mensen met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA-data: uit de variabele 'nomenclatuurcode' van de IMA-databank identificeren we rechtstreeks wie het palliatief statuut kreeg toegekend.
- Norm/richtcijfer: Nog te bepalen.

### C.3 Indicator "Het aantal mensen dat gespecialiseerde palliatieve zorg ontving of het palliatief statuut kreeg toegewezen minder dan 1 week voor het overlijden"

- Bron: (Earle et al., 2003; Grunfeld et al., 2006; Magill and Senf, 1987)



- Reden: Gespecialiseerde palliatieve zorg is er expliciet op gericht gepaste zorg rond het levenseinde te stimuleren. Het ontvangen van gespecialiseerde palliatieve zorg valt samen met een verminderde kans op het ontvangen van agressieve zorg kort voor het levenseinde. Een opname kort voor het levenseinde is echter geen indicatie van gepaste zorg, aangezien palliatieve zorg tijd vergt. Opname minder dan 1 week voor het levenseinde bij een relatief groot aantal mensen is een indicator van ongepaste zorg.

- Teller: Het aantal mensen dat opgenomen werd op een palliatieve eenheid van een ziekenhuis of gebruik maakt van een multidisciplinaire thusequipe of opgenomen werd in een palliatief dagcentrum, of het palliatief statuut krijgt toegekend minder dan 7 dagen voor het overlijden. (afzonderlijk te berekenen)

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA-data: We maken een binaire variabele die aangeeft of iemand opgenomen werd op een palliatieve eenheid. Daarnaast wordt een binaire variabele multidisciplinaire thusequipe en een binaire variabele palliatief dagcentrum aangemaakt via de variabele 'nomenclatuurcode'.

- Norm/richtcijfer: Nog te bepalen.

## **D. Thema 4: Plaats van overlijden en levenseindezorg**

### D.1. Indicator "Het aantal mensen met één of meer opnames op de spoedafdeling van een ziekenhuis tijdens de laatste 6, 3 of 1 maand(en) voor het overlijden"

- Bron: (Earle et al., 2003; Teno et al., 2011)

- Reden: Ziekenhuisopname in het algemeen en opname op een spoedafdeling in het bijzonder zijn ingrijpende en belastende ervaringen voor de mens en vaak ook futiel voor het bevorderen van de overlevingskansen. Vanwege de negatieve invloed op de levenskwaliteit kunnen we zeggen dat opname op een spoedafdeling in de laatste 6, 3 of 1 maand(en) voor het overlijden een teken is van ongepaste zorg, wanneer het bij een relatief groot aantal mensen voorkomt.

- Teller: Het aantal mensen met kanker die minstens eenmaal werden opgenomen op een spoedafdeling tijdens de laatste 6, 3 of 1 maand(en) voor het overlijden.

- Noemer: Het totaal aantal mensen overleden met kanker.

- Exclusie: mensen zonder kanker.

- Operationalisering in IMA data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met opname op een spoedafdeling. Er wordt een nieuwe variabele gecreëerd die aangeeft hoe vaak we de nomenclatuurcode terugvinden.
- Norm/richtcijfer: Nog te bepalen.

#### D.2. Indicator "Het aantal mensen met één of meer ziekenhuisopnames tijdens de laatste 6, 3 of 1 maand(en) voor overlijden"

- Bron: (Earle et al., 2003; Teno et al., 2011)
- Reden: Ziekenhuisopname is een ingrijpende en belastende ervaring voor de mens en vaak ook futiel voor het bevorderen van de overlevingskansen. Vanwege de negatieve invloed op de levenskwaliteit kunnen we zeggen dat ziekenhuisopname in de laatste 6, 3 of 1 maand(en) voor het overlijden een teken is van ongepaste zorg, wanneer het bij een relatief groot aantal mensen met kanker voorkomt.
- Teller: Het aantal mensen met kanker die meer dan eenmaal werden opgenomen in het ziekenhuis tijdens de laatste 3 maanden voor het overlijden.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met ziekenhuisopname. Er wordt een nieuwe variabele gecreëerd die aangeeft hoe vaak we de nomenclatuurcode terugvinden.
- Norm/richtcijfer: Nog te bepalen

#### D.3. Indicator "Het aantal mensen die in het ziekenhuis overlijden"

- Bron: (Earle et al., 2003; Grunfeld et al., 2006)
- Reden: Uit onderzoek blijkt dat een groot aantal mensen verkiest thuis te overlijden. Toch gebeurt dit in de praktijk relatief weinig, om verschillende redenen. In het ziekenhuis overlijden is dan de tegenhanger: wie in het ziekenhuis overlijdt, doet dat vaak niet op de zelf gekozen plaats en loopt bovendien een verhoogd risico op ongepast agressieve zorg aan het levenseinde. Daarom benoemen we overlijden in het ziekenhuis als een teken van ongepaste zorg, wanneer het gebeurt bij een relatief groot aantal mensen.
- Teller: Het aantal mensen die in het ziekenhuis overlijden.

- Noemer: Het totaal aantal mensen met of kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: Via de overlijdenscertificaten identificeren we plaats van overlijden. Ter controle bekijken we of mensen heel kort voor het overlijden al dan niet opgenomen zijn of behandeld werden in het ziekenhuis. We vertalen dit naar een variabele met een binaire variabele die aangeeft of iemand al dan niet in een ziekenhuis overleden is.
- Norm/richtcijfer: Nog te bepalen

#### D.4 Indicator "Het aantal mensen die thuis overlijden"

- Bron: (Beccaro et al., 2006; De Roo et al., 2014; Earle et al., 2003; Grunfeld et al., 2006)
- Reden: Uit onderzoek blijkt dat een groot aantal mensen verkiest thuis te overlijden. Toch gebeurt dit in de praktijk relatief weinig, om verschillende redenen. Het is gemiddeld een indicator van kwaliteitsvolle zorg aan het levenseinde als een patiënt thuis kan overlijden, in overeenstemming met de eigen wens. We kunnen in dit onderzoek niet de wens van de individuele mens vaststellen, maar aangezien een erg groot aantal van de mensen dit verkiest, beschouwen we het gemiddeld als een positieve indicator voor gepaste zorg.
- Teller: Het aantal mensen die thuis overlijden.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: Via de overlijdenscertificaten identificeren we plaats van overlijden. Ter controle bekijken we of mensen heel kort voor het overlijden al dan niet opgenomen zijn of behandeld werden in het ziekenhuis. We vertalen dit naar een variabele met meerdere waarden die de verschillende mogelijkheden voor plaats van overlijden aangeeft. Daaruit leiden we dan een binaire variabele af die aangeeft of iemand al dan niet thuis overleden is.
- Norm/richtcijfer: Nog te bepalen.

#### D.5 Indicator "Het aantal mensen die thuis of in een WZC van residentie overlijden"

- Bron: (Beccaro et al., 2006; De Roo et al., 2014; Earle et al., 2003; Grunfeld et al., 2006)

- Reden: Uit onderzoek blijkt dat een groot aantal mensen kiest thuis te overlijden, of in een woonzorgcentrum (WZC), als dat hun plaats van residentie is. Het is gemiddeld een indicator van kwaliteitsvolle zorg aan het levenseinde als een patiënt kan overlijden in overeenstemming met de eigen wens. We kunnen in dit onderzoek niet de wens van de individuele mens vaststellen, maar aangezien een erg groot aantal (% op te zoeken) van de mensen dit verkiest, beschouwen we thuis of in een WZC overlijden gemiddeld als een positieve indicator voor gepaste zorg.
- Teller: Het aantal mensen die thuis wonen en thuis overlijden en het aantal mensen die in een WZC wonen en in een WZC overlijden.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: Via de overlijdenscertificaten identificeren we plaats van overlijden. Ter controle bekijken we of mensen heel kort voor het overlijden al dan niet opgenomen zijn of behandeld werden in het ziekenhuis. We vertalen dit naar een variabele met meerdere waarden die de verschillende mogelijkheden voor plaats van overlijden aangeeft. Daaruit leiden we dan een binaire variabele af die aangeeft of iemand al dan niet thuis of in een WZC overleden is.
- Norm/richtcijfer: Nog te bepalen

## **E. Thema: Coördinatie en continuïteit van de zorg**

### E.1 Indicator "Het aantal residenten van een woonzorgcentrum met een opname in een ICU tijdens de laatste 6 of 3 maanden en 2 weken of 1 week voor overlijden"

- Bron: expertinterview
- Reden: Wanneer mensen van een woonzorgcentrum (WZC) komen en naar een ICU moeten, is dat vaak een teken van ongepaste zorg. Ze zijn al erg hulpbehoevend, dus ICU heeft doorgaans geen zin meer. Daarom nemen we opname op een ICU voor mensen die overgeplaatst worden vanuit een WZC als teken van ongepaste zorg voor het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal overgangen naar ICU van mensen die in een WZC verblijven in de laatste 6 maanden, 3 maanden, 1 maand, 2 weken en 1 week voor het overlijden.
- Noemer: Het totaal aantal mensen met kanker die verblijven in een WZC en die worden opgenomen op een ICU.

- Exclusie: mensen zonder kanker, of die niet in een WZC verblijven.
- Operationalisering in IMA data: We zoeken in de nomenclatuurcodes de code voor ICU opname, we zoeken in de demografische data informatie over verblijf in een WZC.
- Norm/richtcijfer: Nog te bepalen.

### E.2 Indicator "Het aantal mensen met een gemiddelde toename van het aantal huisartscontacten tijdens de laatste 30 dagen voor het levenseinde"

- Bron: (Grunfeld et al., 2006)
- Reden: Uit onderzoek blijkt dat de ervaren levenskwaliteit van mensen met een levensbedreigende ziekte toeneemt wanneer het huisartscontact de laatste 2 weken voor het overlijden toeneemt. Dit kan verschillende oorzaken hebben, waarover we ons niet uitspreken. We gebruiken dit als een indicator van gepaste zorg: als het contact met de huisarts in de laatste 2 weken voor het overlijden toeneemt.
- Teller 1: Het gemiddeld aantal huisartscontacten per week over alle mensen heen in de laatste twee weken voor het overlijden.
- Noemer 1: Het gemiddeld aantal huisartscontacten per week in de 180 dagen voorafgaand aan de twee laatste weken voor het overlijden.
- Teller 2: Het aantal mensen bij wie het gemiddeld aantal huisartscontacten toenam in de laatste 2 weken voor overlijden.
- Noemer 2: Het totaal aantal mensen met kanker in de populatie.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: We gebruiken de nomenclatuurcodes voor huisartscontact. Voor de teller en de noemer tellen we deze afzonderlijk en delen ze daarna door elkaar. De uitkomst van deze breuk vormt een nieuwe variabele.
- Norm/richtcijfer: Een positieve indicatie van gepaste zorg indien  $>1$ , een negatieve indien  $<1$ .

### E.3 Indicator "Het gemiddeld aantal contacten met de huisarts of andere eerste-lijns-zorgers tijdens de laatste 3 maanden voor overlijden"

- Bron: (Earle et al., 2003; Grunfeld et al., 2006; Magill and Senf, 1987)
- Reden: Uit onderzoek blijkt dat de ervaren levenskwaliteit van mensen met een levensbedreigende ziekte toeneemt wanneer eerste lijnszorg een belangrijke rol inneemt in de laatste levensweken. Bovendien wijst

contact met de eerstelijnszorg vaak ook op een goed contact tussen eerstelijnszorg en specialisten. Daarom nemen we dit aan als een teken van gepaste zorg, wanneer het bij een relatief groot aantal mensen voorkomt.

- Teller: Het totaal aantal contacten met huisarts of thuisverpleegkundige voor alle mensen in de 3 maanden voorafgaand aan het overlijden.
- Noemer: Het totaal aantal overledenen met kanker.
- Exclusie: overledenen zonder kanker.
- Operationalisering in IMA data: We zoeken in de nomenclatuurcodes de code voor huisartsencontact en voor thuisverpleging. Daarna tellen we deze allemaal op om tot een totaalsom te komen.
- Norm/richtcijfer: Nog te bepalen.

#### E.4 Indicator "Het aantal mensen waarvoor een Multidisciplinair Oncologisch Consult plaatsvond in de laatste twee jaar voor overlijden"

- Bron: expertinterview
- Reden: Een MOC of POC (palliatief oncologisch consult) is een teken dat er voldoende overleg is tussen de zorgverstrekkers en duidt zo op een sterkere zorgkwaliteit. Het MOC kan worden teruggevonden in IMA-data, het POC niet. Daarom nemen we het MOC op als indicator van gepaste zorg voor het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal mensen met kanker waarvoor een MOC plaatsvond tijdens de laatste 2 jaar voor overlijden.
- Noemer: Het totaal aantal mensen overleden met kanker.
- Exclusie: mensen zonder kanker.
- Operationalisering in IMA data: We zoeken in de nomenclatuurcodes de code voor MOC. We tellen het aantal positieve cases en berekenen zo hoe vaak het MOC gemiddeld voorkomt.
- Norm/richtcijfer: Nog te bepalen.

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## **Supplementary material S.2:** Indicatoren voor (on)gepaste zorg aan het levenseinde bij mensen met COPD via administratieve data

Volgende kenmerken vindt men bij elke indicator terug:

- Een inhoudelijke beschrijving van de indicator in de titel
- De bron van de indicator, uit literatuur of uit expertinterview
- De reden waarom de indicator een teken is van gepaste of ongepaste zorg
- De teller en noemer om de indicator te berekenen
- Exclusie van subpopulaties waarvoor de indicator niet geldt
- De operationalisering van de indicator in de IMA-databank
- Een norm/richtcijfer voor de score op deze indicator (waar mogelijk)

## **Terminologie**

Een aantal begrippen worden regelmatig herhaald en zijn geen standaard taalgebruik. Van deze termen geven we hier een korte verklaring. Het is nuttig om deze vooraf door te nemen.

1. *Reden*: Wanneer we bij 'reden' spreken over de motivatie om een bepaalde indicator op te nemen als teken van gepaste of ongepaste zorg, is dat steeds bedoeld op geaggregeerd niveau. Een indicator geldt dus niet voor elke mens (persoon/patiënt) in elke situatie. De indicatoren worden op populatieniveau gemeten en zeggen dus iets over het voorkomen van bepaalde zorgpraktijken in België.

2. *De variabele 'nomenclatuurcode'* is een variabele in de IMA-databank "gezondheidszorgen", die alle nomenclatuurcodes van terugbetaalde medische handelingen bevat. Als zodanig wordt hij vaak gebruikt in de operationalisering van indicatoren voor gepaste of ongepaste zorg.

3. *De variabele 'productcode'* is een variabele uit de IMA-databank "farmanet", die alle productcodes van terugbetaalde medicijnen (op voorschrift) bevat. Als zodanig wordt hij vaak gebruikt in de operationalisering van indicatoren voor gepaste of ongepaste zorg.

6. *Norm/richtcijfer* is veelal niet vastgelegd. Ze kan echter worden vastgelegd op basis van de waargenomen verdelingen (bijvoorbeeld op basis van best practice examples, bijvoorbeeld de beste 10%). In de lijst is dit aangegeven met "nog te bepalen".



## **A. Thema: Afwezigheid van agressieve zorg voor het levenseinde**

### A.1 Indicator "Het aantal mensen die Lung Volume Reduction Surgery ondergingen tijdens de laatste 3 maanden voor het levenseinde"

- Bron: (Naunheim et al., 2006)
- Reden: Hoewel Lung Volume Reduction Surgery (LVRS) positief curatief resultaat kan hebben voor mensen met gevorderde emfysemen is het ook geassocieerd met beduidend meer morbiditeit (50%-60% incidentie van ernstige complicaties) en mortaliteit. (>5% 90-dagen mortaliteitsratio) Het is een typevoorbeeld van een invasieve curatieve ingreep die wanneer ze kort voor het overlijden gebeurt onder de noemer van therapeutische hardnekkigheid valt. Een relatief hoog percentage van dit soort ingrepen kan dus beschouwd worden als een indicator van ongepaste zorg.
- Teller: Het aantal mensen bij wie LVRS werd gedaan tijdens de laatste 3 maanden voor het overlijden.
- Noemer: Het totaal aantal mensen met COPD.
- Exclusie: mensen zonder COPD.
- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de behandeling LVRS. We maken een nieuwe binaire variabele die aangeeft of in het zorggebruik van de mens al dan niet LVRS voorkomt.
- Norm/richtcijfer: Nog te bepalen.

### A.2 Indicator "Het aantal mensen die endotracheale intubatie of tracheotomie kregen tijdens de laatste 12, 6, 3 of 1 maanden voor overlijden"

- Bron: (Clini and Ambrosino, 2008);
- Reden: Endotracheale intubatie en tracheotomie zijn invasieve methoden om het ademen te vergemakkelijken of mogelijk te maken. Het zijn beide noodmaatregelen die kort voor het overlijden en wanneer ze langere tijd worden toegepast duiden op ongepaste zorg voor het levenseinde. In deze indicator houden we geen rekening met de duur van de behandeling, dat doen we wel in een tweede indicator (zie verder).
- Teller:
  1. Het aantal mensen waarbij endotracheale intubatie voorkomt tijdens de laatste 365 dagen, 180 dagen, 90 dagen, 30 dagen voor het overlijden.

2. Het aantal mensen waarbij tracheotomie voorkomt tijdens de laatste 365 dagen, 180 dagen, 90 dagen, 30 dagen voor het overlijden.

- Noemer: Het totaal aantal mensen met COPD.

- Exclusie: mensen zonder COPD.

- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met endotracheale intubatie en tracheotomie. We creëren een nieuwe variabele die de prevalentie telt: het aantal mensen die één van beiden of allebei ondergaan.

- Norm/richtcijfer: Nog te bepalen.

A.3 Indicator "Het aantal mensen die endotracheale intubatie kregen gedurende langer dan 5 dagen aansluitend tijdens de laatste 12, 6, 3 of 1 maanden voor overlijden" voor mensen met COPD

- Bron: (Clini and Ambrosino, 2008); bevestigd door expertinterview.

- Reden: Endotracheale intubatie is een invasieve methode om het ademen te vergemakkelijken of mogelijk te maken. Endotracheale intubatie wordt bijvoorbeeld gebruikt tijdens operaties om de luchtwegen vrij te houden. Het is een noodmaatregel die wanneer hij langere tijd (langer dan 5 dagen) worden toegepast bij een relatief groot aantal mensen duidt op ongepaste zorg voor het levenseinde.

- Teller: Het aantal mensen die langdurig (>5 dagen) endotracheale intubatie tijdens de laatste 365 dagen, 180 dagen, 90 dagen, 30 dagen voor het overlijden voor overlijden.

- Noemer:

1. Het totaal aantal mensen die endotracheale intubatie ondergingen tijdens de laatste 2 jaar voor overlijden.

2. Het totaal aantal mensen met COPD.

- Exclusie: mensen zonder COPD.

- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met endotracheale intubatie. We creëren een nieuwe variabele die het aantal mensen telt die endotracheale intubatie ondergingen. We maken een bijkomende variabele die enkel de behandeling telt indien ze meer dan 5 opeenvolgende dagen duurt.

- Norm/richtcijfer: Nog te bepalen.

A.4 Indicator "Het aantal mensen die sondevoeding of intraveneuze (parenterale) voeding kregen in de laatste maand voor overlijden"

(zie Supplementary material S.1, indicator A.3)

A.5 Indicator "Het aantal mensen die benzodiazepinen kregen voor angstbestrijding"

- Bron: (Battaglia et al., 2015; Ekström et al., 2014; Hill et al., 2008)

- Reden: Benzodiazepinen worden onder andere gebruikt voor het bestrijden van angst. Depressie en angst komen regelmatig voor bij personen met COPD. Het gebruik van benzodiazepinen verhoogt echter het risico op een sterke periode van hypercapnie (verhoogd CO<sub>2</sub> gehalte in het bloed). Volgens sommige bronnen is het gebruik van benzodiazepinen bij een relatief groot percentage mensen met COPD een indicator van onangepaste zorg.

- Teller: Het aantal mensen met COPD met een voorschrift voor benzodiazepinen in de laatste 24, 12, 6 en 3 en 1 maand(en) voor het levenseinde.

- Noemer: Het totaal aantal mensen met COPD.

- Exclusie: mensen zonder COPD.

- Operationalisering in IMA-data: Binnen de variabele 'productcode' identificeren we de codes die overeenkomen met geneesmiddelen uit de benzodiazepinengroep. Voorbeelden zijn: Alprazolam, Chloridiazepoxide, Clonazepam, diazepam, lorazepam, oxazepam, prazepam.

- Norm/richtcijfer: Nog te bepalen.

A.6 Indicator "Het aantal mensen met één of meer opnames op de spoedafdeling van een ziekenhuis tijdens de laatste 6, 3 of 1 maand(en) voor het overlijden"

(zie Supplementary material S.1, indicator D.1)

A.7 Indicator "Het aantal mensen met één of meer ziekenhuisopnames tijdens de laatste maand voor overlijden"

(zie Supplementary material S.1, indicator D.2)

A.8 Indicator "Het aantal mensen waarbij diagnostische testen (bloedafname, spirometrie, EKG, dialyse of radiografie) werden afgenomen tijdens de laatste 30 dagen voor het overlijden"

(zie Supplementary material S.1, indicator A.6)

A.9 Indicator "Het aantal mensen waarvoor kinesitherapie wordt opgestart tijdens de laatste 14 dagen voor het levenseinde"

- Bron: expertinterview

- Reden: Kinesitherapie is vaak belastend voor de mens, vooral bij vergevorderde patiënten. Bovendien beïnvloedt het de prognose niet. Bij mensen met COPD kort voor het overlijden is het opstarten van kinesitherapie kort voor het levenseinde daarom een teken van ongepaste zorg, wanneer het bij een voldoende groot aantal mensen voorkomt.

- Teller: het aantal mensen die deelnemen aan kinesitherapie in de laatste 14 dagen voor het overlijden en die in de periode 15-45 dagen voor het overlijden niet deelnamen aan kinesitherapie.

- Noemer: het totaal aantal mensen met COPD.

- Exclusie: alle mensen zonder COPD.

- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling kinesitherapie. We gieten ze in een binaire variabele om aan te geven bij wie wel/niet kinesitherapie opgestart werd tijdens de laatste 14 dagen en 15-45 dagen voor het overlijden.

- Norm/richtcijfer: Nog te bepalen.

A.10 Indicator "Het aantal mensen waarbij een port-a-cath wordt geïnstalleerd in de laatste 14 dagen voor overlijden"

(zie Supplementary material S.1, indicator A.7)

A.11 Indicator "Het aantal mensen met langdurig per-oraal gebruik van corticoiden tijdens het laatste jaar, 6 maanden, 30 dagen en laatste 14 dagen voor overlijden"

(zie Supplementary material S.1, indicator A.8)

A.12 Indicator "Het aantal mensen met herhaaldelijke intubatie tijdens de laatste 12, 6, 3 en 1 maanden voor het overlijden"

- Bron: expertinterview
- Reden: Intubatie kan nuttig zijn voor acute zorg bij mensen met COPD. Het is echter een belastende ingreep voor de patiënt. Wanneer her-intuberen op korte termijn nodig is, betekent dat dat de eerste intubatie niet voldoende effect had. Daarom hanteren we her-intubatie als teken van ongepaste zorg aan het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal mensen met incidentie van herintubatie (2 of meerdere keren geïntubeerd) tijdens de laatste 12, 6, 3 en 1 maanden voor het overlijden.
- Noemer: Het totaal aantal mensen met COPD.
- Exclusie: mensen zonder COPD.
- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met intubatie. We creëren een nieuwe variabele die aangeeft of bij de overledene de intubatie meer dan 1 keer voorkomt binnen de verschillende meetperioden.
- Norm/richtcijfer: Nog te bepalen.

A.13 Indicator "Het aantal mensen dat een coronaire of abdominale ingreep kreeg tijdens de laatste 6 maanden, 3 maanden, of 30 dagen voor het overlijden"

- Bron: expertinterview
- Reden: Coronaire en abdominale operaties zijn enkel effectief op langer termijn. Bovendien is de weerstand van de ernstige COPD-patiënt onvoldoende om een dergelijke operatie te verdragen. Daarom beschouwen we het krijgen van een coronaire of abdominale ingreep als teken van ongepaste zorg voor het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: Het aantal mensen met een coronaire of abdominale ingreep 6, 3 of 1 maanden voor het overlijden.
- Noemer: Het totaal aantal mensen met COPD.
- Exclusie: mensen zonder COPD.
- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met een coronaire of abdominale ingreep. We creëren een nieuwe variabele die aangeeft of bij de overledene in de laatste 6, 3 of 1 maanden voor overlijden een dergelijke ingreep heeft gekregen.

- Norm/richtcijfer: Nog te bepalen.

A.14 Indicator "Het aantal mensen met een reanimatie na intubatie tijdens de laatste 30 dagen voor het overlijden"

- Bron: expertinterview

- Reden: Intubatie kan nuttig zijn voor acute zorg bij mensen met COPD. Reanimatie na intubatie is echter zinloos. Het betekent immers dat de eerste intubatie geen effect had en dat men noodingrepen aan het toepassen is in een chronische setting. Daarom beschouwen we reanimatie na intubatie als een teken van ongepaste zorg kort bij het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.

- Teller: Het aantal mensen met COPD met incidentie van intubatie en minder dan een week nadien reanimatie tijdens de laatste maand voor het overlijden.

- Noemer: Het totaal aantal mensen met COPD.

- Exclusie: mensen zonder COPD.

- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met intubatie en met reanimatie. We creëren een nieuwe variabele die aangeeft of bij de overledene in de laatste maand voor overlijden een reanimatie na intubatie voorkomt.

- Norm/richtcijfer: Nog te bepalen.

A.15 Indicator "Het gemiddeld aantal verstrekkingen per dag van antibiotica tijdens de laatste 2 jaar voor overlijden"

- Bron: expertinterview

- Reden: Gebruik van antibiotica is vaak nuttig. Frequent gebruik van antibiotica bij mensen met COPD hangt echter samen met herhaalde exacerbaties en een verlaagde immuniteit. Daarom is het bij mensen met COPD een indicator van ongepaste zorg, indien het bij een voldoende groot aantal mensen voorkomt.

- Teller: Het aantal voorschriften voor antibiotica over alle mensen heen per dag, bij mensen met COPD, gedurende de laatste 2 jaar voor overlijden.

- Noemer: Het totaal aantal mensen met COPD.

- Exclusie: mensen zonder COPD.

- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met antibioticavoorschriften. Per dag tellen we het aantal voorschriften voor antibiotica dat verstrekt werd. We maken een nieuwe variabele die deze telling representeert: voor elke dag bevat die variabele het aantal voorschriften van antibiotica. We brengen zo de evolutie in kaart naar het levenseinde toe.
- Norm/richtcijfer: hoe lager, hoe positiever voor de kwaliteit van zorg.

A.16 Indicator "Het gemiddeld aantal voorschriften van anxiolytica en antidepressiva tijdens het laatste jaar voor overlijden"

(zie Supplementary material S.1, indicator A.10)

A.17 Indicator "Het aantal mensen dat chirurgie ondergaat 6, 2 of 1 maand(en) voor het overlijden"

(zie Supplementary material S.1, indicator A.11)

A.18 Indicator "Het aantal mensen met een bloedtransfusie tijdens de laatste 2 maanden/1maand/14 dagen voor overlijden" (met uitzondering van mensen met een hematologische aandoening)

(zie Supplementary material S.1, indicator A.12)

## **B. Thema: Behandelen van pijn en fysieke symptomen**

B.1 Indicator "Het aantal mensen die Noninvasive Positive Pressure Ventilation kregen bij hospitalisatie"

- Bron: (Ambrosino and Vaghegghini, 2008; Ramsay and Hart, 2013; Sinuff et al., 2008; Williams et al., 2013)

- Reden: NPPV verlicht symptomen van ademnood aan het levenseinde, verlaagt de nood aan invasieve behandelingen, verlaagt de kans op complicaties en verkort een mogelijk ICU verblijf bij mensen met COPD. Als zodanig is het gebruik ervan bij een relatief hoog percentage mensen een teken van gepaste zorg aan het levenseinde.

- Teller: Het aantal mensen met COPD die NPPV ondergaan. (in de laatste 2 jaar voor het overlijden)

- Noemer: Het totaal aantal mensen met COPD.
- Exclusie: mensen zonder COPD.
- Operationalisering in IMA-data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de behandeling NPPV. Behandelingen met de naam 'continuous positive airway pressure' (CPAP) of 'bilevel positive airway pressure' vallen ook onder de naam NPPV. We maken een nieuwe variabele die aangeeft of in het zorggebruik van de mens al dan niet NPPV voorkomt.
- Norm/richtcijfer: Nog te bepalen.

### B.2 Indicator "Het aantal mensen die opioïden kregen voor pijn- en symptoombestrijding in de laatste maand voor overlijden"

- Bron: (Luce and Luce, 2001), bevestigd door expertinterview.
- Reden: Opioïden bij mensen met COPD verminderen het gevoel van ademnood en de neiging tot te snel ademen, wat een lagere luchtcirculatie per minuut tot gevolg heeft. Het verminderen van het gevoel van ademnood heeft verregaande positieve psychologische en sociale gevolgen voor de patiënt. Bovendien zijn opioïden ook werkzaam als pijnbestrijding. Daarom is een relatief groot percentage mensen waarbij opioïden gebruikt wordt een teken van gepaste zorg aan het levenseinde.
- Teller: Het aantal mensen met COPD met een voorschrift voor opioïden in de laatste 6 maanden, de laatste 3 maanden, de laatste maand en de laatste 14 dagen voor het levenseinde
- Noemer: Het totaal aantal mensen met COPD.
- Exclusie: mensen zonder COPD.
- Operationalisering in IMA-data: Binnen de pharmanet-databank identificeren we de codes die overeenkomen met geneesmiddelen uit de opioïdengroep. Voorbeelden zijn: morfine, codeïne, oxycodone hydrochloride, fentanyl citraat.
- Norm/richtcijfer: Nog te bepalen.

### B.3 Indicator "Het aantal mensen dat inhalatietherapie (inhalatiecorticosteroiden, anticholinergica, Bèta-2 memetica) gebruikte tijdens de laatste 6, 3 of 1 maand(en) voor het levenseinde"

- Bron: expertinterview



- Reden: Inhalatietherapie werkt symptoom-verlichtend voor mensen met COPD. Als zodanig is het een teken van gepaste zorg aan het levenseinde, indien bij voldoende mensen voorkomt.
- Teller: Het aantal mensen met COPD die in de laatste 6 maanden, 3 maanden of de laatste maand voor het levenseinde inhalatietherapie krijgen toegediend.
- Noemer: alle overleden mensen met COPD.
- Exclusie: mensen zonder COPD.
- Operationalisering in IMA-data: we zoeken een nomenclatuurcode voor de verschillende vormen van inhalatietherapie en gaan de aanwezigheid ervan na in de laatste 6, 3 of 1 maand(en) voor overlijden.
- Norm/richtcijfers: Nog te bepalen.

#### B.4 Indicator "het aantal mensen dat contact had met een psycholoog in de laatste 2 maanden voor overlijden"

(zie Supplementary material S.1, indicator B.7)

### **C. Thema: Het (tijdig) opstarten van palliatieve zorg**

#### C.1 Indicator "Het aantal mensen die gespecialiseerde palliatieve zorg ontvingen"

(zie Supplementary material S.1, indicator C.1)

#### C.2 Indicator "Het aantal mensen dat gebruik maakt van de ondersteuningsmaatregel 'palliatief statuut'"

(zie Supplementary material S.1, indicator C.2)

#### C.3 Indicator "Het aantal mensen dat gespecialiseerde palliatieve zorg ontving of het palliatief statuut kreeg toegewezen minder dan 1 week voor het overlijden"

(zie Supplementary material S.1, indicator C.3)

### **D. Thema 4: Plaats van overlijden en levenseindezorg**

#### D.1 Indicator "Het aantal mensen die thuis overlijden"

(zie Supplementary material S.1, indicator D.4)

#### D.2 Indicator "Het aantal mensen die thuis of in een WZC van residentie overlijden"

(zie Supplementary material S.1, indicator D.5)

#### D.3 Indicator "Het aantal mensen die in het ziekenhuis overlijden"

(zie Supplementary material S.1, indicator D.3)

### **E. Thema: Coördinatie en continuïteit van de zorg**

#### E.1 Indicator "Aantal mensen met een gemiddelde toename van het aantal huisartscontacten tijdens de laatste 30 dagen voor het levenseinde"

(zie Supplementary material S.1, indicator E.2)

#### E.2 Indicator "Het gemiddeld aantal contacten met de huisarts of andere eerste-lijns-zorgers tijdens de laatste 3 maanden voor overlijden"

(zie Supplementary material S.1, indicator E.3)

#### E.3 Indicator "Het aantal mensen met een opname op een intensive care unit kort voor het overlijden"

- Bron: expertinterview

- Reden: Opname op een intensive care unit kort voor het levenseinde is een teken van futiele zorg. Bovendien is het vaak er belastend voor wie het ondergaat. Daarom kiezen we het als een teken van ongepaste zorg voor het levenseinde, indien het bij een voldoende groot aantal mensen voorkomt.

- Teller: het aantal mensen met COPD dat opgenomen is op een intensive care unit de laatste 2 maanden, 1 maand en 2 weken voor het levenseinde.

- Noemer: het totaal aantal mensen met COPD.

- Exclusie: alle mensen zonder COPD.

- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we opname op een intensive care unit. We creëren een binaire variabele die weergeeft of de opname al dan niet heeft plaatsgevonden tijdens de laatste twee weken.

- Norm/richtcijfer: Nog te bepalen.

E.4 Indicator "Het aantal residenten van een woonzorgcentrum met een opname in een ICU tijdens de laatste 6 of 3 maanden en 2 weken of 1 week voor overlijden"

(zie Supplementary material S.1, indicator E.1)

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### **Supplementary material S.3:** Indicatoren voor (on)gepaste zorg aan het levenseinde bij mensen met dementie via administratieve data

Volgende kenmerken vindt men bij elke indicator terug:

- Een inhoudelijke beschrijving van de indicator in de titel
- De bron van de indicator, uit literatuur of uit expertinterview
- De reden waarom de indicator een teken is van gepaste of ongepaste zorg
- De teller en noemer om de indicator te berekenen
- Exclusie van subpopulaties waarvoor de indicator niet geldt
- De operationalisering van de indicator in de IMA-databank
- Een norm/richtcijfer voor de score op deze indicator (waar mogelijk)

## **Terminologie**

Een aantal begrippen worden regelmatig herhaald en zijn geen standaard taalgebruik. Van deze termen geven we hier een korte verklaring. Het is nuttig om deze vooraf door te nemen.

1. *Reden*: Wanneer we bij 'reden' spreken over de motivatie om een bepaalde indicator op te nemen als teken van gepaste of ongepaste zorg, is dat steeds bedoeld op geaggregeerd niveau. Een indicator geldt dus niet voor elke mens (persoon/patiënt) in elke situatie. De indicatoren worden op populatieniveau gemeten en zeggen dus iets over het voorkomen van bepaalde zorgpraktijken in België.

2. *De variabele 'nomenclatuurcode'* is een variabele in de IMA-databank "gezondheidszorgen", die alle nomenclatuurcodes van terugbetaalde medische handelingen bevat. Als zodanig wordt hij vaak gebruikt in de operationalisering van indicatoren voor gepaste of ongepaste zorg.

3. *De variabele 'productcode'* is een variabele uit de IMA-databank "farmanet", die alle productcodes van terugbetaalde medicijnen (op voorschrift) bevat. Als zodanig wordt hij vaak gebruikt in de operationalisering van indicatoren voor gepaste of ongepaste zorg.

6. Norm/richtcijfer is veelal niet vastgelegd. Ze kan echter worden vastgelegd op basis van de waargenomen verdelingen (bijvoorbeeld op basis van best practice examples, bijvoorbeeld de beste 10%). In de lijst is dit aangegeven met "nog te bepalen".

## **A. Thema: Afwezigheid van agressieve zorg voor het levenseinde**

### A.1. Indicator "Het aantal mensen die sondevoeding of intraveneuze (parenterale) voeding kregen in de laatste maand voor overlijden"

(zie Supplementary material S.1, indicator A.3)

### A.2. Indicator "Het aantal mensen waarbij diagnostische testen (bloedafname, spirometrie, EKG, dialyse of radiografie) werden afgenomen tijdens de laatste maand voor het overlijden"

(zie Supplementary material S.1, indicator A.6)

### A.3. Indicator "Het aantal mensen waarbij statines niet werden afgebouwd tijdens het laatste jaar, laatste 6 maanden en laatste 30 dagen voor overlijden"

- Bron: expertinterview

- Reden: Een vaak voorkomend probleem bij mensen met Alzheimer is dat ze een veelvoud van medicatie innemen. Dit verhoogt het risico tot sterkere bijwerking en het verminderen van het werkzame effect van deze medicijnen. Bovendien is het positieve effect van bepaalde medicijnen slechts op lange termijn (10 jaar of meer) merkbaar. We hebben het dan bijvoorbeeld over statines. Het niet afbouwen van dergelijke medicatie is een teken van ongepaste zorg aan het levenseinde, indien het bij een voldoende groot aantal mensen voorkomt.

- Teller: het aantal mensen met Alzheimer die onderworpen worden aan statines in de laatste maanden en jaren voor het overlijden. We stellen meetmomenten in op 2 jaar, 1 jaar, 6 maanden en 1 maand voor overlijden.

- Noemer: het totaal aantal mensen overleden met Alzheimer.

- Exclusie: alle mensen zonder Alzheimer.

- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling met statines. We gieten ze in een binaire variabele om aan te geven wie wel/niet statines kreeg tijdens de laatste maanden en jaren voor het overlijden. We berekenen een afzonderlijke periode voor elke tijdsperiode (2 jaar, 1 jaar, 6 maanden en 1 maand voor overlijden)

- Norm/richtcijfer: Nog te bepalen.

A.4. Indicator "Het aantal mensen waarbij een port-a-cath wordt geïnstalleerd in de laatste 7 dagen voor overlijden"

(zie Supplementary material S.1, indicator A.7)

A.5. Indicator "Het aantal mensen met langdurig per-oraal gebruik van corticoïden tijdens het laatste jaar, 6 maanden, 30 dagen en laatste 14 dagen voor overlijden"

(zie Supplementary material S.1, indicator A.8)

A.6. Indicator "Het gemiddeld aantal contacten met een neuroloog tijdens het laatste jaar, 6 maanden, 3 maanden en 30 dagen voor overlijden"

- Bron: expertinterview

- Reden: Contact met specialisten is vaak belastend en duur. Bovendien is het voor mensen met Alzheimer vaak overbodig. Aangezien de prognose niet kan worden beïnvloed, is enkel comfortzorg aan de orde. Dergelijke zorg gebeurt doorgaans door de huisarts, die de patiënt idealiter ook persoonlijk kent. Daarom hanteren we contact met de neuroloog als indicator voor ongepaste zorg aan het levenseinde, wanneer het bij een voldoende aantal mensen in voldoende mate voorkomt.

- Teller: Het totaal aantal bezoeken aan een neuroloog voor mensen met Alzheimer tijdens de laatste 2 jaar, 1 jaar, 6 maanden, 3 maanden en 1 maand voor het overlijden.

- Noemer: het totaal aantal mensen overleden met Alzheimer.

- Exclusie: mensen zonder Alzheimer.

- Operationalisering in IMA data: We zoeken in de gezondheidszorgdata naar codes voor neurologen en creëren een nieuwe variabele die telt hoe vaak iemand die specialist wel of niet bezocht heeft op de verschillende meetmomenten voor overlijden.

- Norm/richtcijfer: Nog te bepalen.

A.7. Indicator "Het aantal mensen waarbij gastric protectors (proton pump inhibitors, H2-blokkers en misoprostol) worden gebruikt tijdens de laatste 6 maanden, 3 maanden, 30 dagen en 7 dagen voor het overlijden"

- Bron: expertinterview



- Reden: Het gebruik van *gastric protectors* wordt nuttig geacht bij het veelvuldig gebruik van medicatie, om de maag te beschermen tegen maagbloeding of maagzweer. Als zodanig duiden ze vaak op polymedicatie. Dit is een ernstig probleem bij ouderen, dat een teken kan zijn van futiele zorg kort voor het levenseinde. Bovendien werken een aantal *gastric protectors* enkel op lange termijn, wat hun gebruik kort voor het levenseinde overbodig maakt. Daarom beschouwen we het gebruik van *gastric protectors* als teken van ongepaste zorg voor het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met Alzheimer die *gastric protectors* krijgen voorgeschreven in de laatste 6 maanden, 3 maanden en 30 dagen en 14 dagen voor het overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling met *gastric protectors*. We berekenen het aantal mensen dat ze kreeg tijdens de een vastgelegde periode (6 of 3 maanden, 30 dagen of 14 dagen) voor het overlijden.
- Norm/richtcijfer: Nog te bepalen.

A.8. Indicator "Het aantal mensen waarbij anti-hypertensiva werden gebruikt in de laatste 6 maanden, 3 maanden, 30 dagen en 14 dagen voor het overlijden"

- Bron: expertinterview
- Reden: Gebruik van anti-hypertensiva wordt nuttig geacht bij een grote groep mensen en veelvuldig voorgeschreven in België. Ze zijn echter enkel effectief in het verlagen van bloeddruk op lange termijn. Bovendien verwachten we naar het levenseinde toe eerder problemen met te lage bloeddruk dan met te hoge. Daarom is het gebruik van anti-hypertensiva kort voor het levenseinde futiel en als zodanig beschouwen we het als teken van ongepaste zorg voor het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met Alzheimer die onderworpen worden aan anti-hypertensiva in de laatste 6 maanden, 3 maanden, 30 dagen en 14 dagen voor het overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.

- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling met anti-hypertensiva. We berekenen het aantal mensen dat ze kreeg tijdens de een vastgelegde periode (6 of 3 maanden, 1 of 4 weken) voor het overlijden.
- Norm/richtcijfer: Nog te bepalen.

A.9. Indicator "Het aantal mensen dat Calcium vitamine D krijgt kort in de laatste 6 maanden, 3 maanden, 30 dagen en 14 dagen voor het overlijden"

- Bron: expertinterview
- Reden: Voedingssupplementen als multivitaminen, ijzerpreparaten en dergelijke zijn overbodig kort voor het levenseinde. Vaak zijn ze niet op voorschrift te krijgen, zodat we ze in het kader van deze studie niet terugvinden in de IMA-databank. Wat wel terug te vinden is in de IMA-gegevens is het gebruik van Calcium vitamine D. We richten ons dus specifiek daarop en benoemen het gebruik van Calcium vitamine D als indicator van ongepaste zorg voor het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met Alzheimer die onderworpen worden aan calcium vitamine D in de laatste 6 maanden, 3 maanden, 30 dagen en 14 dagen voor het overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling met calcium vitamine D. We berekenen het aantal mensen dat ze kreeg tijdens de een vastgelegde periode (6 of 3 maanden, 30 of 14 dagen) voor het overlijden.
- Norm/richtcijfer: Nog te bepalen.

A.10. Indicator "Het aantal mensen dat anti-bloedklontering krijgt in de laatste 3 maanden, 30 dagen en 14 dagen voor het overlijden"

- Bron: expertinterview
- Reden: Gebruik van anti-bloedklontering medicatie (bv. kinderaspirine 80mg) ter preventie van bloedklontering is kort voor het overlijden overbodig. Op middellange termijn is deze medicatie effectief, maar kort voor het overlijden is ze een teken van futiele zorg. Daarom beschouwen we het gebruik van anti-bloedklontering medicatie kort voor het levenseinde als teken van ongepaste zorg voor

het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.

- Teller: het aantal mensen met Alzheimer die onderworpen worden aan anti-bloedklontering medicatie in de laatste 3 maanden, 30 dagen en 14 dagen voor het overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling met anti-bloedklontering medicatie. We berekenen het aantal mensen dat ze kreeg tijdens de een vastgelegde periode (3 maanden, 30 of 14 dagen) voor het overlijden.
- Norm/richtcijfer: Nog te bepalen.

A.11. Indicator "Het aantal mensen dat Allopurinol krijgt in de laatste 6 maanden, 3 maanden, 30 dagen en 14 dagen voor het overlijden"

- Bron: expertinterview
- Reden: Via kristallisering geeft urinezuur aanleiding tot jicht en verlaagt de levenskwaliteit. Allopurinol wordt gebruikt om urinezuur te neutraliseren als preventief geneesmiddel op lange termijn. Kort voor het overlijden kunnen we het beschouwen als overbodige zorg en als zodanig aannemen als indicator van ongepaste zorg, als het bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met Alzheimer die onderworpen worden aan Allopurinol medicatie in de laatste 6 maanden, 3 maanden, 30 dagen en 14 dagen voor het overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling Allopurinol. We berekenen het aantal mensen dat het kreeg voorgeschreven tijdens de een vastgelegde periode (6 of 3 maanden, 30 of 14 dagen) voor het overlijden.
- Norm/richtcijfer: Nog te bepalen.

A.12. Indicator "Het aantal mensen met een reanimatie tijdens de 90 dagen, 30 dagen, 14 dagen of 1 dag voor het overlijden"

- Bron: expertinterview

- Reden: Bij mensen met Alzheimer in een sterke mate van zorgafhankelijkheid is reanimeren een teken van ongepaste zorg, wegens te agressief en vaak overbodig. We veronderstellen dat een groot aantal van de mensen die overlijden met Alzheimer sterk zorgafhankelijk zijn kort voor het levenseinde. Bij deze subpopulatie beschouwen we reanimatie kort voor het overlijden als een teken van ongepaste zorg, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met Alzheimer die een reanimatie ondergingen in de 90 dagen, 30 dagen, 14 dagen of 1 dag voor het overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling 'reanimatie'. Het voorkomen ervan tellen we binnen de vooropgestelde periode (90, 30, 14 of 1 dag voor overlijden).
- Norm/richtcijfer: Nog te bepalen.

A.13. Indicator "Het aantal mensen waarbij gedragsgerichte medicatie (neuroleptica en benzodiazepinen) worden gebruikt kort voor het overlijden"

- Bron: expertinterview
- Reden: Gedragsstoornissen zijn typerend voor een tussenstadium van dementie. Dit stadium ligt doorgaans meer dan 2 jaar voor het overlijden. (we kunnen dit stellen vanwege het relatief voorspelbare verloop van Alzheimer) In dat stadium zijn neuroleptica en benzodiazepinen geschikt om gedragsstoornissen te beperken. In latere stadia zijn ze echter overbodig. Dit betekent dat we het gebruik van neuroleptica en benzodiazepinen kunnen beschouwen als een teken van ongepaste zorg kort bij het levenseinde, wanneer het bij een voldoende groot aantal mensen voorkomt.
- Teller: het aantal mensen met Alzheimer die neuroleptica of benzodiazepinen krijgen voorgeschreven tijdens de laatste 2 jaar, 1 jaar, 6 maanden, 3 maanden of 1 maand voor overlijden.
- Noemer: het totaal aantal mensen overleden met Alzheimer.
- Exclusie: alle mensen zonder Alzheimer.
- Operationalisering in IMA: Via de nomenclatuurcodes identificeren we de behandeling met neuroleptica en benzodiazepinen. We gieten ze in een binaire variabele om aan te geven wie ze wel/niet kreeg tijdens

de genoemde perioden voor het overlijden. We berekenen ze zowel afzonderlijk als de OF modaliteit (of ze één van voorgaande kregen).

- Norm/richtcijfer: Nog te bepalen.

A.14. Indicator "Het aantal mensen met Alzheimer en kanker die chemotherapie ondergaan kort voor het overlijden"

- Bron: expertinterview

- Reden: Bij mensen met een ernstige graad van dementie is het toepassen van chemotherapie een teken van futiele zorg en bovendien erg belastend. Daarom is het een indicator van ongepaste zorg, indien het bij een voldoende groot aantal mensen voorkomt.

- Teller: Het aantal mensen met Alzheimer en kanker die een chemotherapiebehandeling krijgen in de laatste 2 jaar, het laatste jaar, de laatste 6 maanden en de laatste maand voor het overlijden.

- Noemer: Het totaal aantal mensen met zowel Alzheimer als kanker.

- Exclusie: mensen die niet zowel kanker als Alzheimer hebben.

- Operationalisering in IMA data: Binnen de variabele 'nomenclatuurcode' identificeren we de codes die overeenkomen met de verschillende behandelingen chemotherapie. De variabele 'nomenclatuurcode' wordt gekoppeld aan de variabele 'datum' en wordt vervolgens geordend op de variabele 'datum'. We berekenen voor elk meetmoment (2 jaar, 1 jaar, 6 maanden, 1 maand voor overlijden) hoe veel mensen chemotherapiebehandeling kregen.

- Norm/richtcijfer: Nog te bepalen.

A.15. Indicator "Het gemiddeld aantal voorschriften van anxiolytica en antidepressiva tijdens het laatste jaar voor overlijden"

(zie Supplementary material S.1, indicator A.10)

A.16. Indicator "Het aantal mensen dat chirurgie ondergaat 6, 2 of 1 maand(en) voor het overlijden"

(zie Supplementary material S.1, indicator A.11)

A.17. Indicator "Het aantal mensen met een bloedtransfusie tijdens de laatste 2 maanden/1maand/14 dagen voor overlijden" (met uitzondering van mensen met een hematologische aandoening)

(zie Supplementary material S.1, indicator A.12)

## **B. Thema: Behandelen van pijn en fysieke symptomen**

B.1. Indicator "Het aantal mensen die een combinatie kregen van morfine en neuropathische middelen kregen voor pijnbestrijding"

(zie Supplementary material S.1, indicator B.6)

B.2. Indicator "het aantal mensen dat contact had met een psycholoog in de laatste 2 maanden voor overlijden"

(zie Supplementary material S.1, indicator B.7)

## **C. Thema: Het (tijdig) opstarten van palliatieve zorg**

C.1. Indicator "Het aantal mensen die gespecialiseerde palliatieve zorg ontvingen"

(zie Supplementary material S.1, indicator C.1)

C.2. Indicator "Het aantal mensen dat gebruik maakt van de ondersteuningsmaatregel 'palliatief statuut'"

(zie Supplementary material S.1, indicator C.2)

C.3. Indicator "Het aantal mensen dat gespecialiseerde palliatieve zorg ontving of het palliatief statuut kreeg toegewezen minder dan 1 week voor het overlijden"

(zie Supplementary material S.1, indicator C.3)

## **D. Thema 4: Plaats van overlijden en levenseindezorg**

D.1. Indicator "Het aantal mensen die thuis overlijden"

(zie Supplementary material S.1, indicator D.4)

D.2. Indicator "Het aantal mensen die thuis of in een WZC van residentie overlijden"

(zie Supplementary material S.1, indicator D.5)

D.3. Indicator "Het aantal mensen met één of meer opnames in een ziekenhuis tijdens de laatste 6, 3 of 1 maand(en) voor het overlijden"

(zie Supplementary material S.1, indicator D.2)

D.4. Indicator "Het aantal mensen met één of meer opnames op de spoedafdeling van een ziekenhuis tijdens de laatste 6, 3 of 1 maand(en) voor het overlijden"

(zie Supplementary material S.1, indicator D.1)

D.5. Indicator "Het aantal mensen die in het ziekenhuis overlijden"

(zie Supplementary material S.1, indicator D.3)

D.6. Indicator "Het aantal mensen met een opname op een intensive care unit kort voor het overlijden"

(zie Supplementary material S.2, indicator E.3)

**E. Thema: Coördinatie en continuïteit van de zorg**

E.1. Indicator "Het aantal mensen met een gemiddelde toename van het aantal huisartscontacten tijdens de laatste maand voor het levenseinde"

(zie Supplementary material S.1, indicator E.2)

E.2. Indicator "Het gemiddeld aantal contacten met de huisarts of andere eerste lijnszorgers tijdens de laatste 3 maanden voor overlijden"

(zie Supplementary material S.1, indicator E.3)

E.3. Indicator "Het aantal residenten van een woonzorgcentrum met een opname in een ICU tijdens de laatste 6 of 3 maanden en 2 weken of 1 week voor overlijden"

(zie Supplementary material S.1, indicator E.1)

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**Supplementary table S.4:** QIs that were rejected by the expert panel, phase 3b: plenary discussion.

Indicator (brief description)	Indicator of appropriate (A) or inappropriate (I) care	Numerator (Number of people who died with*)	Number of people who died with*	Motivation from the experts for rejection
Chemotherapy Third line <sup>†</sup>	I	*cancer who received a third line of chemotherapy	*cancer	Cancer type determines appropriateness
Prolonged corticoids <sup>‡</sup>	I	*cancer who had prolonged peroral use of corticoids in the last [12, 6, 1] months prior to death	*cancer	Dosage determines appropriateness
Oxygen with lung metastases <sup>‡</sup>	I	*cancer with lung metastases who received oxygen treatment	*cancer	Psychologically comforting and easy to apply
Anti-emetics with cytostatics <sup>‡</sup>	A	*cancer who received cytostatics who received anti-emetics	*cancer	Standard care
Psychologist visit <sup>‡</sup>	A	*cancer who had contact with a psychologist in the last 2 months prior to death	*cancer, COPD or Alzheimer's disease	Not measurable with current data
Died in hospital <sup>†</sup>	I	*cancer who died in hospital	*cancer	No viable alternatives in some patients
Benzodiazepines <sup>†</sup>	I	*COPD who received benzodiazepines in the last year prior to death	*COPD	No viable alternatives. High use in general
Corticoids <sup>‡</sup>	I	*COPD who received prolonged corticoid treatment	*COPD	Unclear definition of 'prolonged'
Antibiotics <sup>‡</sup>	I	Sum of the number of prescriptions for antibiotics per day for people who died with COPD	*COPD	Standard care for exacerbation
Noninvasive positive pressure ventilation <sup>†</sup>	A	*COPD who received Noninvasive positive pressure ventilation while in hospital	*COPD	Not suitable in end-of-life context, uncomfortable
Corticoids <sup>‡</sup>	I	*Alzheimer's disease who had prolonged peroral corticoid use in the last 2 months prior to death	*Alzheimer's disease	Strong individual variation. Unclear definition of 'prolonged'
Neuroleptics or benzodiazepines <sup>‡</sup>	I	*Alzheimer's disease who received neuroleptics or benzodiazepines in the last year prior to death	*Alzheimer's disease	Appropriateness depends on intention of carer

<sup>†</sup>Indicator from literature, <sup>‡</sup>Indicator from interviews

**Supplementary table S.5:** Complete list of variables in the linked dataset (IMA - Statistics Belgium - BCR)

Flag	Variable	Description
<b>Statistics Belgium: Death certificates database</b>		
	Immediate cause of death	The primary disease/cause prior to death, + up to 3 underlying causes.
	Associated causes of death	Up to 3 factors that indirectly contributed to death.
<b>Statistics Belgium: data based on demographic datasets</b>		
	natgr	Nationality-group: indicates to which of 16 most common nationalities in Belgium someone belongs. Less common nationalities are aggregated. (e.g. EU-other, Europe-other, other)
	liprohht	LIPRO-household type: e.g. single parent, married with/without children, ...
<b>Statistics Belgium : Socio-economic survey 2001 and census 2011</b>		
	q9a/EDU	Highest level of education.
	q16a_m/SIE	Main profession.
<b>Statistics Belgium: Composite variables socio-economic survey 2001</b>		
	comf	Housing comfort level, based on number of types of different rooms (e.g. kitchen, bathroom...) and heating system.
<b>Statistics Belgium: IPCAL dataset</b>		
	Net income	Net income in the year prior to death. Provided relative to the entire population, not in absolute numbers.

IMA: Population database		
ANON_BASE	Recoded PP0010 and SS00010	Unique identification of the rightful claimant (coded)
	PP0015	Age (based on year of birth)
	AGE05_CAT	Age of the rightful claimant in categories of 5 years, calculated on December 31 of the reference year.
	PP0020	Sex
Care region (based on NIS code)	Recoded PP0025	Care region on the hospital level (in Flanders)
PROVINCE/DISTRICT	Based on PP0025	Official place of residence at time of death
URB_CAT	Based on PP0025	Degree of urbanisation of the place of residence
	PP0030	Social status (e.g. working, retired, ...)
	PP0040 (A, B, C)	Year of death
	PP1010	Indicates whether the claimant received enhanced reimbursement.
	PP2001	Indicates whether the claimant received a forfeit class B nursing care.
	PP2002	Indicates whether the claimant received a forfeit class C for nursing care.
	PP2003	Indicates whether the claimant received a forfeit class E for physiotherapy.
	PP2005	Indicates whether the claimant received the allowance for the integration of disabled persons (category III, IV, V).
	PP2006	Indicates whether the claimant received the allowance for assistance to the elderly (category III, IV, V).

	PP2007	Indicates whether the claimant received a payment for assistance of third person carers.
	PP2008	Indicates whether the claimant received an increased allowance for help from third parties. (based on degree of disability)
	PP2009	Indicates whether the claimant received a lump sum benefit for 'assistance to others'.
	PP2010	Indicates whether the claimant was hospitalised at least 120 days during the last 2 years.
	PP2011	Indicates whether the claimant was hospitalised at least 6 times during the last 2 years.
	PP3004	Reimbursement category of the family.
	PP3005	Reimbursement category of the individual.
	PP3006	Date of the first claim entitled for maximum billing (provided in days prior to death).
	PP3011	Indicates whether the claimant received special allowances for disabled persons.
	PP3014	Indicates whether the claimant was entitled for maximum billing for the chronically diseased.
	PP4002	Number of days of unemployment due to disability.
	PP4003	Number of days of disability.
	PP4004	Evaluation of degree of functional status
CHRONICAL_YN		Indicates whether the claimant had at least one chronic illness in the last year and/or was entitled to an allowance for disabled persons.

IC_AVAIL_SA11 - IC_AVAIL_SA26		Estimation of the availability of family and informal caregivers, based on age and social status of family members.
<b>IMA: Medical claims database</b>		
	SS00015	Relative starting date of provision
	SS00020	Nomenclature code
	SS00050	Number of cases of provision
	SS00055	Number of days of provision
	SS00060	Amount of reimbursement
	SS00065B	Caregivers' qualifications
	SS00070B	Prescribers' qualifications
	SS00075	Identification of institution of the caregiver or prescriber (coded, not nominative)
	SS00080	Department code of the institution where care was provided
	SS00085	Place of care delivery (coded)
	SS00105	Number of institution which receives the payment
	SS00110	Date of hospitalisation
	SS00115	Date of hospital discharge
NEW_YN		Indication whether provided care is performed at weekends or at night
STAY_NR		Date of hospital admission
STAY_CAT		Type of hospital admission

ADMISSION, ADMISSION_YYYY		The first day that a stay is charged at a residence
DISCHARGE, DISCHARGE_YYYY		The last day that a stay is charged at a residence
LOS		Length of stay
LOS_YYYY		The calculated length of stay in a year
	SS00120	Invoice type
	SS00125	Date of last performance
	SS00130	Invoicing performance code
	SS00135	Pharmaceutical product code
	SS00140	Specification code of provision of care
	SS00150	Billed nomenclature code
	SS00155	Prescription date
	SS00160	Patient co-payment cost
	SS00165	Supplement
	SS00170	Code implant
	SS00175	Third party payer
THIRD_YN		Indicates whether a third party payer was involved
HOSP_ADM	SS00075, SS00085, SS00105	Identification hospital admission
HOSP_TRANS	SS00075, SS00085, SS00135	Identification hospital transfer(s)
<b>IMA: Pharmanet database</b>		
	SS00015	Delivery date

	SS00020	Medication reimbursement category
	SS00050	Drug quantity
	SS00060	National Health and disability insurance contribution 1
	SS00070B	Profession type of prescriber
	SS00075	Type of long-term care
	SS00135	Product number
	SS00155	Date of prescription (in days before death)
	SS00160	Out-of-pocket cost
	SS00165	Reduced repayment amount / Contribution of pharmacists
	SS00180	Reduced insurance contribution
	SS00195	National health and disability insurance contribution 2
	SS00200	Fee coding
	SS00210	Supplement
PHARMACIST_C, PHARMACIST_CAT		Pharmacist C is the coded unique identification number of the supplier of the performance.  Pharmacist_cat indicates the type of the supplier of the performance
UNIT		Indicates the unit to which the quantity is specified
procedure_AH_cat, procedure_group, procedure_detail, procedure_cat		Formats into categories, sub-categories and cost of the nomenclature code as they are determined by the actuary of the National Health Care insurer



Prescriber_c, prescriber_cat		Prescriber C is the coded unique identification of the prescriber's performance. PRESCRIBER_CAT indicates the type of the prescriber
atc_prod_l		The different levels of the ATC code
<b>BCR – Cancer Registry</b>		
	inc_death_mm	Number of complete months between incidence date and date of death
	ICD10_new	Tumour localisation (ICD-10 code)

## **Supplementary material S.6: Statistical analysis**

For the principal component analysis (PCA), we used the last-30-days-version of the quality indicator items as a standard where that time interval was relevant, unless only a shorter time interval was validated for the indicator (e.g. port-a-cath installment was only validated as possibly inappropriate in the last 14 days before death). We only withheld items with a minimum loading of .40 on the component.

We performed an unbalanced ANOVA using the SAS General Linear Model (GLM) procedure, that uses the method of least squares to fit general linear models, with the factor scores as dependent variables and as independent variables gender, age, region, nationality, household type, housing comfort, level of education, level of urbanization of residence, net taxable income and type of cancer. We hand-built the model, starting from all independent variables and gradually excluding those variables that had no significant influence on the factor. The alpha level of 0.01 defined statistical significance.

**Table S.7:** Four components identified in the different quality indicator items using Principal Component Analysis, with component loadings

	Component loadings of the QI items
<b>Component 1: Inappropriate curative tumor treatment</b>	
Chemotherapy in last 30 days	0.71
Surgery in the last 30 days	0.71
<b>Component 2: Inappropriate hospital transitions and hospital care</b>	
ED admissions in last 30 days	0.40
Hospital admission in last 30 days	0.45
Diagnostic testing in last 14 days	0.41
<b>Component 3: Appropriate comfort and palliative care</b>	
Official palliative care status	0.67
Received specialized palliative care	0.72
Family physician contact increase in last 30 days (compared to period before)	0.46
No. of primary caregiver contact in last 30 days	0.70
Death at home or in nursing home of residence	0.65
<b>Component 4: Appropriate pain and symptom treatment</b>	
Opioids prescription in last 30 days	0.76
Opioids and neuropathic pain medication prescription in last 30 days	0.71

**Supplementary table S.8:** Overview of all measured population characteristics of people dying from cancer in Belgium, from 2010 until 2015.

People who died from cancer in Belgium, 2010-2015 (N = 159,590)							
		2010 (N = 26,768)	2011 (N = 26,820)	2012 (N = 26,464)	2013 (N = 26,654)	2014 (N = 26,391)	2015 (N = 26,493)
<b>Average age</b>		68.2	71	69.4	73.5	73.7	73.8
<b>Agecategory</b>	<65	24.6	24.4	24.4	23.3	22.8	22.9
	65-74	23.6	23.5	23.5	24.3	24.8	24.3
	75-84	35.6	35.1	34.6	34.7	34.2	34.4
	>84	16.2	16.9	17.4	17.8	18.2	18.4
<b>Sex</b>	Female	43.6	44.2	43.5	43.9	44.1	44.1
<b>Nationality</b>	Belgian	95.0	94.8	95.1	95.1	95.1	94.5
<b>Householdtype</b>	Single	29.3	28.9	29.8	30.0	30.2	29.9
	Single parent	5.0	5.0	5.3	5.0	5.3	5.3
	Couple with children	12.1	12.0	11.7	11.9	11.6	11.5
	Couple without children	44.7	44.8	44.0	44.4	44.1	44.4
	Collective (i.e. nursing home)	7.1	7.2	7.1	6.9	7.0	7.2
	Other	1.9	2.0	2.1	1.9	1.9	1.7
<b>Housing Comfort</b>	High	47.2	49.1	49.6	50.4	51.5	51.6
	Average	17.1	16.2	16.4	15.7	15.0	14.9
	Low	26.9	26.2	25.9	26.5	26.1	26.3
	None	8.8	8.5	8.1	7.4	7.3	7.2

<b>Highest attained educational level</b>	Higher education	.	11.4	12.3	12.3	13.0	13.1
	Higher secondary	.	17.2	17.2	18.0	18.4	18.7
	Lower Secondary	.	24.6	24.5	25.2	25.1	25.7
	Primary	.	28.7	28.4	27.3	27.0	25.8
	None	.	7.3	6.6	6.6	6.4	6.5
<b>Degree of urbanization of residence</b>	Very high	31.5	30.8	30.4	30.6	30.3	30.0
	High	28.2	28.7	28.2	28.4	28.4	28.8
	Average	26.7	26.2	26.7	26.1	26.6	26.2
	Low	13.6	14.1	13.9	14.0	13.8	13.9
	missing	0.1	0.1	0.7	1.0	1.0	1.1
<b>Region</b>	Flanders	58.9	58.8	58.5	58.6	59.0	58.3
	Wallonia	33.1	33.3	33.4	33.7	33.2	34.0
	Brussels	8.0	7.9	8.1	7.8	7.9	7.7
<b>Net taxable income</b>	Quintile 1	2.0	2.0	1.7	1.9	1.8	1.8
	Quintile 2	13.0	12.5	12.2	11.3	11.4	12.7
	Quintile 3	46.2	45.7	46.2	45.9	45.5	46.1
	Quintile 4	27.4	28.0	28.0	29.2	29.3	28.6
	Quintile 5	11.4	11.8	11.9	11.8	12.0	10.9
<b>Cancertype</b>	Respiratory	27.8	27.4	26.3	26.2	26.3	25.2
	Digestive tract	28.9	29.0	29.1	28.5	28.5	28.4
	Urinary tract	6.4	6.1	6.5	6.3	6.3	6.5

	Head and neck	3.2	2.9	3.2	3.4	3.4	3.4
	Melanoma	2.6	2.9	2.9	3.3	3.2	3.4
	Breast	6.9	7.2	7.6	7.5	7.6	7.6
	Female genital organs	5.2	5.2	5.2	4.7	4.9	4.9
	Male genital organs	4.9	5.3	4.7	5.6	5.5	5.9
	Other	13.9	13.9	14.5	14.5	14.3	14.7

\*All missings were under 10%, except with education level, since no data are available for 2010.

**Supplementary table S.9:** Overview of all measured population characteristics of people dying from COPD in Belgium, from 2010 until 2015.

People who died with COPD in Belgium (N = 37,930)							
		2010 (N = 6,878)	2011 (N = 6,568)	2012 (N = 6,336)	2013 (N = 6,274)	2014 (N = 5,689)	2015 (N = 6,185)
<b>Average age</b>		71.97	75.77	73.63	78.22	78.2	78.21
<b>Agecategory</b>	<65	11.72	11.81	11.16	11.44	11.55	11.62
	65-74	19.35	21.01	20.01	20.31	20.83	21.24
	75-84	44.5	42.43	41.91	41.23	40.73	40.58
	>84	24.43	24.74	26.92	27.02	26.89	26.55
<b>Sex</b>	Female	32.68	34.61	35.63	35.58	36.23	36.7
<b>Nationality</b>	Belgian	93.18	93.61	93.29	93.7	93.65	93.73
<b>Living situation</b>	Single	31.63	31.07	32.74	31.42	31.79	31.29
	Single parent	5.22	4.42	4.79	4.71	4.89	4.68
	Couple with children	7.58	7.91	7.2	7.53	6.74	7.12
	Couple without children	37.18	37.88	37.34	37.91	37.04	36.5
	Collective (i.e. nursing home)	15.91	16.37	15.76	16.22	17.32	18.18
	Other	2.48	2.35	2.16	2.19	2.22	2.23
<b>Housing Comfort</b>	High	35.77	36.77	37.03	38.83	38.79	39.77
	Average	20.61	20.35	20.44	18.6	18.99	18.73
	Low	30.51	30.36	31.02	31.39	31.02	31.32
	None	13.1	12.52	11.51	11.17	11.2	10.18
<b>Highest attained educational level</b>	Higher education	.	6.06	6.22	5.51	7.05	6.77

	Higher secondary	.	11.39	11.98	12.86	12.09	12.76
	Lower Secondary	.	21.44	22.03	22.68	22.85	23.31
	Primary	.	35.87	35.87	34.91	34.89	34.54
	None	.	10.72	9.78	9.99	9.44	9.09
<b>Degree of urbanization of residence</b>	Very high	32.6	31.82	31.91	30.3	30.74	30.88
	High	26.32	27.41	26.72	27.72	28.92	27.53
	Average	25.71	25.03	24.49	23.92	23.13	24.28
	Low	15.28	15.67	16.29	16.83	15.77	16.23
<b>Region</b>	Flanders	49.64	48.99	46.86	47.15	46.23	48.1
	Wallonia	41.68	41.99	45.25	45.07	46.17	44.47
	Brussels	8.67	9.02	7.89	7.78	7.6	7.44
<b>Net taxable income</b>	Quintile 1	2.1	1.7	1.5	1.5	1.8	1.6
	Quintile 2	9.5	9.3	8.8	8.7	7.8	9.2
	Quintile 3	57.8	56.1	58.2	57.5	55.3	58.9
	Quintile 4	25.4	27.6	25.6	27.0	28.8	25.6
	Quintile 5	5.2	5.3	5.9	5.4	6.4	4.8

\*All missings were under 10%, except with education level, since no data are available for 2010.



**Supplementary table S.10:** Overview of all measured population characteristics of people dying with dementia in Belgium, from 2010 until 2015.

<b>People who died with Dementia in Belgium, 2010-2015 (N = 59,967)</b>							
		<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
		<b>(N = 10,017)</b>	<b>(N = 9,891)</b>	<b>(N = 10,137)</b>	<b>(N = 9,411)</b>	<b>(N = 9,882)</b>	<b>(N = 10,629)</b>
<b>Average age</b>		79.48	83.46	83.25	85.99	86.19	86.6
<b>Agecategory</b>	<65	1.3	1.01	0.94	0.86	0.67	0.82
	65-74	5.06	4.64	4.52	4.47	3.95	3.87
	75-84	41.5	40.82	38.27	36.9	37.01	34.26
	>84	52.14	53.52	56.26	57.77	58.37	61.05
<b>Sex</b>	Female	65.35	65.37	65.95	66.12	66.4	65.82
<b>Nationality</b>	Belgian	96.12	95.72	95.67	95.9	95.62	95.61
<b>Householdtype</b>	Single	20.44	20.16	20.23	19.77	19.31	18.77
	Single parent	3.76	4.14	4.18	4	3.8	3.65
	Couple with children	4.4	4.34	4.08	3.9	4.03	3.92
	Couple without children	27.17	26.37	25.73	25.82	25.89	24.91
	Collective (i.e. nursing home)	41.87	42.79	43.65	44.23	44.97	46.53
	Other	2.36	2.21	2.14	2.29	2.01	2.21
<b>Housing Comfort</b>	High	34.54	35.13	37.33	39.01	39.62	39.98
	Average	27.4	26.9	26.24	24.42	24.61	23.38
	Low	25.76	25.27	25.11	25.83	25.72	26.48
	None	12.31	12.69	11.32	10.74	10.05	10.16
<b>Highest attained</b>	Higher education	.	6.76	6.69	7.56	7.43	7.8

<b>educational level</b>							
	Higher secondary	.	10.48	10.97	11.57	11.5	11.97
	Lower Secondary	.	20.62	20.98	21.89	21.51	21.21
	Primary	.	37.51	38.94	36.82	37.06	37.44
	None	.	9.17	8.44	8.39	9.14	8.62
<b>Degree of urbanization of residence</b>	Very high	33.85	33.39	31.79	31.78	31.28	30.92
	High	28.57	29.09	29.63	28.77	28.75	28.78
	Average	24.88	24.09	24.67	24.57	24.18	25.42
	Low	12.61	13.41	13.16	12.97	14.25	13.2
	missing	0.09	0.02	0.76	1.9	1.53	1.67
<b>Region</b>	Flanders	57.86	58.5	56.47	58.26	56.18	56.99
	Wallonia	32.34	32.39	34.99	33.72	35.67	35.3
	Brussels	9.79	9.11	8.54	8.02	8.15	7.71
<b>Net taxable income</b>	Quintile 1	1.1	1.0	0.7	0.8	1.0	0.8
	Quintile 2	11.3	11.4	11.1	10.9	10.8	11.3
	Quintile 3	52.8	52.9	52.0	50.0	50.6	53.0
	Quintile 4	27.3	28.2	28.3	29.8	28.8	27.1
	Quintile 5	7.5	7.7	7.93	8.62	8.8	7.8

\*All missings were under 10%, except with education level, since no data are available for 2010.

**Supplementary table S.11:** All logistic regression models with odds ratios and area under the curve for each quality indicator for people with COPD.

Note: The goal of these regression models is not to be the best predictive models possible, but rather to control for possible non-health care use population differences between regions.

	Inhalation Therapy			Endotracheo			Continuous intubation			Repeated intubation			Late physiotherapy			Coroabdominal surgery			Reanimation after intubation			
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	
Age													1.05	1.00	1.09							
Sex	1.90	1.42	2.53										2.19	1.29	3.72							
High care needs - handicap																						
High care needs - elderly													2.67	1.41	5.07							
High care needs - home care																						
High care needs - hospitalization	0.55	0.34	0.88	0.26	0.08	0.83	0.08	0.01	1.35	0.26	0.08	0.83										
Degree of urbanisation of residence 1 vs 99	0.41	0.15	1.12																			
Degree of urbanisation of residence 2 vs 99	0.43	0.16	1.17																			
Degree of urbanisation of residence 3 vs 99	0.28	0.10	0.78																			
Degree of urbanisation of residence 4 vs 99	0.62	0.22	1.76																			
Education level 1 vs 0																						
Education level 2 vs 0																						
Education level 3 vs 0																						
Education level 4 vs 0																						
Education level 99 vs 0																						
Retireable income																						
Householdtype Couple with children vs Single Patient																						
Householdtype Couple without children vs Single Patient																						
Householdtype Collective vs Single Patient																						
Householdtype Other vs Single Patient																						
Householdtype Single vs Single Patient																						
Com fort level of residence 1 vs 4																						
Com fort level of residence 2 vs 4																						
Com fort level of residence 3 vs 4																						
Belgian or other nationality	0.39	0.22	0.67	0.26	0.07	0.93				0.26	0.07	0.93							0.06	0.00	0.90	
Lungcancer																0.18	0.02	1.52				
AUC	0.64			0.66			0.50			0.66			0.67			0.50			0.72			

	Starting a new antidepr			Specialist palliative care			Official palliative status			Homedeath			Homedeath or nursing home death			Increased GP contact						
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max				
Age				0.96	0.93	0.98	0.95	0.92	0.99													
Sex	2.32	1.32	4.07																			
High care needs - handicap																						
High care needs - elderly	2.49	1.29	4.78																			
High care needs - home care	0.42	0.23	0.77	0.20	0.13	0.29	0.12	0.07	0.19	0.17	0.11	0.26										
High care needs - hospitalization													4.23	2.44	7.34	2.66	1.68	4.21				
Degree of urbanisation of residence 1 vs 99										2.06	0.22	19.67										
Degree of urbanisation of residence 2 vs 99										1.60	0.17	15.34										
Degree of urbanisation of residence 3 vs 99										1.87	0.20	17.98										
Degree of urbanisation of residence 4 vs 99										4.17	0.43	40.63										
Education level 1 vs 0																						
Education level 2 vs 0																						
Education level 3 vs 0																						
Education level 4 vs 0																						
Education level 99 vs 0																						
Retireable income																						
Householdtype Couple with children vs Single Patient				1.24	0.47	3.24	1.23	0.40	3.76	0.80	0.29	2.20	0.88	0.38	2.09	0.38	0.14	1.03				
Householdtype Couple without children vs Single Patient				0.74	0.33	1.69	0.62	0.23	1.62	0.57	0.25	1.32	0.60	0.29	1.22	0.46	0.19	1.10				
Householdtype Collective vs Single Patient				0.33	0.14	0.80	0.03	0.00	0.22	0.06	0.02	0.20	3.22	1.55	6.70	0.67	0.27	1.62				
Householdtype Other vs Single Patient				0.60	0.13	2.71	0.63	0.10	3.81	0.83	0.20	3.45	1.62	0.49	5.41	0.22	0.06	0.78				
Householdtype Single vs Single Patient				0.54	0.23	1.29	0.56	0.20	1.58	0.59	0.24	1.41	0.98	0.47	2.05	0.43	0.18	1.05				
Com fort level of residence 1 vs 4																						
Com fort level of residence 2 vs 4																						
Com fort level of residence 3 vs 4													2.68	1.49	4.82							
Belgian or other nationality																1.83	1.05	3.16				
Lungcancer																						
AUC	0.67			0.75			0.86			0.82			0.75			0.63						

	Diagnostic Testing			Medical Imaging			EGC or Spirometry			Reanimation			Surgery			Bloodtransfusion			Late start of palliative care			Hospital admission			
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	
Age	1.53	1.17	2.01												0.89	0.81	0.98								
Sex				1.73	1.35	2.22	1.34	1.02	1.76													1.48	1.13	1.95	
High care needs - handicap																									
High care needs - elderly	1.79	1.37	2.34	2.02	1.55	2.64	1.75	1.31	2.35													1.87	1.42	2.47	
High care needs - home care																									
High care needs - hospitalisation	0.41	0.25	0.66	0.35	0.22	0.57	0.56	0.35	0.89				0.47	0.14	1.64								0.34	0.21	0.55
Degree of urbanisation of residence 1 vs 99																			0.18	0.06	0.54				
Degree of urbanisation of residence 2 vs 99																			0.18	0.06	0.54				
Degree of urbanisation of residence 3 vs 99																			0.17	0.05	0.52				
Degree of urbanisation of residence 4 vs 99																			0.24	0.07	0.80				
Education level 1 vs 0																									
Education level 2 vs 0																									
Education level 3 vs 0																									
Education level 4 vs 0																									
Education level 99 vs 0																									
Nettaxable income	0.91	0.84	0.99	0.89	0.82	0.97									1.99	1.20	3.30						0.91	0.83	0.99
Householdtype Couple with children vs Single Parent	1.49	0.63	3.51																				1.37	0.58	3.23
Householdtype Couple without children vs Single Parent	1.27	0.62	2.61																				1.21	0.58	2.51
Householdtype Collective vs Single Parent	0.78	0.38	1.59																				0.69	0.33	1.43
Householdtype Other vs Single Parent	1.12	0.35	3.61																				0.99	0.30	3.26
Householdtype Single vs Single Parent	1.13	0.54	2.35																				0.96	0.46	2.02
Com fort level of residence 1 vs 4										<0.001	<0.001	>999.999													
Com fort level of residence 2 vs 4										0.20	0.02	2.20													
Com fort level of residence 3 vs 4										0.17	0.02	1.90													
Belgian or other nationality	0.53	0.30	0.92	0.52	0.30	0.90	0.53	0.31	0.92																
Lungcancer																							0.57	0.33	0.99
AUC	0.66			0.66			0.61			0.50			0.50			0.87			0.55			0.67			

	ED admission			Death in hospital			ICU admission			ICU admission from nursing home			PAC installment		
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max
Age				0.98	0.96	1.00	0.95	0.90	1.01	0.90	0.83	0.98			
Sex	1.45	1.11	1.88												
High care needs - handicap															
High care needs - elderly	1.46	1.10	1.93	1.73	1.29	2.31									
High care needs - home care															
High care needs - hospitalisation	0.57	0.36	0.89	0.23	0.14	0.38							<0.001	<0.001	>999.999
Degree of urbanisation of residence 1 vs 99															
Degree of urbanisation of residence 2 vs 99															
Degree of urbanisation of residence 3 vs 99															
Degree of urbanisation of residence 4 vs 99															
Education level 1 vs 0															
Education level 2 vs 0															
Education level 3 vs 0															
Education level 4 vs 0															
Education level 99 vs 0															
Nettaxable income															
Householdtype Couple with children vs Single Parent				1.15	0.48	2.79									
Householdtype Couple without children vs Single Parent				1.37	0.65	2.89									
Householdtype Collective vs Single Parent				0.57	0.27	1.21									
Householdtype Other vs Single Parent				0.81	0.23	2.84									
Householdtype Single vs Single Parent				0.74	0.34	1.60									
Com fort level of residence 1 vs 4															
Com fort level of residence 2 vs 4															
Com fort level of residence 3 vs 4															
Belgian or other nationality				0.43	0.25	0.74									
Lungcancer															
AUC	0.59			0.69			0.50			0.70			0.50		

**Supplementary table S.12:** All logistic regression models with odds ratios and area under the curve for each quality indicator for people with dementia.

Note: The goal of these regression models is not to be the best predictive models possible, but rather to control for possible non-health care use population differences between regions.

	Morphine and neuropathics			Specialist palliative care			Official palliative status			Homedeath			Homedeath or nursing home death			Increase in GP contact		
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max
Age	0.92	0.91	0.94	0.98	0.97	0.99				0.99	0.98	1.00	1.02	1.01	1.03	1.01	1.00	1.02
Sex	0.66	0.49	0.89										0.79	0.67	0.93	0.85	0.77	0.94
High case needs - handicap										1.26	1.07	1.48	0.83	0.72	0.96	0.72	0.66	0.80
High case needs - w/daily										1.26	1.07	1.48	0.83	0.72	0.96	2.04	1.66	2.51
High case needs - home care										1.26	1.07	1.48	0.83	0.72	0.96			
High case needs - hospitalisation	0.43	0.27	0.67							1.80	1.27	2.56	4.19	3.01	5.85			
Degree of substitution of residence 1 vs 99				0.66	0.37	1.19	0.89	0.36	2.25	1.11	0.54	2.28				0.84	0.58	1.23
Degree of substitution of residence 2 vs 99				0.72	0.40	1.30	1.10	0.44	2.77	1.14	0.56	2.34				1.23	0.84	1.80
Degree of substitution of residence 3 vs 99				0.81	0.45	1.44	1.18	0.47	2.96	1.27	0.62	2.61				1.10	0.75	1.61
Degree of substitution of residence 4 vs 99				1.00	0.55	1.82	1.58	0.62	4.00	1.93	0.93	4.00				1.02	0.69	1.51
Education level 1 vs 0																		
Education level 2 vs 0																		
Education level 3 vs 0																		
Education level 4 vs 0																		
Education level 99 vs 0																		
Retireable income										0.94	0.89	0.98						
Household type Couple with children vs Single Parent				1.23	0.84	1.78	1.12	0.72	1.72	1.31	0.91	1.88	1.01	0.54	1.89	1.11	0.81	1.52
Household type Couple without children vs Single Parent				0.87	0.64	1.17	0.92	0.66	1.29	0.93	0.70	1.23	1.32	0.82	2.13	1.28	1.00	1.63
Household type Collective vs Single Parent				0.30	0.22	0.41	0.05	0.03	0.09	0.08	0.05	0.12	1.54	0.99	2.40	1.75	1.38	2.21
Household type Other vs Single Parent				0.93	0.59	1.46	0.84	0.49	1.43	0.97	0.63	1.51	0.85	0.44	1.64	0.82	0.57	1.17
Household type Single vs Single Parent				0.54	0.39	0.74	0.40	0.27	0.60	0.58	0.43	0.79	1.27	0.79	2.03	1.00	0.78	1.27
Com Sub level of residence 1 vs 4																		
Com Sub level of residence 2 vs 4																		
Com Sub level of residence 3 vs 4																		
Belgian or other nationality													1.87	1.36	2.56	1.45	1.17	1.80
AUC	0.69			0.76			0.88			0.85			0.61			0.62		

	Diagnostic Testing			Medical Imaging			ECG or Spirometry			Chemotherapy			Reanimation			Surgery			Bloodtransfusion		
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max
Age	0.99	0.98	1.00	0.99	0.98	1.00															
Sex	1.50	1.36	1.65	1.50	1.36	1.65	1.39	1.25	1.55							2.57	1.61	4.09			
High case needs - handicap																					
High case needs - w/daily																					
High case needs - home care																					
High case needs - hospitalisation	1.51	1.38	1.65	1.52	1.38	1.66	1.37	1.23	1.52												
Degree of substitution of residence 1 vs 99	0.47	0.38	0.58	0.49	0.40	0.61	0.66	0.54	0.82	0.27	0.12	0.59							0.27	0.14	0.56
Degree of substitution of residence 2 vs 99																					
Degree of substitution of residence 3 vs 99																					
Degree of substitution of residence 4 vs 99																					
Education level 1 vs 0	0.92	0.78	1.08	0.91	0.78	1.08	0.92	0.77	1.11												
Education level 2 vs 0	0.90	0.76	1.07	0.89	0.75	1.06	0.85	0.70	1.04												
Education level 3 vs 0	0.75	0.62	0.91	0.74	0.61	0.90	0.74	0.59	0.92												
Education level 4 vs 0	0.76	0.61	0.94	0.78	0.63	0.97	0.76	0.60	0.97												
Education level 99 vs 0	1.04	0.85	1.27	1.05	0.86	1.29	0.99	0.79	1.23												
Retireable income																					
Household type Couple with children vs Single Parent	0.91	0.68	1.23	0.90	0.67	1.22	0.79	0.57	1.08												
Household type Couple without children vs Single Parent	0.98	0.78	1.23	0.96	0.76	1.21	0.78	0.61	1.00												
Household type Collective vs Single Parent	0.50	0.40	0.63	0.50	0.40	0.62	0.43	0.34	0.54												
Household type Other vs Single Parent	0.94	0.67	1.33	0.88	0.62	1.24	0.87	0.60	1.26												
Household type Single vs Single Parent	1.04	0.83	1.31	1.04	0.82	1.31	0.78	0.61	0.99												
Com Sub level of residence 1 vs 4	0.79	0.68	0.92	0.81	0.69	0.94	0.78	0.65	0.92												
Com Sub level of residence 2 vs 4	0.86	0.73	1.01	0.86	0.73	1.01	0.78	0.65	0.93												
Com Sub level of residence 3 vs 4	0.94	0.81	1.10	0.93	0.80	1.09	0.90	0.76	1.08												
Belgian or other nationality	0.58	0.47	0.71	0.56	0.46	0.69	0.71	0.57	0.89												
AUC	0.65			0.65			0.63			0.55			0.50			0.62			0.55		

	Late Palliative care			Hospital admission			ED admission			ICU admission			ICU admission from nursing home			Statines		
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max
Age	0.98	0.97	0.99	0.99	0.98	1.00	0.99	0.98	1.00	0.96	0.94	0.97	0.94	0.92	0.97	0.96	0.95	0.98
Sex				1.51	1.37	1.67	1.41	1.28	1.57							1.50	1.26	1.78
High care needs - handicap																		
High care needs - elderly				1.46	1.32	1.60	1.33	1.20	1.46	1.46	1.07	1.99				1.22	1.02	1.45
High care needs - home care	0.45	0.35	0.57													1.43	1.08	1.88
High care needs - hospitalization				0.46	0.37	0.57	0.68	0.55	0.84									
Degree of urbanisation of residence 1 vs 99	0.49	0.25	0.97															
Degree of urbanisation of residence 2 vs 99	0.55	0.28	1.07															
Degree of urbanisation of residence 3 vs 99	0.61	0.31	1.20															
Degree of urbanisation of residence 4 vs 99	0.75	0.38	1.50															
Education level 1 vs 0																0.90	0.68	1.20
Education level 2 vs 0																0.82	0.60	1.11
Education level 3 vs 0																0.66	0.46	0.93
Education level 4 vs 0																0.51	0.34	0.76
Education level 99 vs 0																0.84	0.59	1.21
Net taxable income				0.95	0.92	0.98												
Household type Couple with children vs Single Parent	1.70	0.96	3.02	0.88	0.66	1.19	0.75	0.55	1.03	1.39	0.57	3.37				0.65	0.37	1.14
Household type Couple without children vs Single Parent	1.46	0.90	2.36	0.91	0.72	1.14	0.75	0.59	0.96	1.03	0.49	2.16				0.97	0.64	1.46
Household type Collective vs Single Parent	0.64	0.39	1.06	0.45	0.36	0.56	0.47	0.37	0.59	0.64	0.30	1.36				0.55	0.37	0.83
Household type Other vs Single Parent	1.62	0.83	3.15	0.89	0.63	1.27	0.98	0.68	1.40	0.64	0.17	2.44				0.79	0.40	1.53
Household type Single vs Single Parent	0.95	0.57	1.58	0.92	0.73	1.16	0.82	0.64	1.04	1.46	0.69	3.09				0.89	0.59	1.36
Com fort level of residence 1 vs 4				0.77	0.66	0.90	0.70	0.60	0.82									
Com fort level of residence 2 vs 4				0.85	0.72	1.01	0.77	0.65	0.92									
Com fort level of residence 3 vs 4				0.96	0.82	1.13	0.83	0.71	0.99									
Belgian or other nationality				0.61	0.49	0.75	0.62	0.50	0.77									
<b>AUC</b>	<b>0.67</b>			<b>0.66</b>			<b>0.62</b>			<b>0.66</b>			<b>0.63</b>			<b>0.64</b>		

	Proton Pump Inhibitors			Anti-hypertensives			Calcium with Vit D			NOAC			Gout prevention medication			SSRI		
	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max	OR	CI min	CI max
Age				1.02	1.01	1.03										0.97	0.96	0.98
Sex	1.20	1.08	1.32							1.39	1.26	1.52	2.21	1.61	3.03	0.81	0.70	0.94
High care needs - handicap																		
High care needs - elderly	1.19	1.08	1.30	1.17	1.07	1.28				1.25	1.15	1.37						
High care needs - home care				1.21	1.05	1.39										1.28	1.01	1.62
High care needs - hospitalization	0.39	0.32	0.48	0.61	0.50	0.75	0.46	0.36	0.60	0.50	0.41	0.62						
Degree of urbanisation of residence 1 vs 99							1.36	0.73	2.55									
Degree of urbanisation of residence 2 vs 99							0.96	0.51	1.80									
Degree of urbanisation of residence 3 vs 99							0.94	0.50	1.78									
Degree of urbanisation of residence 4 vs 99							1.18	0.62	2.24									
Education level 1 vs 0				0.97	0.84	1.13				0.96	0.82	1.13						
Education level 2 vs 0				0.99	0.84	1.16				0.93	0.79	1.10						
Education level 3 vs 0				0.79	0.66	0.95				0.80	0.66	0.97						
Education level 4 vs 0				0.74	0.60	0.91				0.84	0.68	1.04						
Education level 99 vs 0				0.82	0.68	0.99				1.05	0.86	1.27						
Net taxable income																1.09	1.04	1.14
Household type Couple with children vs Single Parent	0.98	0.71	1.34	0.72	0.54	0.96	1.01	0.60	1.68	1.13	0.84	1.51	0.85	0.30	2.39			
Household type Couple without children vs Single Parent	0.85	0.67	1.09	0.70	0.56	0.87	1.23	0.83	1.81	0.99	0.79	1.24	1.04	0.47	2.30			
Household type Collective vs Single Parent	0.76	0.60	0.96	0.56	0.45	0.70	0.68	0.46	1.00	0.71	0.57	0.88	0.62	0.28	1.36			
Household type Other vs Single Parent	0.82	0.56	1.20	0.72	0.51	1.01	1.26	0.72	2.23	0.96	0.68	1.36	0.70	0.18	2.72			
Household type Single vs Single Parent	0.94	0.74	1.21	0.75	0.60	0.95	1.44	0.97	2.14	1.11	0.88	1.39	1.09	0.49	2.46			
Com fort level of residence 1 vs 4	0.77	0.66	0.91	0.85	0.74	0.99				0.87	0.74	1.01						
Com fort level of residence 2 vs 4	0.86	0.73	1.02	0.89	0.76	1.03				0.90	0.77	1.05						
Com fort level of residence 3 vs 4	0.92	0.78	1.08	0.97	0.84	1.13				1.03	0.88	1.20						
Belgian or other nationality	0.71	0.58	0.88	0.79	0.65	0.97				0.73	0.60	0.90						
<b>AUC</b>	<b>0.57</b>			<b>0.57</b>			<b>0.62</b>			<b>0.60</b>			<b>0.61</b>			<b>0.57</b>		