

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

Palliative home care support improves quality of care and decreases costs at the end of life: a population-level matched cohort study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-025180
Article Type:	Research
Date Submitted by the Author:	03-Jul-2018
Complete List of Authors:	Maetens, Arno; Vrije Universiteit Brussel, End-of-Life Care Research Group Beernaert, Kim; Vrije Universiteit Brussel, End-of-Life Care Research Group De Schreye, Robrecht; Vrije Universiteit Brussel, End-of-Life Care Research Group Faes, Kristof; Universiteit Gent Faculteit Geneeskunde en Gezondheidswetenschappen, Interuniversity Center for Health Economic Research (ICHER) Annemans, Lieven; Ghent University, Interuniversity Center for Health Economic Research (ICHER) Pardon, Koen; Vrije Universiteit Brussel, End-of-Life Care Research Group Deliens, Luc; Vrije Universiteit Brussel, End-of-Life Care Research Group; Universiteit Gent Faculteit Geneeskunde en Gezondheidswetenschappen, Public health and primary care Cohen, Joachim; Vrije Universiteit Brussel, End-of-Life Care Research Group
Keywords:	PALLIATIVE CARE, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health economics < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

SCHOLARONE™
Manuscripts

1
2
3 1 **Full title:** Palliative home care support improves quality of care and decreases costs at the end of life:
4 a population-level matched cohort study

5
6
7 3 **Short title:** Palliative home care support and quality and costs of end-of-life care

8
9
10 4 Arno Maetens*¹ Kim Beernaert¹ Robrecht De Schreye¹ Kristof Faes^{1,2} Lieven Annemans² Koen
11 Pardon¹ Luc Deliens^{1,3} Joachim Cohen¹

12
13
14 6 ¹ End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) and Ghent University, Brussels,
15 Belgium;

16
17
18 8 ² Department of Public Health, Interuniversity Center for Health Economic Research (ICHER), Ghent
19 University, Ghent;

20
21
22
23 10 ³ Department of Medical Oncology, Ghent University Hospital, De Pintelaan 185, 9000 Ghent,
24 Belgium;

25
26
27
28
29
30
31 13 * corresponding author:

32
33 14 E-mail: arno.maetens@vub.be

34
35 15 Address: Laarbeeklaan 103, 1090 Jette, Belgium

36
37 16 Telephone: +32 2 477 49 59

38
39
40 17

18 **Abstract**

19 Objectives: To evaluate the impact of using palliative home care support on the quality of care and
20 costs in the last 14 days of life.

21 Design: Matched cohort study using linked administrative databases.

22 Setting: All people who died in Belgium in 2012 (n=107847).

23 Participants: 8837 people who received palliative home care support in the last 720 to 15 days of life
24 matched 1:1 by propensity score to 8837 people who received usual care.

25 Intervention: The use of any available palliative home care support measure in the last 720 to 15 days
26 of life.

27 Main outcome measures: For appropriateness or inappropriateness of end-of-life care: home death,
28 number of family physician contacts, number of primary caregiver contacts, hospital death, hospital
29 admission, ICU admission, ED admission, diagnostic testing, blood transfusion, surgery. Total
30 inpatient and outpatient costs. All outcomes were measured in the last 14 days of life.

31 Results: Those using palliative home care support had more contacts with their family physician (3.1
32 [SD=6.5] vs. 0.8 [SD=1.2]), more often died at home (56.2% vs. 13.8%; RR=4.08, 95%CI: 3.86-4.31),
33 had a lower risk of hospital admission (27.4% vs. 60.8%; RR=0.45, 95%CI 0.43-0.46), ICU admission
34 (18.3% vs. 40.4%; RR=0.45, 95%CI 0.43-0.48), ED admission (15.2% vs. 28.1%; RR=0.54, 95%CI
35 0.51-0.57), undergoing diagnostic testing (27.2% vs. 63.2%). Average total costs of care were lower
36 for those using palliative home care support (€3081 [SD=€2669] vs. €4698 [SD=€4233]).

37 Conclusions: Palliative home care support use positively impacts quality of care and reduces total
38 costs of care at the end of life. To improve the quality of care provided at the end of life of patients and
39 at the same time reduce the expenses, policy makers and healthcare practitioners should increasingly
40 focus on communicating the existing options for palliative home care support to patients and their
41 caregivers, to achieve the desired uptake.

42 **Keywords:** end-of-life care, cohort study, quality of care

Strengths and limitations of this study

- By using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain underrepresented subgroups and lack the strength necessary for generalisability.
- A matched cohort study design with a high-quality matching is the best possible technique to evaluate the impact of policy on quality and costs of care.
- No previous work has evaluated the impact of all palliative home care support measures available in one country for the full population.
- Our operationalisation of palliative home care support as the use of any of available supportive measures increases the reproducibility of our study in other countries, and allows comparison studies that focus on the impact of other existing types of palliative home care support.
- Important aspects of quality end-of-life care are not visible in administrative data, such as quality of communication, existential or psychological care. Qualitative research can complement our findings.

43

44 **Background**

45 A majority of the growing population encountered with chronic and life-limiting illnesses prefers to
46 receive high quality care and to die at home.[1,2] Palliative home care support aims to meet the needs
47 of these people by managing symptoms, improving quality of life, and preventing avoidable healthcare
48 interventions such as hospitalisations at the end of life.[3] It is estimated that palliative care could be
49 beneficial in 38 to 74 percent of all deaths worldwide.[4] In recent years, policy makers internationally
50 have focussed on promoting the integration of palliative care services into the community and on
51 developing supportive measures for palliative care at home to meet the growing demand for high
52 quality home-based palliative care and to reduce costs related to acute hospital care use at the end of
53 life.[5–7] Several countries offer palliative home care support in the form of multidisciplinary
54 palliative home care teams, palliative nursing care at home or financial support for those wanting to
55 receive palliative care at home.[8–11]

56 The impact of palliative home care support on the quality and costs of care at the end of life remains
57 poorly evaluated.[12] A Cochrane review that included 23 studies found that use of home palliative
58 care services more than doubled the odds of dying at home and reduced symptom burdens.[13] Six
59 studies focussing on costs and findings reported up to 35% lower costs in the intervention group
60 compared with a control group, but not all studies reported significant differences. Another recently
61 updated Cochrane review included four trial studies that evaluated ‘hospital at home’ services,
62 demonstrating the positive impact of this type of home-based end-of-life care on the chances of having
63 a home death, but results on hospital admissions and healthcare costs varied and were found
64 inconclusive.[14] However, traditional experimental study designs, such as those evaluated in the
65 above mentioned reviews, are limited due to ethical and practical concerns. Therefore, they are not
66 suitable for evaluating the impact of palliative home care support that are available nationally to
67 everyone across a healthcare system.[3] A matched cohort study design with a high-quality matching
68 of a group receiving palliative home care support and a group not receiving it is the best possible
69 technique to evaluate this impact.[15] The increasing availability and improving quality of routinely-
70 collected databases and the technical possibilities of linking data from various sources have opened up

1
2
3 71 new possibilities for such designs.[16] Four retrospective cohort studies found an impact of palliative
4
5 72 home care support on reducing hospitalisations at the end of life and on lower chances for hospital
6
7 73 deaths in Canada, England, Italy and the US.[17–20] Findings from another retrospective cohort study
8
9 74 suggested that a proactive home-based palliative care programme ‘helped to avoid the escalation in
10
11 75 hospital use and costs commonly seen in the final months of life’.[21] However, these studies focused
12
13 76 only on a limited number of outcomes as indicators of quality of end of life care (hospital use and
14
15 77 place of death) and only one focused additionally on costs, without distinguishing inpatient and
16
17 78 outpatient costs. None of the studies used full-population national data, therefore limiting the findings
18
19 79 to one specific province or region.

20
21 80 In Belgium, palliative home care support is available in the form of (1) a multidisciplinary palliative
22
23 81 home care team, (2) palliative home care nursing or physiotherapy, and (3) the allowance for palliative
24
25 82 home care patients, available twice and meant for non-reimbursed palliative care-related costs. These
26
27 83 supportive measures are entirely free to the patient and their informal caregivers. Using linked
28
29 84 register-based databases on all deaths in Belgium, the current study aims to evaluate the impact of
30
31 85 using palliative home care support on the appropriateness and costs of care in the last 14 days of life
32
33 86 on a population level.

34
35
36 87

38 39 88 **Methods**

40 41 42 89 **Study design**

43
44
45 90 We conducted a matched cohort study on all deaths in Belgium in 2012, using linked data from eight
46
47 91 administrative databases. A cohort that used at least one type of palliative home care support was
48
49 92 matched to a control cohort from the same pool that used no palliative home care support. To reduce
50
51 93 selection bias between the groups and to balance measured covariates across them, we used propensity
52
53 94 score matching.[22] We followed an extension of the STROBE guidelines for reporting observational
54
55 95 studies to report the propensity score matching analysis.[16]

96 **Study setting and participants**

97 The study was conducted for all those who were registered with a Belgian sickness fund at time of
98 death in 2012 (98.8% of all deaths). We excluded people younger than 18 years and those who had
99 permanent residence in a nursing home during the last year of life. Additionally, to avoid any overlap
100 between the timing of exposure and the timing of the outcomes we excluded those for whom palliative
101 home care support was initiated for the first time in the last 14 days of life. Figure 1 presents the study
102 population selection process.

103 **Figure 1 here.**

104 The data used involved eight administrative databases, linked on an individual level using a unique
105 identifier by a third party responsible for data protection and linkage in Belgium. The linked data
106 included person-level reimbursed healthcare use in the last two years of life (recorded as nomenclature
107 codes) including dispensed medication in the hospital and community pharmacy in the last two years
108 of life (recorded as ATC codes). For all healthcare data the exact date of delivery (coded as number of
109 days before death) is recorded. Additionally the data include demographic data, fiscal data, and death
110 certificate data (including underlying cause of death, coded using ICD-10 codification).[23] The data
111 linkage process and content is described in detail elsewhere.[24]

112 **Exposure group**

113 Our exposure group consisted of people who used at least one type of palliative home care support
114 between the last 720 and 15 days of life (See Box 1). The inclusion criteria were: (combined by 'OR'):
115 (1) having received the allowance for palliative home patients, (2) having a visit by a multidisciplinary
116 palliative home care team visit, or (3) having a visit by a palliative nurse or physiotherapist at home.
117 Using specific nomenclature codes, we could identify delivery and timing of a specific palliative home
118 care support. The data were sorted to identify the earliest use of palliative home care support when
119 multiple measures were used.

Box 1. Description of the exposure: palliative home care support in Belgium

Policy measures to support palliative care at home, here defined as “palliative home care support”, exist in Belgium since 1985[25]. In 2002, palliative care was recognised by Belgian law as a right for all Belgian citizens. Since then, seriously ill patients with a short life expectancy (defined by law as “more than 24 hours and less than three months”) and an intention to die at home are eligible to receive specific supportive measures from the Belgian government [26]. These are:

- a. The use of a **multi-disciplinary palliative home care team**: which includes at least one general practitioner, two nurses and an administrative assistant. The main goal of the multi-disciplinary palliative home care teams is to advise GPs, health professionals, counsellors, informal carers and volunteers involved in the provision of palliative home care of a patient, and to organize and coordinate the provision of that palliative care at home between different care providers. The use of these teams is free of charge for the patient and not limited in time.
- b. **Palliative home care nursing or physiotherapy**: type of nursing care or physiotherapy at home, differing from standard nursing care or physiotherapy at home for heavily dependent home-patients in the number of caring tasks provided and round-the-clock availability. Free of charge for the patient.
- c. The **allowance for palliative home patients**: a lump sum of €647.16 (in 2012) which is obtainable twice (possibility to claim a second after one month) and meant to cover for non- or partially reimbursed costs that are related to the provision of palliative care at home (e.g. certain medicines, care materials and tools).

121

122 It is important to note that all healthcare insured people in Belgium have the right to access these
123 palliative home care support measures. Family physicians play a gatekeeping role in this: they remain
124 responsible for all care provided at home and need to give their written permission to initiate any of
125 the palliative home care support measures. Receiving any of these palliative home care support
126 measures is chosen as exposure because we consider the different types of support to be an indication

1
2
3 127 of the same intervention: initiation of palliative home care. However, sensitivity analyses are
4
5 128 performed in which each separate support measure is selected as the basis for the exposure group.
6

7 129 **Non-exposure group**

8
9
10 130 People who did not use palliative home care support in the last two years of life were included in the
11
12 131 non-exposure group.
13

14 15 132 **Outcomes for appropriateness and inappropriateness of end-of-life care**

16
17
18 133 We used RAND/UCLA validated quality indicators (QI) for end-of-life care to measure
19
20 134 appropriateness and inappropriateness of end-of-life care on an aggregated level. The development,
21
22 135 validation process and use of these indicators to study end-of-life care on a population level is
23
24 136 described in detail in De Schreye et al. [27]. From the total set of quality indicators that were validated
25
26 137 in previous research, we excluded those that were disease-specific (e.g. only validated as relevant for
27
28 138 cancer patients) or that were applicable only with regard to nursing homes (e.g. “ICU admission from
29
30 139 nursing home”). The quality indicators measure the prevalence of specific medication types (recorded
31
32 140 in the data sources using Anatomical Therapeutic Chemical Classification System [ATC] codes) or
33
34 141 health care interventions (recorded in the data sources as nomenclature codes for reimbursement
35
36 142 purposes) within a specified period before death. For example, the quality indicator “average number
37
38 143 of primary caregiver contacts in the last fourteen days of life” is calculated as the mean number of
39
40 144 contacts with a family physician or other primary care professional (based on the number of relevant
41
42 145 registered nomenclature codes) in the last fourteen days of life.
43

44
45 146 We included the following indicators for appropriateness of end-of-life care, all pertaining to the last
46
47 147 14 days of life: dying at home; the average number of primary caregiver contacts; and the average
48
49 148 number of family physician contacts. We included the following indicators for inappropriateness of
50
51 149 end-of-life care: dying in a hospital; being admitted to hospital; being admitted to an emergency
52
53 150 department (ED); being admitted to an intensive care unit (ICU); being submitted to diagnostic testing
54
55 151 (i.e. medical imaging, electrocardiogram or pulmonary function testing); having a blood transfusion;
56
57 152 and having surgery.
58

153 **Costs of end-of-life**

154 Based on all specific healthcare consumption data, we calculated total health care costs from a third-
155 party and patient copayment perspective, consisting of total inpatient cost and total outpatient cost for
156 both groups. Inpatient costs included all specific intervention and medication costs in the hospital.
157 Outpatient costs included all specific intervention and medication costs outside the hospital. For a
158 detailed description see supplementary box 1. Based on the exact dates of delivery we calculated the
159 total costs for the last 14 days of life. All costs were actualized to 2017 values based on the unit cost of
160 all defined resources in that year.

161 **Propensity score matching and statistical analysis**

162 Descriptive statistics were used to describe population characteristics, stratified by having received
163 palliative home care support (exposure group) or not (non-exposure group).

164 People who received palliative home care support were matched to those who did not, based on an
165 individual estimation of their propensity for receiving palliative home care support. The propensity
166 score was calculated using baseline covariates that were considered relevant predictors for receiving
167 palliative home care: age at death, sex, underlying cause of death (as a proxy for diagnosis using ICD-
168 10 codification, these were recoded into: neoplasms [C00-D48], respiratory diseases [J40-44, J47],
169 other organ failures i.e. heart, renal, and liver failure [I11-I13, I50, K70-72, N10-12, N18-19],
170 neurodegenerative diseases i.e. Alzheimer's, Parkinson's, motor neurone, and Huntington's disease
171 [F01, F03, G10, G12, G20, G30], HIV/aids [B20-24]; other underlying causes of death were recoded
172 as 'other'), household type, personal annual taxable income, highest attained educational level, degree
173 of urbanisation of residence, region of residence, and hospital use in the last two years of life (based
174 on the criteria: 'having had at least six hospitalisations' and 'being at least 120 days in the hospital').
175 We used a greedy one to one case-control propensity score matching algorithm.[28] For every case,
176 the best match was made first and a next-best match next, in a hierarchical sequence until no more
177 matches could be made. Best matches are those with the highest digit match on propensity score. First,
178 cases are matched to controls on eight digits of the propensity score. For those that do not match, cases

1
2
3 179 are then matched to controls on seven digits of the propensity score, etcetera. The algorithm proceeds
4
5 180 sequentially to the lowest digit match on the propensity score (one digit). In view of performing
6
7 181 sensitivity analyses, we performed separate matchings with respectively: allowance for palliative
8
9 182 home care patients, multidisciplinary palliative home care team visit, and palliative nursing care or
10
11 183 physiotherapy at home on its own as exposure, to evaluate whether these types of support showed
12
13 184 different results.

14
15 185 Two sampled t-test statistics were used to test for significant differences in age, and chi-square
16
17 186 statistics were used to test for significant differences in dichotomous and categorical variables
18
19 187 describing the unmatched and matched exposed and non-exposed groups. Risk ratios were calculated
20
21 188 to measure the differences in outcomes between the exposed group and the non-exposed group. Costs
22
23 189 were presented as means, medians, standard errors and interquartile ranges. All analyses were
24
25 190 performed using SAS Enterprise Guide version 7.1 (SAS Institute, Cary, NC).

191 Results

192 Study population characteristics

193 Of all deaths in Belgium in 2012 (n=107.847), we excluded 25.226 individuals from our study
 194 population because they resided in a nursing home (18.9% of total population), were minors (0.4%), or
 195 used palliative home care support only during the last 14 days of life (4.5%) (Figure 1). Our final
 196 unmatched set consisted of 82.612 individuals of which 11.149 (13.5%) had initiated palliative home
 197 care support (Figure 1). Before matching, the sociodemographic characteristics of the cohort exposed
 198 to palliative home care support differed largely from the unexposed cohort (e.g. in cause of death,
 199 household composition, and hospital use during the last two years of life) (Table 1). After propensity
 200 score matching, 8837 exposed people were matched to as many unexposed people. We performed
 201 sensitivity analyses on each supportive measure separately (shown in appendix) with no substantial
 202 differences between these measures in the impact on the quality and cost outcomes.

203 **Table 1. Characteristics of people using palliative home care support (exposed) and people who did not**
 204 **use palliative home care support (unexposed) before and after propensity score matching.**

Characteristics	Before propensity score matching		After propensity score matching	
	Exposed	Unexposed	Exposed	Unexposed
<i>No. of patients</i>	11 149	71 472	8837	8837
<i>Earliest use of palliative home care in days, median (IQR)</i>	75 (154)	/	73 (152)	/
<i>Mean age at time of death (SD)</i>	74.2 (12.8)	76.5 (14.2)	74.4 (12.7)	75.0 (12.3)
<i>Sex</i>				
Men	55.2	54.6	56.0	55.1
Women	44.8	45.4	44.0	44.9
<i>Cause of death</i>				
Neoplasm	74.6	20.6	72.7	72.8
COPD	2.5	4.6	2.7	2.8
Other organ failure	3.2	5.9	3.5	3.1
Neurodegenerative	4.4	5.0	4.9	5.1
Other	15.3	63.8	16.2	16.3
<i>Household composition</i>				
Married	60.4	44.6	60.4	61.4
Single person household	26.2	41.5	26.7	26.4

Living together	4.1	4.2	4.0	3.6
One-parent family	6.4	6.7	6.2	5.9
Other	2.9	3.0	2.7	2.7
Education level				
No education	8.1	8.7	7.9	7.7
Primary school education	34.7	34.9	34.7	35.2
Secondary school education	44.8	45.2	45.0	44.6
Post-secondary school education	12.5	11.2	12.4	12.6
Income in quartiles*				
Lowest income quartile	29.2	26.2	28.4	28.7
Second income quartile	22.5	23.5	21.7	21.9
Third income quartile	24.1	24.5	24.3	24.8
Highest income quartile	24.3	25.9	25.6	24.6
Region				
Flemish region	66.4	53.1	65.4	64.5
Walloon region	28.8	36.8	29.6	30.4
Brussels Capital region	4.8	10.1	5.0	5.1
Urbanisation				
Very high	25.1	33.7	25.7	25.6
High	28.5	27.5	29.2	28.7
Average	32.0	24.4	30.7	30.6
Low	12.9	13.0	13.0	13.7
Rural	1.5	1.5	1.5	1.5
Hospital use in the last two years				
>=120 days hospitalised	4.7	5.3	4.6	4.0
>= 6 hospitalisations	46.5	14.7	44.5	44.6

205 Values are percentages of patients unless stated otherwise. All percentages are valid percentages. Missing values existed in
 206 the full population (n=107 847) for household composition (n=1399; 1.6%), education level (n=11 382; 13.1%), income
 207 (n=3563; 4.1%), region (1657; 1.9%), urbanisation (1657; 1.9%). *Income quartiles were calculated on the full population of
 208 decedents (n=107 847).

209

210 Indicators of appropriate end-of-life care

211 Fifty-six percent of the people using palliative home care support died at home, compared to 13.8
 212 percent of those who did not use palliative home care support (Relative Risk (RR)=4.08; 95%
 213 Confidence Interval (CI) (3.86-4.31) (Table 2). On average, people in the palliative home care support
 214 cohort had nine primary caregiver contacts and three family physician contacts in the last two weeks
 215 of life, compared to two primary caregiver contacts and less than one family physician contact for
 216 those in the unexposed cohort.

217 **Table 2. Indicators of appropriate and inappropriate end-of-life care in the last 14 days of life in the**
 218 **matched cohorts**

	Palliative home care support, %		RR (95% CI)
	Yes (n=8837)	No (n=8837)	
Indicators of appropriate end-of-life care			
<i>Home death</i>	56.2	13.8	4.08 (3.86-4.31)
<i>Mean number of family physician contacts (SD)*</i>	3.1 (3.0)	0.8 (1.2)	/
<i>Mean number of primary caregiver contacts (SD)*</i>	9.0 (6.2)	2.3 (4.0)	/
Indicators of inappropriate end-of-life care			
<i>Hospital death</i>	39.0	74.8	0.52 (0.51-0.54)
<i>Hospital admission</i>	27.4	60.8	0.45 (0.43-0.47)
<i>ICU admission</i>	18.3	40.4	0.45 (0.43-0.48)
<i>ED admission</i>	15.2	28.1	0.54 (0.51-0.57)
<i>Diagnostic testing</i>	27.2	63.2	0.43 (0.41-0.45)
<i>Blood transfusion</i>	2.7	5.9	0.47 (0.40-0.54)
<i>Surgery</i>	0.5	2.8	0.19 (0.14-0.26)

219 RR = relative risk; CI = confidence interval; SD = standard deviation; ICU = intensive care unit; ED = emergency
 220 department. * P<0.0001 calculated using two-sided T-test statistic.

221

222 **Indicators of inappropriate end-of-life care**

223 Thirty-nine percent of the people using palliative home care support died in the hospital, compared to
 224 74.8 percent of the people not using palliative home care support (RR=0.52; 95%CI 0.51-0.54). Less
 225 people in the palliative home care support cohort were admitted to a hospital (27.4% vs 60.8%;
 226 RR=0.45, 95%CI 0.43-0.46), to an intensive care unit (18.3% vs 40.4%; RR=0.45, 95%CI 0.43-0.48),
 227 or to an emergency department (15.2% vs 28.1%; RR=0.54, 95%CI 0.51-0.57) in the last two weeks of
 228 life. Less people who used palliative home care support were submitted to diagnostic testing (27.2%
 229 vs 63.2%; RR=0.43, 95%CI 0.41-0.45), received blood transfusion (2.7% vs 5.9%; RR=0.47, 95%CI
 230 0.40-0.54), or surgery (0.5% vs 2.8%; RR=0.19, 95%CI 0.14-0.26). (Table 2)

231 **Medical care costs**

232 Mean total inpatient costs were lower for people using palliative home care support (€1766; Standard
 233 Error=30.6) compared to those who did not use palliative home care support (€4222; SE=45.6) (Table
 234 3). Mean total outpatient costs were higher for people using palliative home care support (€1314;

SE=11.6) compared to those who did not (€476; SE=7.9). Mean incremental total costs for exposed versus unexposed people in the last two weeks of life was -€1617 (SE=53.2).

Table 3 Healthcare costs in the last 14 days of life in the matched cohorts, in euro

	Palliative home care support				
	Yes (n=8837)		No (n=8837)		Mean incremental (SE)
	Mean (SE)	Median (Q1-Q3)	Mean (SD)	Median (Q1-Q3)	
Total inpatient costs	1766 (30.6)	0 (0-2724)	4222 (45.6)	3400 (513-6754)	-2454 (54.9)
Total outpatient costs	1314 (11.6)	1243 (449-1829)	476 (7.9)	251 (11-647)	838 (14.0)
Total costs	3081 (28.4)	2055 (1305-4227)	4698 (45.0)	3996 (1077-7124)	-1617 (53.2)

SE = standard error ; Q1-Q1 = interquartile range. All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.

Discussion

To our knowledge, this is the first nationwide matched cohort study on the impact of palliative home care support on the quality and costs of care at the end of life, using validated quality indicators. We found that people using palliative home care support received more appropriate and less inappropriate care at the end of life, and had lower total medical care costs in the last two weeks of life, compared with those who did not use palliative home care support. More than four times as many people using palliative home care support died at home than those not using palliative home care support. Fewer people in the exposed cohort were admitted to the hospital, emergency department, or ICU, and fewer were underwent diagnostic testing, blood transfusion, or surgery in the last two weeks of life.

Our study found that the use of palliative home care support lowered the average total medical care costs per person in the last two weeks of life by €1617. Costs of palliative home care support use that was continued in the last two weeks of life are also taken into account. A literature review on costs of palliative care interventions in all settings between 2002-2011 also found that palliative care (including but not confined to palliative home care) was overall less costly than for comparator

1
2
3 256 groups, despite large differences in the settings and study designs of the observed studies.[29]
4
5 257 However, the review notes that randomisation is absent in most of the studies, highlighting the
6
7 258 importance of controlling for confounding factors and selection bias when analysing the impact of a
8
9 259 palliative care intervention. Our study design could to a large extent tackle these issues of confounding
10
11 260 and bias. A retrospective study using observational data evaluated the impact of a home-based
12
13 261 palliative care programme in southern California on costs in four disease-groups, and found that
14
15 262 participants had in the last six months of life monthly net savings of \$4258 for cancer, \$4017 for
16
17 263 COPD, \$3447 for heart failure and \$2690 for dementia.[21] Although generalising and comparing
18
19 264 costs across different healthcare jurisdictions is difficult due to differences in healthcare regulations
20
21 265 and reimbursement schemes, these numbers are in line with our findings.

22
23 266 Our finding that people who used palliative home care support more often died at home confirms
24
25 267 findings in previous studies [13,17,30–32]. In Belgium, a mortality follow-back study on a sample of
26
27 268 1.690 non-sudden deaths found that the involvement of a multidisciplinary palliative home care team
28
29 269 was strongly associated with home death.[31] The rate of home deaths in the exposed and unexposed
30
31 270 groups of our study, respectively 56.2% and 13.8%, was comparable to findings from an Italian study
32
33 271 that compared the home death rates between users of palliative home care versus non-users
34
35 272 (respectively 60.8% and 29.3%). Although we were not able to take into account individual
36
37 273 preferences on place of death and quality of death itself [33], our results show that the palliative home
38
39 274 care support measures are effective in increasing the chance for home deaths on a population level,
40
41 275 which is an important policy goal of these measures [26].

42
43
44 276 Additionally, our study found that the use of palliative home care support has an impact on reducing
45
46 277 hospital, emergency department and intensive care unit admissions in the last two weeks of life. This
47
48 278 finding is in line with previous research,[17,20,34], but our study is the first to confirm such findings
49
50 279 on a full population level.

51
52
53 280 Strikingly, only 14 percent of all home-dwelling adults who died in Belgium in 2012 used palliative
54
55 281 home care support in the last two years of life. This uptake is far below the actual need in the Belgian

1
2
3 282 population for palliative care, which the most conservative estimation has set at 40% need in the
4
5 283 population.[4] Currently, physicians in Belgium can grant patients an official “palliative home care
6
7 284 status” only when the estimated life expectancy is three months or less. Although this status does not
8
9 285 exclude the patient from receiving specific types of health care, such as in the hospice benefit system
10
11 286 in the USA, the life-expectancy criterion possibly discourages physicians from offering palliative
12
13 287 home care support, especially in younger and non-cancer patients, and removing it could increase the
14
15 288 use of palliative home care support.

17 289 **Strengths and limitations**

19
20 290 An important strength of this study is that, by using nationwide administrative data on every death
21
22 291 over one whole year, our findings are generalisable to the full population, whereas experimental
23
24 292 studies, surveys or sample-based observational studies often have difficulties in reaching certain
25
26 293 underrepresented subgroups and lack the strength necessary for generalisability [3]. Secondly, we used
27
28 294 a previously validated set of quality indicators specifically developed to evaluate end-of-life care on a
29
30 295 population level.[27]. This allows comparing appropriateness of end-of-life care between different
31
32 296 populations, both nationally and internationally. This approach is particularly useful for those parts of
33
34 297 the healthcare sector that do not deliver direct individual patient care, such as health service
35
36 298 researchers, public health and other policy makers [35]. Our operationalisation of palliative home care
37
38 299 support as the use of any of available supportive measures increases the reproducibility of our study in
39
40 300 other countries, and allows comparison studies that focus on the impact of other existing types of
41
42 301 palliative home care support. Other countries that have palliative home care support measures can use
43
44 302 the same methodology to measure the impact of their measures on the quality and costs of end-of-life
45
46 303 care. Additionally, countries that have no or other palliative home care support measures can use our
47
48 304 results to research the possibility to implement such measures in their own healthcare system. Another
49
50 305 strength of using administrative data is that, compared with other data collections methods, it is
51
52 306 relatively inexpensive to collect data for a large population without causing any burden to potentially
53
54 307 vulnerable people.[36] In Belgium—where health insurance is obligatory—administrative health
55
56 308 claims data provide information on 99% of the population’s health care use. Moreover, propensity

1
2
3 309 score matching as a causal inference technique for treatment effect estimation in large observational
4 310 studies is a particularly useful method when a traditional randomised controlled trial design is not
5
6 311 feasible nor ethical, as is the case for our research questions.[16]
7
8

9 312 Our study also has limitations. Even though our matched cohort study allows to cancel out several
10
11 313 sources of confounding, it does not account for unmeasured covariates, such as patients' or caregivers'
12
13 314 personality features, knowledge of and preferences with regard to the end of life, which can influence
14
15 315 both home palliative care support use and the outcomes we evaluated. It cannot be ruled out, therefore,
16
17 316 that the strong association between palliative home care use and the characteristics of end-of-life care
18
19 317 reflect underlying choices by patients, caregivers and family that impact both. For instance, to receive
20
21 318 the palliative home care support in our study, patients should have a wish to die at home, which has
22
23 319 been found to be an important predictor for actual home death.[30] However, even if it would be that
24
25 320 patients needed a certain knowledge, attitude or mental switch to use palliative care our results show
26
27 321 that in these people quality of life increases and cost decreases. This is relevant information for policy
28
29 322 makers to convince people of the added value of palliative care.
30
31

32 323 The use of retrospective data also has limitations. Because palliative home care support is in reality
33
34 324 often used relatively late in the disease trajectory, we chose to restrict the outcome measurement
35
36 325 period to the last 14 days of life to restrict the number of persons excluded from the intervention
37
38 326 group. An additional limitation of using administrative data is that important aspects of quality end-of-
39
40 327 life care that are not reimbursed, such as communication, existential or psychological care, are not
41
42 328 visible. The quality indicators are not meant to serve as indicators for (in)appropriate care at the level
43
44 329 of the individual patient, because clinical factors that justify an intervention and personal preferences
45
46 330 can vary widely across patients. However, they are deemed valid at a population level. Our findings
47
48 331 should be interpreted as an evaluation of the supportive policy measures for palliative home care on
49
50 332 the aggregated level.
51

52 333
53

54 334 **Conclusion**

55
56
57
58
59
60

1
2
3 335 Palliative home care is an important part of end-of-life care. Those who want to be cared for at home
4
5 336 and want to die at home have the right to use support to receive appropriate home care at the end of
6
7 337 life. The findings from our nationwide retrospective cohort study show the positive impact of
8
9 338 palliative home care support on the quality of end-of-life care. Additionally, we found that while the
10
11 339 total costs for home care is higher, the average total reimbursed costs of medical care at the end of life
12
13 340 is significantly lower for those who used palliative home care support. Our findings based on full
14
15 341 population national data add important scientific evidence of the positive impacts palliative home care
16
17 342 support has on the appropriateness of end-of-life care and on reducing societal costs related to care at
18
19 343 the end of life. Because palliative home care support remains widely underused, our results suggest
20
21 344 that increasing its availability and stimulating its use, therefore, has a potential to improve the
22
23 345 appropriateness of care at the end of life of patients and at the same time reduce the expenses for the
24
25 346 health insurer.
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 347 **Declarations**
4
5

6 348 **Authorship**
7

8
9 349 The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study
10
11 350 being reported; that no important aspects of the study have been omitted; and that any discrepancies
12
13 351 from the study as planned (and, if relevant, registered) have been explained.
14

15 352 Arno Maetens, Kim Beernaert, Joachim Cohen and Luc Deliens contributed to the conception and
16
17 353 design of the article. Collection, analysis, and interpretation of data were done by Arno Maetens, Kim
18
19 354 Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and
20
21 355 Joachim Cohen. Arno Maetens wrote the manuscript. The final approval of the manuscript was done
22
23 356 by Kim Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens,
24
25 357 and Joachim Cohen.
26
27

28 358 **Declaration of conflicting interests**
29

30
31 359 The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or
32
33 360 publication of this article.
34
35

36 361 **Funding**
37

38
39 362 This study is supported by a grant from the Flemish government agency for Innovation by Science and
40
41 363 Technology (Agentschap voor Innovatie door Wetenschap en Technologie; SBO IWT nr. 140009).
42
43

44 364 **Ethics approval and consent to participate**
45

46 365 In accordance with Belgian law, approvals for access to the various databases and the database
47
48 366 integrating all databases were obtained from two separate national sectoral committees for privacy
49
50 367 protection: the 'Sectoral Committee of Social Security and Health, Section Health' and the 'Statistical
51
52 368 Supervisory Committee'. Both are subcommittees of the Belgian Commission for the Protection of
53
54
55
56
57
58
59
60

1
2
3 369 Privacy. Additionally, the ethics committee of the Ghent University Hospital provided approval
4
5 370 (B670201422382).

6
7
8 371 **Acknowledgements**

9
10 372 The authors thank Jane Ruthven for manuscript language editing.
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

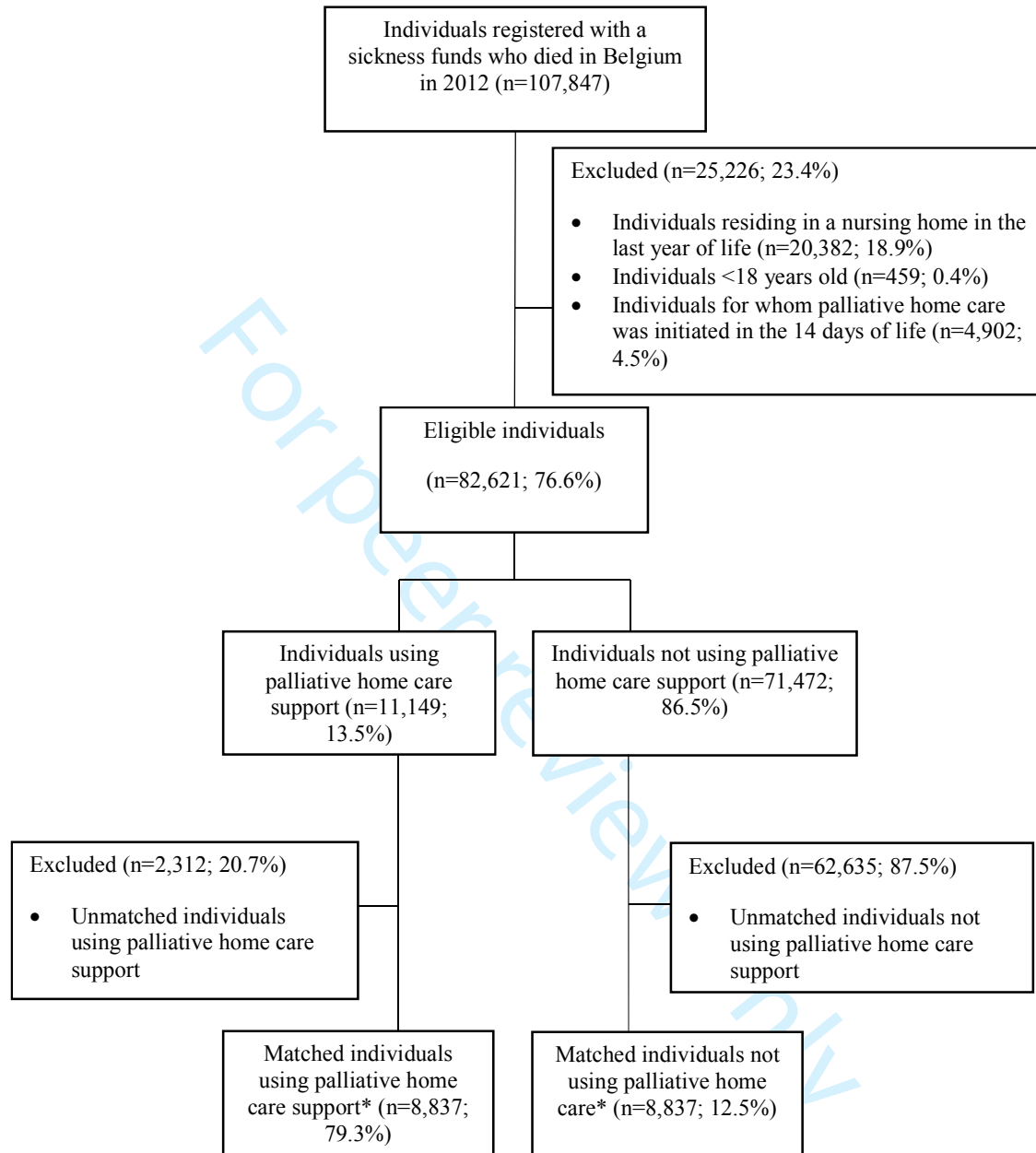
373 **References**

- 374 1. Higginson I, Sen-Gupta G. Place of care in advanced cancer: a qualitative systematic
375 literature review of patient preferences. *J Palliat Med.* 2000;3(3):287–300.
- 376 2. Connor S, Bermedo M. Global atlas of palliative care at the end of life. 2014 [cited 2015
377 Oct 9]; Available from: <http://www.who.int/cancer/publications/palliative-care-atlas/en/>
- 378 3. Murtagh F. Can palliative care teams relieve some of the pressure on acute services?
379 *BMJ.* 2014 Jun 6;348:g3693.
- 380 4. Morin L, Aubry R, Frova L, MacLeod R, Wilson DM, Loucka M, et al. Estimating the
381 need for palliative care at the population level: A cross-national study in 12 countries.
382 *Palliat Med.* 2017 Jun 1;31(6):526–36.
- 383 5. Davies E, Higginson IJ, editors. Palliative care. The solid facts [Internet]. World Health
384 Organization; 2004 [cited 2017 Apr 14]. Available from:
385 [http://www.euro.who.int/en/health-topics/environment-and-health/urban-](http://www.euro.who.int/en/health-topics/environment-and-health/urban-health/publications/2004/palliative-care.-the-solid-facts)
386 [health/publications/2004/palliative-care.-the-solid-facts](http://www.euro.who.int/en/health-topics/environment-and-health/urban-health/publications/2004/palliative-care.-the-solid-facts)
- 387 6. Paz-Ruiz S, Gomez-Batiste X, Espinosa J, Porta-Sales J, Esperalba J. The Costs and
388 Savings of a Regional Public Palliative Care Program: The Catalan Experience at 18
389 Years. *J Pain Symptom Manage.* 2009 Jul 1;38(1):87–96.
- 390 7. Stjernswärd J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. *J*
391 *Pain Symptom Manage.* 2007 May;33(5):486–93.
- 392 8. European Commission. Long-term care in the European Union. Brussels: European
393 Commission, Employment, Social Affairs and Equal Opportunities, DG, Social
394 Protection and Integration; 2008.
- 395 9. Gori C, Fernandez J-L. Long-term Care Reforms in OECD Countries. Policy Press;
396 2015. 328 p.
- 397 10. Woitha K, Carrasco JM, Clark D, Lynch T, Garralda E, Martin-Moreno JM, et al. Policy
398 on palliative care in the WHO European region: an overview of progress since the
399 Council of Europe's (2003) recommendation 24. *Eur J Public Health.* 2015 Nov
400 6;ckv201.
- 401 11. Maetens A, Beernaert K, Deliens L, Aubry R, Radbruch L, Cohen J. Policy Measures to
402 Support Palliative Care at Home: A Cross-Country Case Comparison in Three European
403 Countries. *J Pain Symptom Manage* [Internet]. 2017 Jul 20 [cited 2017 Sep 27];0(0).
404 Available from: [http://www.jpmsjournal.com/article/S0885-3924\(17\)30285-3/fulltext](http://www.jpmsjournal.com/article/S0885-3924(17)30285-3/fulltext)
- 405 12. Cohen J, Deliens L. A Public Health Perspective on End of Life Care. Oxford University
406 Press; 2012. 272 p.
- 407 13. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-
408 effectiveness of home palliative care services for adults with advanced illness and their
409 caregivers. *Cochrane Database Syst Rev.* 2013;6:CD007760.

- 1
2
3 410 14. Shepperd S, Gonçalves-Bradley DC, Straus SE, Wee B. Hospital at home: home-based
4 411 end-of-life care. In: Cochrane Database of Systematic Reviews [Internet]. John Wiley &
5 412 Sons, Ltd; 2016 [cited 2017 Nov 30]. Available from:
6 413 <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009231.pub2/abstract>
7
- 8 414 15. Garrido MM, Kelley AS, Paris J, Roza K, Meier DE, Morrison RS, et al. Methods for
9 415 Constructing and Assessing Propensity Scores. *Health Serv Res.* 2014
10 416 oktober;49(5):1701–20.
- 11
12 417 16. Yao XI, Wang X, Speicher PJ, Hwang ES, Cheng P, Harpole DH, et al. Reporting and
13 418 Guidelines in Propensity Score Analysis: A Systematic Review of Cancer and Cancer
14 419 Surgical Studies. *JNCI J Natl Cancer Inst* [Internet]. 2017 Aug 1 [cited 2017 Oct
15 420 3];109(8). Available from:
16 421 [https://academic.oup.com/jnci/article/109/8/djw323/3078530/Reporting-and-Guidelines-](https://academic.oup.com/jnci/article/109/8/djw323/3078530/Reporting-and-Guidelines-in-Propensity-Score)
17 422 [in-Propensity-Score](https://academic.oup.com/jnci/article/109/8/djw323/3078530/Reporting-and-Guidelines-in-Propensity-Score)
- 18
19 423 17. Seow H, Brazil K, Sussman J, Pereira J, Marshall D, Austin PC, et al. Impact of
20 424 community based, specialist palliative care teams on hospitalisations and emergency
21 425 department visits late in life and hospital deaths: a pooled analysis. *BMJ.*
22 426 2014;348:g3496.
- 23
24 427 18. Seow H, Dhaliwal G, Fassbender K, Rangrej J, Brazil K, Fainsinger R. The Effect of
25 428 Community-Based Specialist Palliative Care Teams on Place of Care. *J Palliat Med.*
26 429 2016 Jan;19(1):16–21.
- 27
28 430 19. Riolfi M, Buja A, Zanardo C, Marangon CF, Manno P, Baldo V. Effectiveness of
29 431 palliative home-care services in reducing hospital admissions and determinants of
30 432 hospitalization for terminally ill patients followed up by a palliative home-care team: A
31 433 retrospective cohort study. *Palliat Med.* 2014 May 1;28(5):403–11.
- 32
33 434 20. Chitnis XA, Georghiou T, Steventon A, Bardsley MJ. Effect of a home-based end-of-life
34 435 nursing service on hospital use at the end of life and place of death: a study using
35 436 administrative data and matched controls. *BMJ Support Palliat Care.* 2013
36 437 Dec;3(4):422–30.
- 37
38 438 21. Cassel JB, Kerr KM, McClish DK, Skoro N, Johnson S, Wanke C, et al. Effect of a
39 439 Home-Based Palliative Care Program on Healthcare Use and Costs. *J Am Geriatr Soc.*
40 440 2016 Nov;64(11):2288–95.
- 41
42 441 22. Garrido MM, Kelley AS, Paris J, Roza K, Meier DE, Morrison RS, et al. Methods for
43 442 Constructing and Assessing Propensity Scores. *Health Serv Res.* 2014 Oct;49(5):1701–
44 443 20.
- 45
46 444 23. World Health Organization. International Classification of Diseases (ICD) [Internet].
47 445 WHO. 2016 [cited 2016 Feb 1]. Available from:
48 446 <http://www.who.int/classifications/icd/en/>
- 49
50 447 24. Maetens A, De Schreye R, Faes K, Houttekier D, Deliëns L, Gielen B, et al. Using
51 448 linked administrative and disease-specific databases to study end-of-life care on a
52 449 population level. *BMC Palliat Care.* 2016;15:86.
- 53
54
55
56
57
58
59

- 1
2
3 450 25. Houttekier D, Cohen J, Van den Block L, Bossuyt N, Deliens L. Involvement of
4 451 palliative care services strongly predicts place of death in Belgium. *J Palliat Med.* 2010
5 452 Dec;13(12):1461–8.
- 6
7 453 26. Keirse M, Thibo T. Evaluatierapport palliatieve zorg [Internet]. 2014 Maart. Available
8 454 from:
9 455 http://www.palliatief.be/accounts/143/attachments/rapporten/rapport_evaluatieceel_palliatieve_zorg_maart_2014_nl.pdf
10 456
- 11
12 457 27. De Schreye R, Houttekier D, Deliens L, Cohen J. Developing indicators of appropriate
13 458 and inappropriate end-of-life care in people with Alzheimer’s disease, cancer or chronic
14 459 obstructive pulmonary disease for population-level administrative databases: A
15 460 RAND/UCLA appropriateness study. *Palliat Med.* 2017 Dec 1;31(10):932–45.
- 16
17 461 28. Parsons LS. Performing a 1:N Case-Control Match on Propensity Score [Internet].
18 462 Ovation Research Group, Seattle, Washington; 2004. Available from:
19 463 <http://www2.sas.com/proceedings/sugi29/165-29.pdf>
- 20
21 464 29. Smith S, Brick A, O’Hara S, Normand C. Evidence on the cost and cost-effectiveness of
22 465 palliative care: A literature review. *Palliat Med.* 2014 Feb 1;28(2):130–50.
- 23
24 466 30. Cantwell P, Turco S, Brenneis C, Hanson J, Neumann CM, Bruera E. Predictors of home
25 467 death in palliative care cancer patients. *J Palliat Care.* 2000;16(1):23–8.
- 26
27 468 31. Houttekier D, Cohen J, Van den Block L, Bossuyt N, Deliens L. Involvement of
28 469 palliative care services strongly predicts place of death in Belgium. *J Palliat Med.* 2010
29 470 Dec;13(12):1461–8.
- 30
31 471 32. Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative
32 472 home care and place of death among cancer patients: a population-based study. *Palliat*
33 473 *Med.* 1993;7(4):323–31.
- 34
35 474 33. Cohen J, Pivodic L, Miccinesi G, Onwuteaka-Philipsen BD, Naylor WA, Wilson DM, et
36 475 al. International study of the place of death of people with cancer: a population-level
37 476 comparison of 14 countries across 4 continents using death certificate data. *Br J Cancer.*
38 477 2015 Nov 3;113(9):1397–404.
- 39
40 478 34. Winthereik AK, Hjertholm P, Neergaard MA, Jensen AB, Vedsted P. Propensity for
41 479 paying home visits among general practitioners and the associations with cancer
42 480 patients’ place of care and death: a register-based cohort study. *Palliat Med.* 2017 Aug
43 481 1;269216317727387.
- 44
45 482 35. Murdoch, Detsky. The inevitable application of big data to health care. *JAMA.* 2013 Apr
46 483 3;309(13):1351–2.
- 47
48 484 36. Teno JM. Measuring end-of-life care outcomes retrospectively. *J Palliat Med.* 2005;8
49 485 Suppl 1:S42-49.
- 50
51 486
- 52
53
54
55
56
57
58
59
60

Figure 1: Flowchart of the study population selection



* The full propensity score matching procedure, including variables used in the matching, are described in detail further.

1
2
3
4
5 **Supplementary file for manuscript: Impact of palliative home care support on the quality and costs of care at the end of life: a nationwide matched**
6 **cohort study**
7
8
9

10
11
12 **Conflict of interest statement and funding**
13
14

15 The authors report a grant during the conduct of the study. There are no potential conflicts of interest to be reported.
16

17
18 All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any
19 organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three
20 years, no other relationships or activities that could appear to have influenced the submitted work.
21
22
23

24 **Ethical approvals**
25

26
27 The study was approved by an ethical commission, and the data linkage and use was approved by the relevant statistical supervisory bodies.
28
29

30 **Acknowledgements**
31

32
33 The authors thank XXXX for language editing, and XXXX for guidance in performing the statistical analysis.
34
35
36
37
38
39
40
41
42
43
44

Supplementary table 1: Sensitivity analyses using different intervention models to construct the propensity score matching (outcomes in percentages)

	Model: Use of allowance for palliative home patient			Model: Use of a multidisciplinary palliative home care team			Model: Use of palliative nursing care or physiotherapy for palliative patients at home		
	Yes (n=7972)	No (n=7972)	RR (95% CI)	Yes (n=4108)	No (n=4108)	RR (95% CI)	Yes (n=6171)	No (n=6171)	RR (95% CI)
Indicators of appropriate end-of-life care									
<i>Home death</i>	57.6	14.7	3.91 (3.70-4.14)	59.6	23.8	2.50 (2.35-2.66)	60.9	18.7	3.26 (3.09-3.45)
<i>Mean number of family physician contacts (SD)*</i>	3.2 (3.0)	0.8 (1.3)	/	3.3 (3.0)	1.3 (2.1)	/	3.4 (3.0)	1.0 (1.7)	/
<i>Mean number of primary caregiver contacts (SD)*</i>	9.4 (6.0)	2.2 (3.9)	/	9.3 (6.1)	3.8 (5.3)	/	10.6 (5.6)	2.6 (4.2)	/
Indicators of inappropriate end-of-life care									
<i>Hospital death</i>	39.7	74.8	0.50 (0.48-0.52)	34.8	69.6	0.50 (0.48-0.52)	36.4	69.9	0.52 (0.50-0.54)
<i>Hospital admission</i>	27.4	59.7	0.46 (0.44-0.48)	21.9	55.6	0.39 (0.37-0.42)	25.2	56.2	0.45 (0.43-0.47)
<i>ICU admission</i>	18.2	39.0	0.47 (0.44-0.49)	14.8	36.5	0.41 (0.37-0.44)	16.5	36.9	0.45 (0.42-0.48)
<i>ED admission</i>	15.0	27.2	0.55 (0.52-0.59)	13.0	25.7	0.51 (0.46-0.56)	14.7	26.7	0.55 (0.51-0.59)
<i>Diagnostic testing</i>	27.2	62.1	0.44 (0.42-0.46)	21.5	56.5	0.38 (0.36-0.41)	24.7	59.6	0.42 (0.40-0.44)
<i>Blood transfusion</i>	2.8	5.7	0.49 (0.42-0.58)	2.3	5.8	0.39 (0.31-0.49)	2.3	5.4	0.42 (0.34-0.51)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

<i>Surgery</i>	0.5	2.7	0.19 (0.14-0.27)	0.3	2.6	0.13 (0.08-0.23)	0.5	2.5	0.18 (0.12-0.28)
----------------	-----	-----	------------------	-----	-----	------------------	-----	-----	------------------

* P<0.0001 calculated using two-sided T-test statistic.

For peer review only

Supplementary table 2: Sensitivity analyses using different intervention models to calculate healthcare costs in the last 14 days of life; presented as means (SE)

	Model: Use of allowance for palliative home patient		Model: Use of a multidisciplinary palliative home care team		Model: Use of palliative nursing care or physiotherapy for palliative patients at home	
	Yes (n=7972)	No (n=7972)	Yes (n=8216)	No (n=8216)	Yes (n=6171)	No (n=6171)
Total inpatient costs	1775 (32.2)	4118 (47.6)	1585 (43.8)	3864 (66.4)	1634 (35.9)	3821 (53.1)
Total outpatient costs	1330 (12.3)	519 (9.1)	1310 (15.7)	687 (14.4)	1496 (14.0)	595 (10.7)
Total costs	3105 (29.8)	4637 (46.7)	2895 (40.9)	4551 (64.2)	3129 (32.8)	4416 (52.0)

SE = standard error ; All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.

Supplementary box 1: Determination of inpatient and outpatient care costs

Persons affiliated to the Belgian National Institute for Health and Disability Insurance are entitled to reimbursement of the cost of healthcare services, treatments and fees provided that the services in question meet certain requirements. Not every healthcare profession or service is entitled to reimbursement.

A list of reimbursable services or **acts** for each profession, the so called **nomenclature** assigns a specific code (nomenclature code) to each act that determines the financial cost and is used as a base for the reimbursement of healthcare costs. **Nomenclature codes** can be divided into acts which are assigned to ambulatory care i.e. outpatient care and institutionalized care i.e. inpatient care. There are more than 26 thousand reimbursed acts.

Inpatient or institutionalized care refers to any medical service or act that requires an hospitalization or an act which is provided during an admission and stay into a hospital. To qualify as an inpatient, a patient must be under the care of a physician while staying overnight in the hospital.

Outpatient or ambulatory care includes all acts that does not require an overnight stay in a hospital or medical facility. Outpatient care is mainly administered in a medical office, hospital, nursing home facility or at home.

The total cost is the sum of all inpatient and outpatient acts described in the nomenclature.

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	p.1	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	p.1
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported	p.3-4		
Objectives	3	State specific objectives, including any prespecified hypotheses	p.4		
Methods					
Study Design	4	Present key elements of study design early in the paper	p.4-5		
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	p.5		
Participants	6	(a) <i>Cohort study</i> - Give the eligibility criteria, and the		RECORD 6.1: The methods of study population selection (such as codes or	p.5

		<p>sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p><i>(b) Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>		<p>algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p>	<p>p.5</p>
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	p.6-7
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	p.6-7		
Bias	9	Describe any efforts to address potential sources of bias	p.6-7		
Study size	10	Explain how the study size was	p.6-7		

				level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (<i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (<i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	p.8 and p.15
Descriptive data	14	(a) Give characteristics of study participants (<i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time (<i>e.g.</i> , average and total amount)	p.8		
Outcome data	15	<i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or summary measures	p.8		
Main results	16	(a) Give unadjusted estimates	p.8		

		and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	p.8		
Discussion					
Key results	18	Summarise key results with reference to study objectives	p.9		
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	p.10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	p.9		
Generalisability	21	Discuss the generalisability (external validity) of the study results	p.11		

Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	p.12		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	

*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

*Checklist is protected under Creative Commons Attribution ([CC BY](https://creativecommons.org/licenses/by/4.0/)) license.

BMJ Open

Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-025180.R1
Article Type:	Research
Date Submitted by the Author:	30-Oct-2018
Complete List of Authors:	Maetens, Arno; Vrije Universiteit Brussel, End-of-Life Care Research Group Beernaert, Kim; Vrije Universiteit Brussel, End-of-Life Care Research Group De Schreye, Robrecht; Vrije Universiteit Brussel, End-of-Life Care Research Group Faes, Kristof; Universiteit Gent Faculteit Geneeskunde en Gezondheidswetenschappen, Interuniversity Center for Health Economic Research (ICHER) Annemans, Lieven; Ghent University, Interuniversity Center for Health Economic Research (ICHER) Pardon, Koen; Vrije Universiteit Brussel, End-of-Life Care Research Group Deliens, Luc; Vrije Universiteit Brussel, End-of-Life Care Research Group; Universiteit Gent Faculteit Geneeskunde en Gezondheidswetenschappen, Public health and primary care Cohen, Joachim; Vrije Universiteit Brussel, End-of-Life Care Research Group
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Health policy, Health services research, Public health
Keywords:	PALLIATIVE CARE, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health economics < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

SCHOLARONE™
Manuscripts

1
2
3 1 **Full title:** Impact of palliative home care support on the quality and costs of care at the end of life: a
4
5 2 population-level matched cohort study
6
7

8 3 **Short title:** Palliative home care support and quality and costs of end-of-life care
9

10
11 4 Arno Maetens*¹ Kim Beernaert¹ Robrecht De Schreye¹ Kristof Faes^{1,2} Lieven Annemans² Koen Pardon¹
12
13 5 Luc Deliens^{1,3} Joachim Cohen¹
14

15 6 ¹ End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) and Ghent University, Brussels,
16
17 7 Belgium;
18

19
20 8 ² Department of Public Health, Interuniversity Center for Health Economic Research (ICHER), Ghent
21
22 9 University, Ghent;
23

24
25 10 ³ Department of Medical Oncology, Ghent University Hospital, De Pintelaan 185, 9000 Ghent, Belgium;
26
27

28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

12 * corresponding author:

13 E-mail: arno.maetens@vub.be

14 Address: Laarbeeklaan 103, 1090 Jette, Belgium

15 Telephone: +32 2 477 49 59

16

17 **Abstract**

18 Objectives: To evaluate the impact of palliative home care support on the quality of care and costs in
19 the last 14 days of life.

20 Design: Matched cohort study using linked administrative databases.

21 Setting: All people who died in Belgium in 2012 (n=107847).

22 Participants: 8837 people who received palliative home care support in the last 720 to 15 days of life
23 matched 1:1 by propensity score to 8837 people who received usual care.

24 Intervention: Receiving the allowance for palliative home patients, multidisciplinary palliative home
25 care team visit, or palliative nurse or physiotherapist visit at home.

26 Main outcome measures: Home death, number of family physician contacts, number of primary
27 caregiver contacts, hospital death, hospital admission, ICU admission, ED admission, diagnostic testing,
28 blood transfusion, surgery. Total inpatient and outpatient costs. All outcomes were measured in the last
29 14 days of life.

30 Results: In the unmatched cohort, 11,149 (13.5%) people received palliative home care support in the
31 last 720 to 15 days of life. After matching, those using palliative home care support had, compared to
32 those who did not, more family physician contacts (mean 3.1 [SD=6.5] vs. 0.8 [SD=1.2]), more chance
33 of home death (56.2% vs. 13.8%; RR=4.08, 95%CI: 3.86-4.31), lower risk of hospital admission (27.4%
34 vs. 60.8%; RR=0.45, 95%CI 0.43-0.46), ICU admission (18.3% vs. 40.4%; RR=0.45, 95%CI 0.43-
35 0.48), or ED admission (15.2% vs. 28.1%; RR=0.54, 95%CI 0.51-0.57). Mean total costs of care were
36 lower for those using palliative home care support (€3081 [95%CI 3025-3136] vs. €4698 [95%CI 4610-
37 4787]; incremental cost: -€1617 [p<0.001]).

38 Conclusions: Palliative home care support use positively impacts quality of care and reduces total costs
39 of care at the end of life in Belgium. Policy makers and healthcare practitioners should increasingly
40 focus on communicating the existing options for palliative home care support to patients and their
41 caregivers.

42 Keywords: end-of-life care, cohort study, quality of care

Strengths and limitations of this study

- By using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain underrepresented subgroups and lack the strength necessary for generalisability.
- A matched cohort study design with a high-quality matching is the best possible technique to evaluate the impact of policy on quality and costs of care, given ethical and practical concerns.
- No previous work has evaluated the impact of all palliative home care support available in one country for the full population.
- Our operationalisation of palliative home care support as the use of any of available policy measure increases the reproducibility of our study in other countries, and allows comparison studies that focus on the impact of other existing types of palliative home care support, especially in countries with similar health care service delivery models and funding.
- Important aspects of quality end-of-life care are not visible in administrative data, such as quality of communication, existential or psychological care. Qualitative research can complement our findings.

43

44 **Background**

45 A majority of the growing population encountered with chronic and life-limiting illnesses prefers to
46 receive high quality care and to die at home.[1,2] Palliative home care support aims to meet the needs
47 of these people by managing symptoms, improving quality of life, and preventing avoidable healthcare
48 interventions such as hospitalisations at the end of life.[3] It is estimated that palliative care could be
49 beneficial in 38 to 74 percent of all deaths worldwide.[4] In recent years, policy makers internationally
50 have focussed on promoting the integration of palliative care services into the community and on
51 developing supportive policy measures for palliative care at home to meet the growing demand for high
52 quality home-based palliative care and to reduce costs related to acute hospital care use at the end of
53 life.[5–7] Several countries offer palliative home care support in the form of multidisciplinary palliative
54 home care teams, palliative nursing care at home or financial support for those wanting to receive
55 palliative care at home.[8–11]

56 The impact of using palliative home care support on the quality and costs of care at the end of life
57 remains poorly evaluated.[12] A Cochrane review that included 23 studies found that use of home
58 palliative care services more than doubled the odds of dying at home and reduced symptom burdens.[13]
59 Six studies focussed on costs and reported up to 35% lower costs in the intervention group compared
60 with a control group. Only one study reported statistically significant differences, but the authors pointed
61 out that “the existence of economically significant differences [in the other studies] cannot be ruled out
62 due to small sample sizes unlikely to have sufficient power to detect statistical significance”. Another
63 recently updated Cochrane review included four trial studies that evaluated ‘hospital at home’ services,
64 demonstrating the positive impact of this type of home-based end-of-life care on the chances of having
65 a home death, but results on hospital admissions and healthcare costs varied and were found
66 inconclusive.[14]

67 However, traditional experimental study designs, such as those evaluated in the above mentioned
68 reviews, are limited due to ethical and practical concerns (e.g. it would be illegal to refrain patients from
69 receiving any palliative home care in a trial). Therefore, they are not suitable for evaluating the impact

1
2
3 70 of palliative home care support that are available nationally to everyone across a healthcare system.[3]
4
5 71 A matched cohort study design with a high-quality matching on the propensity of receiving palliative
6
7 72 home care is the best possible technique to evaluate this impact.[15] The increasing availability and
8
9 73 improving quality of routinely-collected databases and the technical possibilities of linking data from
10
11 74 various sources have opened up new possibilities for such designs.[16] Three retrospective cohort
12
13 75 studies using matched controls found an impact of palliative home care support on reducing
14
15 76 hospitalisations at the end of life and on lower chances for hospital deaths in Canada, England, and the
16
17 77 US.[17–20] Findings from another retrospective cohort study suggested that a proactive home-based
18
19 78 palliative care programme ‘helped to avoid the escalation in hospital use and costs commonly seen in
20
21 79 the final months of life’.[21] However, these studies focused only on a limited number of outcomes as
22
23 80 indicators of quality of end of life care (hospital use and place of death) and only one focused
24
25 81 additionally on costs, without distinguishing inpatient and outpatient costs. None of the studies used
26
27 82 population-level national data, therefore limiting the findings to one specific province or region.
28
29
30
31 83 In Belgium, palliative home care support is available in the form of (1) a multidisciplinary palliative
32
33 84 home care team, (2) palliative home care nursing or physiotherapy, and (3) the allowance for palliative
34
35 85 home care patients, available twice and meant for non-reimbursed palliative care-related costs. These
36
37 86 supportive policy measures are entirely free to the patient and their informal caregivers. Using linked
38
39 87 register-based databases on all deaths in Belgium, the current study aims to evaluate the impact of using
40
41 88 palliative home care support on the appropriateness and costs of care in the last 14 days of life on a
42
43 89 population level.
44
45
46
47
48
49

50 **Methods**

53 **Study design**

56 93 We conducted a matched cohort study on all deaths in Belgium in 2012, using linked data from eight
57
58 94 administrative databases. An individual that used at least one type of palliative home care support was
59
60

1
2
3 95 matched to an individual that used no palliative home care support. To reduce selection bias between
4
5 96 the groups and to balance measured covariates across them, we used propensity score matching.[22] We
6
7 97 followed an extension of the STROBE guidelines for reporting observational studies to report the
8
9 98 propensity score matching analysis.[16]
10

11 12 99 **Study setting and participants**

13
14
15 100 The study was conducted for all those who were registered with a Belgian sickness fund at time of death
16
17 101 in 2012 (98.8% of all deaths). We excluded people younger than 18 years and those who had permanent
18
19 102 residence in a nursing home during the last year of life. Additionally, to avoid any overlap between the
20
21 103 timing of exposure and the timing of the outcomes we excluded those for whom palliative home care
22
23 104 support was initiated for the first time in the last 14 days of life. Figure 1 presents the study population
24
25
26 105 selection process.
27

28 29 106 **Figure 1: Flowchart of the study population selection.**

30
31
32 107 The data used involved eight administrative databases, linked on an individual level using a unique
33
34 108 identifier by a third party responsible for data protection and linkage in Belgium. The linked data
35
36 109 included person-level reimbursed healthcare use in the last two years of life (recorded as nomenclature
37
38 110 codes) including dispensed medication in the hospital and community pharmacy in the last two years of
39
40 111 life (recorded as ATC codes). For all healthcare data the exact date of delivery (coded as number of days
41
42 112 before death) is recorded. Additionally the data include demographic data, fiscal data (i.e. net taxable
43
44 113 annual income), and death certificate data (including underlying cause of death, coded using ICD-10
45
46 114 codification).[23] The data linkage process and content is described in detail elsewhere.[24]
47

48 49 115 **Patient and public involvement**

50
51
52 116 We used previously validated quality indicators (QI) for end-of-life care to measure appropriateness and
53
54 117 inappropriateness of end-of-life care on an aggregated level. Patients were not directly involved in the
55
56 118 design of the study or development of the QIs. The design of the study, using population-level decedent
57
58
59
60

1
2
3 119 data, did not allow to disseminate results to or involve observed patients in the development of the
4
5 120 research questions or outcome measures.
6
7

8 121 **Exposure group**

9

10
11 122 Our exposure group consisted of people who used at least one type of palliative home care support
12
13 123 between the last 720 and 15 days of life (See Box 1). We included all persons receiving palliative home
14
15 124 care support for the longest time-frame available in our data, i.e. up to 720 days before death. We did
16
17 125 not want to exclude persons on the basis of a (retrospectively) predefined timeframe, as this information
18
19 126 (time before death) would not be known using a prospective design. The inclusion criteria were:
20
21 127 (combined by ‘OR’): (1) having received the allowance for palliative home patients, (2) having a visit
22
23 128 by a multidisciplinary palliative home care team visit, or (3) having a visit by a palliative nurse or
24
25 129 physiotherapist at home. Using specific nomenclature codes, we could identify delivery, health-
26
27 130 insurance reimbursed cost and timing of a specific palliative home care support. The data were sorted
28
29 131 to identify the earliest use of palliative home care support when multiple measures were used.
30
31
32

33 132 **Box 1. Description of the exposure: palliative home care support in Belgium**

34

35 Policy measures to support palliative care at home, here defined as “palliative home care support”,
36 exist in Belgium since 1985[25]. In 2002, palliative care was recognised by Belgian law as a right for
37 all Belgian citizens. Since then, seriously ill patients with a short life expectancy (defined by law as
38 “more than 24 hours and less than three months”) and an intention to die at home are eligible to
39 receive specific supportive measures from the Belgian government [26]. These are:
40
41
42
43
44

- 45
46 a. The use of a **multi-disciplinary palliative home care team**: which includes at least one
47 general practitioner, two nurses and an administrative assistant. The main goal of the multi-
48 disciplinary palliative home care teams is to advise family physicians, health professionals,
49 counsellors, informal carers and volunteers involved in the provision of palliative home care
50 of a patient, and to organize and coordinate the provision of that palliative care at home
51 between different care providers. The use of these teams is free of charge for the patient and
52 not limited in time.
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
- b. **Palliative home care nursing or physiotherapy:** type of nursing care or physiotherapy at home, differing from standard nursing care or physiotherapy at home for heavily dependent home-patients in the number of caring tasks provided and round-the-clock availability. Free of charge for the patient.
- c. The **allowance for palliative home patients:** a lump sum of €647.16 (in 2012) which is obtainable twice (possibility to claim a second after one month) and meant to cover for non- or partially reimbursed costs that are related to the provision of palliative care at home (e.g. certain medicines, care materials and tools).

20 133

21
22
23 134 The Belgian health system is primarily funded through social security contributions and taxation, with
24
25 135 a compulsory national health insurance, which covers the whole population. Compulsory health
26
27 136 insurance is combined with a private system of health care delivery, based on independent medical
28
29 137 practice, free choice of service provider and predominantly fee-for-service payment. It is important to
30
31 138 note that all healthcare insured people in Belgium have the legal right to access palliative home care
32
33 139 support. Family physicians play a gatekeeping role in this: they remain responsible for all care provided
34
35 140 at home and need to give their written permission to initiate any of the palliative home care support.
36
37 141 Receiving any of these was chosen as exposure because we considered the different types of support to
38
39 142 be an indication of the same intervention: initiation of palliative home care. However, sensitivity
40
41 143 analyses were performed in which each separate support type is selected as the basis for the exposure
42
43
44 144 group.

45 46 47 145 **Non-exposure group**

48
49
50 146 People who did not use palliative home care support in the last two years of life were included in the
51
52 147 non-exposure group.

53 54 55 148 **Outcomes for appropriateness and inappropriateness of end-of-life care**

1
2
3 149 We used quality indicators for appropriate and inappropriate end-of-life care that were developed using
4
5 150 the RAND/UCLA Appropriateness method, that aims “to combine the best available scientific evidence
6
7 151 with the collective judgment of experts to yield a statement regarding the appropriateness of performing
8
9 152 a procedure at the level of patient-specific symptoms, medical history, and test results” [27]. We
10
11 153 included the following indicators for appropriateness of end-of-life care, all pertaining to the last 14
12
13 154 days of life: dying at home; the average number of primary caregiver contacts; and the average number
14
15 155 of family physician contacts. We included the following indicators for inappropriateness of end-of-life
16
17 156 care: dying in a hospital; being admitted to hospital; being admitted to an emergency department (ED);
18
19 157 being admitted to an intensive care unit (ICU); being submitted to diagnostic testing (i.e. medical
20
21 158 imaging, electrocardiogram or pulmonary function testing); having a blood transfusion; and having
22
23 159 surgery.

24
25
26
27 160 The quality indicators measure the prevalence of specific medication types (recorded in the data sources
28
29 161 using Anatomical Therapeutic Chemical Classification System [ATC] codes) or health care
30
31 162 interventions (recorded in the data sources as nomenclature codes for reimbursement purposes) within
32
33 163 a specified period before death. For example, the quality indicator “average number of primary caregiver
34
35 164 contacts in the last fourteen days of life” is calculated as the mean number of contacts with a family
36
37 165 physician or other primary care professional (based on the number of relevant registered nomenclature
38
39 166 codes) in the last fourteen days of life. The development, validation process and use of these indicators
40
41 167 to study end-of-life care on a population level is described in detail in De Schreye et al. [28].
42
43
44

168 **Costs of end-of-life**

45
46
47
48 169 Based on all specific healthcare consumption data, we calculated total health care costs from a third-
49
50 170 party and patient copayment perspective, consisting of total inpatient cost and total outpatient cost for
51
52 171 both groups. Inpatient costs included all specific intervention and medication costs in the hospital.
53
54 172 Outpatient costs included all specific intervention and medication costs outside the hospital. For a
55
56 173 detailed description see supplementary box 1. Based on the exact dates of delivery we calculated the
57
58
59
60

1
2
3 174 total costs for the last 14 days of life. All costs were actualized to 2017 values based on the unit cost of
4
5 175 all defined resources in that year.
6
7

8 176 **Propensity score matching and statistical analysis**

9

10
11 177 Descriptive statistics were used to describe population characteristics, stratified by having received
12
13 178 palliative home care support (exposure group) or not (non-exposure group).
14
15

16 179 People who received palliative home care support were matched to those who did not, based on an
17
18 180 individual estimation of their propensity for receiving palliative home care support. To calculate the
19
20 181 propensity scores, relevant predictors for receiving palliative home care, based on previous research
21
22 182 findings, were used as baseline covariates [13]. The following baseline covariates were used: age at
23
24 183 death, sex, underlying cause of death (as a proxy for diagnosis using ICD-10 codification, these were
25
26 184 recoded into: neoplasms [C00-D48], respiratory diseases [J40-44, J47], other organ failures i.e. heart,
27
28 185 renal, and liver failure [I11-I13, I50, K70-72, N10-12, N18-19], neurodegenerative diseases i.e.
29
30 186 Alzheimer's, Parkinson's, motor neurone, and Huntington's disease [F01, F03, G10, G12, G20, G30],
31
32 187 HIV/aids [B20-24]; other underlying causes of death were recoded as 'other'), household type, personal
33
34 188 annual taxable income, highest attained educational level, degree of urbanisation of residence, region of
35
36 189 residence, and hospital use in the last two years of life (based on the criteria: 'having had at least six
37
38 190 hospitalisations' and 'being at least 120 days in the hospital'). We used a greedy one to one case-control
39
40 191 propensity score matching algorithm.[29] For every case, the best match was made first and a next-best
41
42 192 match next, in a hierarchical sequence until no more matches could be made. Best matches are those
43
44 193 with the highest digit match on propensity score. First, cases are matched to controls on eight digits of
45
46 194 the propensity score. For those that do not match, cases are then matched to controls on seven digits of
47
48 195 the propensity score, etcetera. The algorithm proceeds sequentially to the lowest digit match on the
49
50 196 propensity score (one digit). In view of performing sensitivity analyses, we performed separate
51
52 197 matchings with respectively: allowance for palliative home care patients, multidisciplinary palliative
53
54 198 home care team visit, and palliative nursing care or physiotherapy at home on its own as exposure, to
55
56 199 evaluate whether these types of support showed different results.
57
58
59
60

1
2
3 200 Two sampled t-test statistics were used to test for significant differences in age, and chi-square statistics
4
5 201 were used to test for significant differences in dichotomous and categorical variables describing the
6
7 202 unmatched and matched exposed and non-exposed groups. Risk ratios were calculated to measure the
8
9 203 differences in outcomes between the exposed group and the non-exposed group. Costs were presented
10
11 204 as means, medians, standard errors and interquartile ranges. All analyses were performed using SAS
12
13 205 Enterprise Guide version 7.1 (SAS Institute, Cary, NC).
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

206 Results

207 Study population characteristics

208 Of all deaths in Belgium in 2012 (n=107 847), we excluded 25 226 individuals from our study population
 209 because they resided in a nursing home (18.9% of total population), were minors (0.4%), or used
 210 palliative home care support only during the last 14 days of life (4.5%) (Figure 1). Our final unmatched
 211 set consisted of 82 621 individuals of which 11 149 (13.5%) had initiated palliative home care support
 212 in the last 720-15 days of life (Table 1). Before matching, the sociodemographic characteristics of the
 213 cohort exposed to palliative home care support differed largely from the unexposed cohort (e.g. in cause
 214 of death, household composition, and hospital use during the last two years of life). After propensity
 215 score matching, 8837 exposed people were matched to as many unexposed people. We performed
 216 sensitivity analyses on each support type separately with no substantial differences in the impact on the
 217 quality indicator outcomes (Supplementary table 1).

218 **Table 1. Characteristics of people using palliative home care support (exposed) and people who did not**
 219 **use palliative home care support (unexposed) before and after propensity score matching.**

Characteristics	Before propensity score matching (n=82 621)		After propensity score matching (n=17 674)	
	Exposed	Unexposed	Exposed	Unexposed
<i>No. of patients (%)</i>	11 149 (13.5)	71 472 (86.5)	8837 (50)	8837 (50)
<i>Earliest use of palliative home care in days, median (IQR)</i>	75 (154)	/	73 (152)	/
<i>Mean age at time of death (SD)</i>	74.2 (12.8)	76.5 (14.2)	74.4 (12.7)	75.0 (12.3)
Sex				
Men	55.2	54.6	56.0	55.1
Women	44.8	45.4	44.0	44.9
Cause of death				
Neoplasm	74.6	20.6	72.7	72.8
COPD	2.5	4.6	2.7	2.8
Other organ failure	3.2	5.9	3.5	3.1
Neurodegenerative	4.4	5.0	4.9	5.1
Other	15.3	63.8	16.2	16.3
Household composition				
Married	60.4	44.6	60.4	61.4
Single person household	26.2	41.5	26.7	26.4

Living together	4.1	4.2	4.0	3.6
One-parent family	6.4	6.7	6.2	5.9
Other	2.9	3.0	2.7	2.7
<i>Education level</i>				
No education	8.1	8.7	7.9	7.7
Primary school education	34.7	34.9	34.7	35.2
Secondary school education	44.8	45.2	45.0	44.6
Post-secondary school education	12.5	11.2	12.4	12.6
<i>Income in quartiles*</i>				
Lowest income quartile	29.2	26.2	28.4	28.7
Second income quartile	22.5	23.5	21.7	21.9
Third income quartile	24.1	24.5	24.3	24.8
Highest income quartile	24.3	25.9	25.6	24.6
<i>Region</i>				
Flemish region	66.4	53.1	65.4	64.5
Walloon region	28.8	36.8	29.6	30.4
Brussels Capital region	4.8	10.1	5.0	5.1
<i>Urbanisation</i>				
Very high	25.1	33.7	25.7	25.6
High	28.5	27.5	29.2	28.7
Average	32.0	24.4	30.7	30.6
Low	12.9	13.0	13.0	13.7
Rural	1.5	1.5	1.5	1.5
<i>Hospital use in the last two years</i>				
≥120 days hospitalised	4.7	5.3	4.6	4.0
≥ 6 hospitalisations	46.5	14.7	44.5	44.6

Values are percentages of patients unless stated otherwise. All percentages are valid percentages. Missing values existed in the full population (n=107 847) for household composition (n=1399; 1.6%), education level (n=11 382; 13.1%), income (n=3563; 4.1%), region (1657; 1.9%), urbanisation (1657; 1.9%). *Income quartiles were calculated on the full population of decedents (n=107 847).

Indicators of appropriate end-of-life care

Fifty-six percent of the people using palliative home care support died at home, compared to 13.8 percent of those who did not use palliative home care support (Relative Risk (RR)=4.08; 95% Confidence Interval (CI) (3.86-4.31) (Table 2). On average, people in the palliative home care support cohort had nine primary caregiver contacts and three family physician contacts in the last two weeks of life, compared to two primary caregiver contacts and less than one family physician contact for those in the unexposed cohort.

232 **Table 2. Indicators of appropriate and inappropriate end-of-life care in the last 14 days of life in the**
 233 **matched cohorts**

	Palliative home care support (n=17 674)		RR (95% CI)
	Yes (n=8837)	No (n=8837)	
Indicators of appropriate end-of-life care			
<i>Home death</i>	56.2	13.8	4.08 (3.86-4.31)
<i>Mean number of family physician contacts (SD)*</i>	3.1 (3.0)	0.8 (1.2)	/
<i>Mean number of primary caregiver contacts (SD)*</i>	9.0 (6.2)	2.3 (4.0)	/
Indicators of inappropriate end-of-life care			
<i>Hospital death</i>	39.0	74.8	0.52 (0.51-0.54)
<i>Hospital admission</i>	27.4	60.8	0.45 (0.43-0.47)
<i>ICU admission</i>	18.3	40.4	0.45 (0.43-0.48)
<i>ED admission</i>	15.2	28.1	0.54 (0.51-0.57)
<i>Diagnostic testing</i>	27.2	63.2	0.43 (0.41-0.45)
<i>Blood transfusion</i>	2.7	5.9	0.47 (0.40-0.54)
<i>Surgery</i>	0.5	2.8	0.19 (0.14-0.26)

234 RR = relative risk; CI = confidence interval; SD = standard deviation; ICU = intensive care unit; ED = emergency
 235 department. * P<0.0001 calculated using two-sided T-test statistic.

236

237 **Indicators of inappropriate end-of-life care**

238 Thirty-nine percent of the people using palliative home care support died in the hospital, compared to
 239 74.8 percent of the people not using palliative home care support (RR=0.52; 95%CI 0.51-0.54). Less
 240 people in the palliative home care support cohort were admitted to a hospital (27.4% vs 60.8%; RR=0.45,
 241 95%CI 0.43-0.46), to an intensive care unit (18.3% vs 40.4%; RR=0.45, 95%CI 0.43-0.48), or to an
 242 emergency department (15.2% vs 28.1%; RR=0.54, 95%CI 0.51-0.57) in the last two weeks of life. Less
 243 people who used palliative home care support were submitted to diagnostic testing (27.2% vs 63.2%;
 244 RR=0.43, 95%CI 0.41-0.45), received blood transfusion (2.7% vs 5.9%; RR=0.47, 95%CI 0.40-0.54),
 245 or surgery (0.5% vs 2.8%; RR=0.19, 95%CI 0.14-0.26). (Table 2)

246 **Medical care costs**

247 Mean total inpatient costs were lower for people using palliative home care support (€1766; 95%CI:
 248 €1706-€1826) compared to those who did not use palliative home care support (€4222; 95%CI: €4133-
 249 €4311) (p<0.001) (Table 3). Mean total outpatient costs were higher for people using palliative home

care support (€1314; 95%CI: €1291-€1337) compared to those who did not (€476; 95%CI: €461-€492) (p<0.001). Mean incremental total costs for exposed versus unexposed people in the last two weeks of life was -€1617 (SE=53.2). We performed sensitivity analyses on each support type separately with no substantial differences in the impact on the costs of care at the end of life (Supplementary table 2).

Table 3 Healthcare costs in the last 14 days of life in the matched cohorts, in euro

	Palliative home care support (n=17 674)				Mean incremental (p-value)
	Yes (n=8837)		No (n=8837)		
	Mean (95%CI)	Median (Q1-Q3)	Mean (95%CI)	Median (Q1-Q3)	
Total	1766 (1706-1826)	0 (0-2724)	4222 (4133-4311)	3400 (513-6754)	-2454 (p<0.001)
inpatient costs					
Total	1314 (1291-1337)	1243 (449-1829)	476 (461-492)	251 (11-647)	838 (p<0.001)
outpatient costs					
Total costs	3081 (3025-3136)	2055 (1305-4227)	4698 (4610-4787)	3996 (1077-7124)	-1617 (p<0.001)

SE = standard error ; Q1-Q1 = interquartile range. All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.

Discussion

To our knowledge, this is the first nationwide matched cohort study on the impact of palliative home care support on the quality and costs of care at the end of life, using validated quality indicators. We found that people using palliative home care support received more appropriate and less inappropriate care at the end of life, and had lower total medical care costs in the last two weeks of life, compared with those who did not use palliative home care support. More than four times as many people using palliative home care support died at home than those not using palliative home care support. Fewer people in the exposed cohort were admitted to the hospital, emergency department, or ICU, and fewer were underwent diagnostic testing, blood transfusion, or surgery in the last two weeks of life.

1
2
3 268 Our study found that the use of palliative home care support lowered the average total medical care costs
4
5 269 per person in the last two weeks of life by €1617. Costs of palliative home care support use that was
6
7 270 continued in the last two weeks of life are also taken into account. A literature review on costs of
8
9 271 palliative care interventions in all settings between 2002-2011 also found that palliative care (including
10
11 272 but not confined to palliative home care) was overall less costly than for comparator groups, despite
12
13 273 large differences in the settings and study designs of the observed studies.[30] However, the review
14
15 274 notes that randomisation is absent in most of the studies, highlighting the importance of controlling for
16
17 275 confounding factors and selection bias when analysing the impact of a palliative care intervention. Our
18
19 276 study design could to a large extent tackle these issues of confounding and bias. A retrospective study
20
21 277 using observational data evaluated the impact of a home-based palliative care programme in southern
22
23 278 California on costs in four disease-groups, and found that participants had in the last six months of life
24
25 279 monthly net savings of \$4258 for cancer, \$4017 for COPD, \$3447 for heart failure and \$2690 for
26
27 280 dementia.[21] Although generalising and comparing costs across different healthcare jurisdictions is
28
29 281 difficult due to differences in healthcare regulations and reimbursement schemes, these numbers are in
30
31 282 line with our findings.
32
33

34
35 283 Our finding that people who used palliative home care support more often died at home confirms
36
37 284 findings in previous studies [13,17,31–33]. In Belgium, a mortality follow-back study on a sample of
38
39 285 1.690 non-sudden deaths found that the involvement of a multidisciplinary palliative home care team
40
41 286 was strongly associated with home death.[32] The rate of home deaths in the exposed and unexposed
42
43 287 groups of our study, respectively 56.2% and 13.8%, was comparable to findings from an Italian study
44
45 288 that compared the home death rates between users of palliative home care versus non-users (respectively
46
47 289 60.8% and 29.3%). Although we were not able to take into account individual preferences on place of
48
49 290 death and quality of death itself [34], our results show that the palliative home care support was effective
50
51 291 in increasing the chance for home deaths on a population level, which is an important policy goal [26].
52
53
54
55 292 Additionally, our study found that the use of palliative home care support has an impact on reducing
56
57 293 hospital, emergency department and intensive care unit admissions in the last two weeks of life. This
58
59
60

1
2
3 294 finding is in line with previous research,[17,20,35], but our study is the first to confirm such findings on
4
5 295 a complete population level.
6
7

8 296 Strikingly, only 14 percent of all home-dwelling adults who died in Belgium in 2012 used palliative
9
10 297 home care support in the last two years of life. This uptake is far below the actual need in the Belgian
11
12 298 population for palliative care, which the most conservative estimation has set at 40% need in the
13
14 299 population.[4] Currently, physicians in Belgium can grant patients an official “palliative home care
15
16 300 status” only when the estimated life expectancy is three months or less. Although this status does not
17
18 301 exclude the patient from receiving specific types of health care, such as in the hospice benefit system in
19
20 302 the USA, the life-expectancy criterion possibly discourages physicians from offering palliative home
21
22 303 care support, especially in younger and non-cancer patients, and removing it could increase the use and
23
24 304 timely initiation of palliative home care support. Further research should also be done to investigate the
25
26 305 implications of accessing support at a different period in the disease trajectory on the quality and costs
27
28 306 of care at the end-of-life.
29
30
31

32 **Strengths and limitations** 33

34
35 308 An important strength of this study is that, by using nationwide administrative data on every death over
36
37 309 one whole year, our findings are generalisable to the full population, whereas experimental studies,
38
39 310 surveys or sample-based observational studies often have difficulties in reaching certain
40
41 311 underrepresented subgroups and lack the strength necessary for generalisability [3]. Secondly, we used
42
43 312 a previously validated set of quality indicators specifically developed to evaluate end-of-life care on a
44
45 313 population level.[28]. This allows comparing appropriateness of end-of-life care between different
46
47 314 populations, both nationally and internationally. This approach is particularly useful for those parts of
48
49 315 the healthcare sector that do not deliver direct individual patient care, such as health service researchers,
50
51 316 public health and other policy makers [36]. Our operationalisation of palliative home care support as the
52
53 317 use of any of available supportive measures increases the reproducibility of our study in other countries,
54
55 318 and allows comparison studies that focus on the impact of other existing types of palliative home care
56
57 319 support. Other countries that have palliative home care support measures can use the same methodology
58
59
60

1
2
3 320 to measure the impact of their measures on the quality and costs of end-of-life care. Additionally,
4
5 321 countries that have no or other palliative home care support measures can use our results to research the
6
7 322 possibility to implement such measures in their own healthcare system. It should be noted however that
8
9 323 the generalizability of the results remains largely limited to countries or regions with similar health care
10
11 324 delivery and funding systems.

12
13
14 325 Another strength of using administrative data is that, compared with other data collections methods, it
15
16 326 is relatively inexpensive to collect data for a large population without causing any burden to potentially
17
18 327 vulnerable people.[37] In Belgium—where health insurance is obligatory—administrative health claims
19
20 328 data provide information on 99% of the population's health care use. Moreover, propensity score
21
22 329 matching as a causal inference technique for treatment effect estimation in large observational studies
23
24 330 is a particularly useful method when a traditional randomised controlled trial design is not feasible nor
25
26 331 ethical, as is the case for our research questions.[16]

27
28
29
30 332 Our study also has limitations. Even though our matched cohort study allows to cancel out several
31
32 333 sources of confounding, it does not account for unmeasured covariates, such as patients' or caregivers'
33
34 334 personality features, knowledge of and preferences with regard to the end of life, which can influence
35
36 335 both home palliative care support use and the outcomes we evaluated. It cannot be ruled out, therefore,
37
38 336 that the strong association between palliative home care use and the characteristics of end-of-life care
39
40 337 reflect underlying choices by patients, caregivers and family that impact both. For instance, to receive
41
42 338 the palliative home care support in our study, patients should have a wish to die at home, which has been
43
44 339 found to be an important predictor for actual home death.[31] However, even if it would be that patients
45
46 340 needed a certain knowledge, attitude or mental switch to use palliative care our results show that in these
47
48 341 groups quality of life increases and cost decreases. Although the circumstances of palliative care
49
50 342 decisions clearly warrant further investigation, as they are still only partially understood, our findings
51
52 343 are relevant information for policy makers to convince people of the added value of palliative care.

53
54
55
56 344 The use of retrospective data also has limitations. Because palliative home care support is in reality
57
58 345 often used relatively late in the disease trajectory, we chose to restrict the outcome measurement period
59
60

1
2
3 346 to the last 14 days of life to restrict the number of persons excluded from the intervention group. An
4
5 347 additional limitation of using administrative data is that important aspects of quality end-of-life care that
6
7 348 are not reimbursed, such as communication, existential or psychological care, are not visible. The quality
8
9 349 indicators are not meant to serve as indicators for (in)appropriate care at the level of the individual
10
11 350 patient, because clinical factors that justify an intervention and personal preferences can vary widely
12
13 351 across patients. However, they are deemed valid at a population level. Our findings should be interpreted
14
15 352 as an evaluation of the supportive policy measures for palliative home care on the aggregated level.
16
17
18
19 353

21 354 **Conclusion**

25 355 Palliative home care is an important part of end-of-life care. Those who want to be cared for at home
26
27 356 and want to die at home have the right to use support to receive appropriate home care at the end of life.
28
29 357 The findings from our nationwide retrospective matched cohort study show the positive impact of
30
31 358 palliative home care support on the quality of end-of-life care. Additionally, we found that while the
32
33 359 total costs for home care is higher, the average total reimbursed costs of medical care at the end of life
34
35 360 is significantly lower for those who used palliative home care support. Our findings based on complete
36
37 361 population national data add important scientific evidence of the positive impacts palliative home care
38
39 362 support has on the appropriateness of end-of-life care and on reducing societal costs related to care at
40
41 363 the end of life. Because palliative home care support appears widely underused, our results suggest that
42
43 364 increasing its availability and stimulating its use, therefore, has a potential to improve the
44
45 365 appropriateness of care at the end of life of patients and at the same time reduce the expenses for the
46
47 366 health insurer.
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 367 **Declarations**
4
5

6 368 **Contributorship statement**
7
8

9 369 The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study
10
11 370 being reported; that no important aspects of the study have been omitted; and that any discrepancies
12
13 371 from the study as planned (and, if relevant, registered) have been explained.
14
15

16 372 Arno Maetens, Kim Beernaert, Joachim Cohen and Luc Deliens contributed to the conception and design
17
18 373 of the article. Collection, analysis, and interpretation of data were done by Arno Maetens, Kim
19
20 374 Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and
21
22 375 Joachim Cohen. Arno Maetens wrote the manuscript. The final approval of the manuscript was done by
23
24 376 Kim Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and
25
26 377 Joachim Cohen.
27
28

29
30 378 **Declaration of competing interests**
31
32

33 379 The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or
34
35 380 publication of this article.
36
37

38 381 **Funding**
39
40

41 382 This study is supported by a grant from the Flemish government agency for Innovation by Science and
42
43 383 Technology (Agentschap voor Innovatie door Wetenschap en Technologie; SBO IWT nr. 140009).
44
45

46 384 **Data sharing statement**
47
48

49 385 In accordance with Belgian law, approvals for access to the various databases and the database
50
51 386 integrating all databases were obtained from two separate national sectoral committees for privacy
52
53 387 protection. Due to ethical concerns with regard to sensitive and potentially identifying data, the
54
55 388 supporting data cannot be made openly available, as stated by the Sectoral Committee of Social Security
56
57 389 and Health - Department Health and the Data Protection Authority. Both are subcommittees of the
58
59
60

1
2
3 390 Belgian Commission for the Protection of Privacy. Additionally, the ethics committee of the Ghent
4
5 391 University Hospital provided approval (B670201422382). Further information about the data and access
6
7 392 regulations are available upon request.
8
9

10 393 **Acknowledgements**
11
12

13 394 The authors thank Jane Ruthven for manuscript language editing.
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

395 **References**

- 396 1 Higginson I, Sen-Gupta G. Place of care in advanced cancer: a qualitative systematic
397 literature review of patient preferences. *J Palliat Med* 2000;**3**:287–300.
398 doi:10.1089/jpm.2000.3.287
- 399 2 Connor S, Bermedo M. Global atlas of palliative care at the end of life. Published Online
400 First: 2014.<http://www.who.int/cancer/publications/palliative-care-atlas/en/> (accessed 9
401 Oct 2015).
- 402 3 Murtagh F. Can palliative care teams relieve some of the pressure on acute services? *BMJ*
403 2014;**348**:g3693. doi:10.1136/bmj.g3693
- 404 4 Morin L, Aubry R, Frova L, *et al.* Estimating the need for palliative care at the population
405 level: A cross-national study in 12 countries. *Palliat Med* 2017;**31**:526–36.
406 doi:10.1177/0269216316671280
- 407 5 Davies E, Higginson IJ, editors. Palliative care. The solid facts.
408 2004.[http://www.euro.who.int/en/health-topics/environment-and-health/urban-](http://www.euro.who.int/en/health-topics/environment-and-health/urban-health/publications/2004/palliative-care.-the-solid-facts)
409 [health/publications/2004/palliative-care.-the-solid-facts](http://www.euro.who.int/en/health-topics/environment-and-health/urban-health/publications/2004/palliative-care.-the-solid-facts) (accessed 14 Apr 2017).
- 410 6 Paz-Ruiz S, Gomez-Batiste X, Espinosa J, *et al.* The Costs and Savings of a Regional
411 Public Palliative Care Program: The Catalan Experience at 18 Years. *J Pain Symptom*
412 *Manage* 2009;**38**:87–96. doi:10.1016/j.jpainsymman.2009.04.011
- 413 7 Stjernswärd J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. *J*
414 *Pain Symptom Manage* 2007;**33**:486–93. doi:10.1016/j.jpainsymman.2007.02.016
- 415 8 European Commission. Long-term care in the European Union. 2008.
- 416 9 Gori C, Fernandez J-L. *Long-term Care Reforms in OECD Countries*. Policy Press 2015.
- 417 10 Woitha K, Carrasco JM, Clark D, *et al.* Policy on palliative care in the WHO European
418 region: an overview of progress since the Council of Europe's (2003) recommendation
419 24. *Eur J Public Health* 2015;:ckv201. doi:10.1093/eurpub/ckv201
- 420 11 Maetens A, Beernaert K, Deliëns L, *et al.* Policy Measures to Support Palliative Care at
421 Home: A Cross-Country Case Comparison in Three European Countries. *J Pain Symptom*
422 *Manage* 2017;**0**. doi:10.1016/j.jpainsymman.2017.07.022
- 423 12 Cohen J, Deliëns L. *A Public Health Perspective on End of Life Care*. Oxford University
424 Press 2012.
- 425 13 Gomes B, Calanzani N, Curiale V, *et al.* Effectiveness and cost-effectiveness of home
426 palliative care services for adults with advanced illness and their caregivers. *Cochrane*
427 *Database Syst Rev* 2013;**6**:CD007760. doi:10.1002/14651858.CD007760.pub2
- 428 14 Shepperd S, Gonçalves-Bradley DC, Straus SE, *et al.* Hospital at home: home-based end-
429 of-life care. In: *Cochrane Database of Systematic Reviews*. John Wiley & Sons, Ltd 2016.
430 doi:10.1002/14651858.CD009231.pub2

- 1
2
3 431 15 Garrido MM, Kelley AS, Paris J, *et al.* Methods for Constructing and Assessing
4 432 Propensity Scores. *Health Serv Res* 2014;**49**:1701–20. doi:10.1111/1475-6773.12182
5
6 433 16 Yao XI, Wang X, Speicher PJ, *et al.* Reporting and Guidelines in Propensity Score
7 434 Analysis: A Systematic Review of Cancer and Cancer Surgical Studies. *JNCI J Natl*
8 435 *Cancer Inst* 2017;**109**. doi:10.1093/jnci/djw323
9
10 436 17 Seow H, Brazil K, Sussman J, *et al.* Impact of community based, specialist palliative care
11 437 teams on hospitalisations and emergency department visits late in life and hospital deaths:
12 438 a pooled analysis. *BMJ* 2014;**348**:g3496.
13
14 439 18 Seow H, Dhaliwal G, Fassbender K, *et al.* The Effect of Community-Based Specialist
15 440 Palliative Care Teams on Place of Care. *J Palliat Med* 2016;**19**:16–21.
16 441 doi:10.1089/jpm.2015.0063
17
18 442 19 Riolfi M, Buja A, Zanardo C, *et al.* Effectiveness of palliative home-care services in
19 443 reducing hospital admissions and determinants of hospitalization for terminally ill patients
20 444 followed up by a palliative home-care team: A retrospective cohort study. *Palliat Med*
21 445 2014;**28**:403–11. doi:10.1177/0269216313517283
22
23 446 20 Chitnis XA, Georghiou T, Steventon A, *et al.* Effect of a home-based end-of-life nursing
24 447 service on hospital use at the end of life and place of death: a study using administrative
25 448 data and matched controls. *BMJ Support Palliat Care* 2013;**3**:422–30.
26 449 doi:10.1136/bmjspcare-2012-000424
27
28 450 21 Cassel JB, Kerr KM, McClish DK, *et al.* Effect of a Home-Based Palliative Care Program
29 451 on Healthcare Use and Costs. *J Am Geriatr Soc* 2016;**64**:2288–95. doi:10.1111/jgs.14354
30
31 452 22 Garrido MM, Kelley AS, Paris J, *et al.* Methods for Constructing and Assessing
32 453 Propensity Scores. *Health Serv Res* 2014;**49**:1701–20. doi:10.1111/1475-6773.12182
33
34 454 23 World Health Organization. International Classification of Diseases (ICD). WHO.
35 455 2016.<http://www.who.int/classifications/icd/en/> (accessed 1 Feb 2016).
36
37 456 24 Maetens A, De Schreye R, Faes K, *et al.* Using linked administrative and disease-specific
38 457 databases to study end-of-life care on a population level. *BMC Palliat Care* 2016;**15**:86.
39 458 doi:10.1186/s12904-016-0159-7
40
41 459 25 Houttekier D, Cohen J, Van den Block L, *et al.* Involvement of palliative care services
42 460 strongly predicts place of death in Belgium. *J Palliat Med* 2010;**13**:1461–8.
43 461 doi:10.1089/jpm.2010.0279
44
45 462 26 Keirse M, Thibo T. Evaluatierapport palliatieve zorg. 2014.
46 463 http://www.palliatief.be/accounts/143/attachments/rapporten/rapport_evaluatieceel_palliati
47 464 [eve_zorg_maart_2014_nl.pdf](http://www.palliatief.be/accounts/143/attachments/rapporten/rapport_evaluatieceel_palliati)
48
49 465 27 Fitch K, Bernstein SJ, Aguilar MD, *et al.* The RAND/UCLA Appropriateness Method
50 466 User's Manual. 2001.https://www.rand.org/pubs/monograph_reports/MR1269.html
51 467 (accessed 3 Oct 2018).
52
53 468 28 De Schreye R, Houttekier D, Deliens L, *et al.* Developing indicators of appropriate and
54 469 inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic

- 1
2
3 470 obstructive pulmonary disease for population-level administrative databases: A
4 471 RAND/UCLA appropriateness study. *Palliat Med* 2017;**31**:932–45.
5 472 doi:10.1177/0269216317705099
6
7
8 473 29 Parsons LS. Performing a 1:N Case-Control Match on Propensity Score.
9 474 2004.<http://www2.sas.com/proceedings/sugi29/165-29.pdf>
10
11 475 30 Smith S, Brick A, O'Hara S, *et al*. Evidence on the cost and cost-effectiveness of
12 476 palliative care: A literature review. *Palliat Med* 2014;**28**:130–50.
13 477 doi:10.1177/0269216313493466
14
15 478 31 Cantwell P, Turco S, Brenneis C, *et al*. Predictors of home death in palliative care cancer
16 479 patients. *J Palliat Care* 2000;**16**:23–8.
17
18
19 480 32 Houttekier D, Cohen J, Van den Block L, *et al*. Involvement of palliative care services
20 481 strongly predicts place of death in Belgium. *J Palliat Med* 2010;**13**:1461–8.
21 482 doi:10.1089/jpm.2010.0279
22
23 483 33 Costantini M, Camoirano E, Madeddu L, *et al*. Palliative home care and place of death
24 484 among cancer patients: a population-based study. *Palliat Med* 1993;**7**:323–31.
25 485 doi:10.1177/026921639300700410
26
27
28 486 34 Cohen J, Pivodic L, Miccinesi G, *et al*. International study of the place of death of people
29 487 with cancer: a population-level comparison of 14 countries across 4 continents using
30 488 death certificate data. *Br J Cancer* 2015;**113**:1397–404. doi:10.1038/bjc.2015.312
31
32 489 35 Winthereik AK, Hjertholm P, Neergaard MA, *et al*. Propensity for paying home visits
33 490 among general practitioners and the associations with cancer patients' place of care and
34 491 death: a register-based cohort study. *Palliat Med* 2017;**31**:269216317727387.
35 492 doi:10.1177/0269216317727387
36
37
38 493 36 Murdoch, Detsky. The inevitable application of big data to health care. *JAMA*
39 494 2013;**309**:1351–2. doi:10.1001/jama.2013.393
40
41 495 37 Teno JM. Measuring end-of-life care outcomes retrospectively. *J Palliat Med* 2005;**8**
42 496 **Suppl 1**:S42-49. doi:10.1089/jpm.2005.8.s-42
43
44 497
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

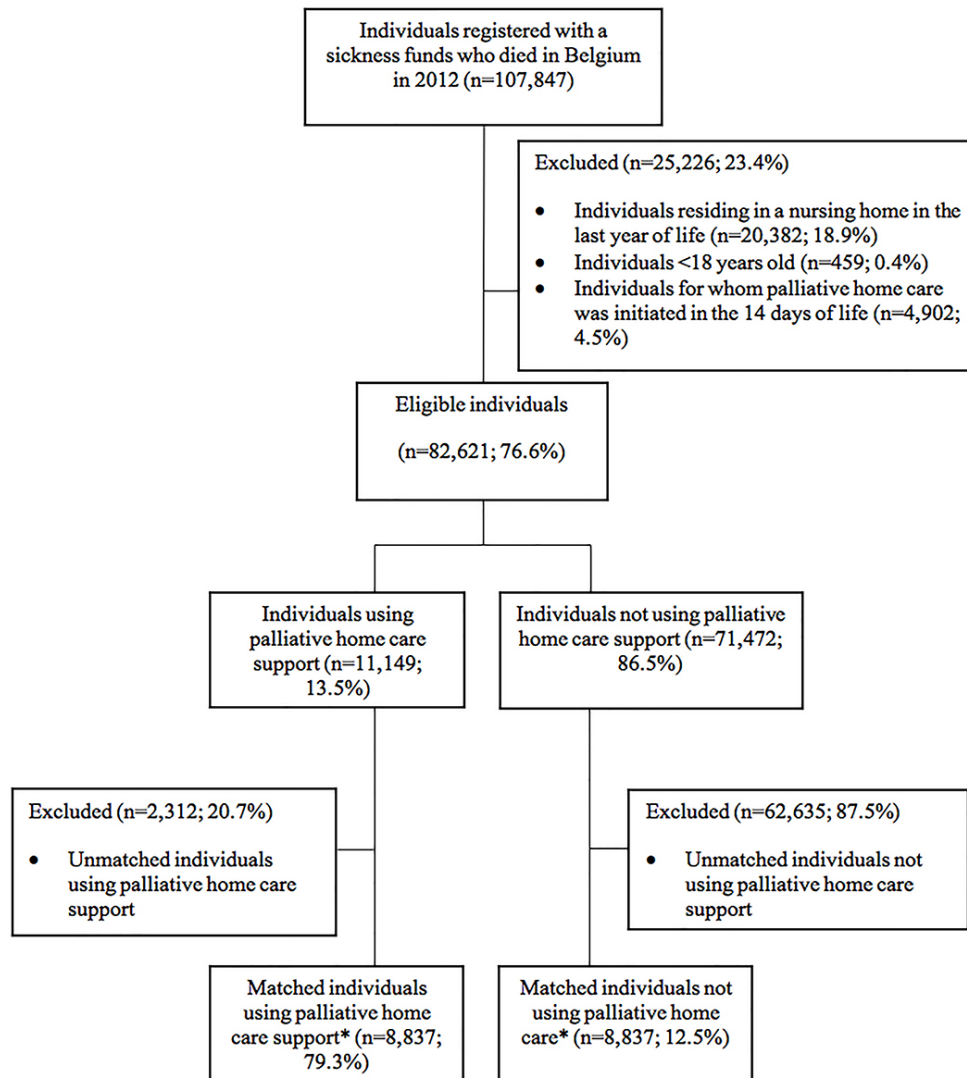


Figure 1: Flowchart of the study population selection

91x99mm (300 x 300 DPI)

Supplementary file for manuscript: Impact of palliative home care support on the quality and costs of care at the end of life: a nationwide matched cohort study

Supplementary table 1: Sensitivity analyses using different intervention models to construct the propensity score matching (outcomes in percentages)

	Model: Use of any palliative home care support			Model: Use of allowance for palliative home patient			Model: Use of a multidisciplinary palliative home care team			Model: Use of palliative nursing care or physiotherapy for palliative patients at home		
	Yes (n=8837)	No (n=8837)	Risk Ratio (95% CI)	Yes (n=7972)	No (n=7972)	Risk Ratio (95% CI)	Yes (n=4108)	No (n=4108)	Risk Ratio (95% CI)	Yes (n=6171)	No (n=6171)	Risk Ratio (95% CI)
Indicators of appropriate end-of-life care												
<i>Home death</i>	56.2	13.8	4.08 (3.86-4.31)	57.6	14.7	3.91 (3.70-4.14)	59.6	23.8	2.50 (2.35-2.66)	60.9	18.7	3.26 (3.09-3.45)
<i>Mean number of family physician contacts (SD)*</i>	3.1 (3.0)	0.8 (1.2)	/	3.2 (3.0)	0.8 (1.3)	/	3.3 (3.0)	1.3 (2.1)	/	3.4 (3.0)	1.0 (1.7)	/
<i>Mean number of primary caregiver contacts (SD)*</i>	9.0 (6.2)	2.3 (4.0)	/	9.4 (6.0)	2.2 (3.9)	/	9.3 (6.1)	3.8 (5.3)	/	10.6 (5.6)	2.6 (4.2)	/
Indicators of inappropriate end-of-life care												
<i>Hospital death</i>	39.0	74.8	0.52 (0.51-0.54)	39.7	74.8	0.50 (0.48-0.52)	34.8	69.6	0.50 (0.48-0.52)	36.4	69.9	0.52 (0.50-0.54)
<i>Hospital admission</i>	27.4	60.8	0.45 (0.43-0.47)	27.4	59.7	0.46 (0.44-0.48)	21.9	55.6	0.39 (0.37-0.42)	25.2	56.2	0.45 (0.43-0.47)
<i>ICU admission</i>	18.3	40.4	0.45 (0.43-0.48)	18.2	39.0	0.47 (0.44-0.49)	14.8	36.5	0.41 (0.37-0.44)	16.5	36.9	0.45 (0.42-0.48)
<i>ED admission</i>	15.2	28.1	0.54 (0.51-0.57)	15.0	27.2	0.55 (0.52-0.59)	13.0	25.7	0.51 (0.46-0.56)	14.7	26.7	0.55 (0.51-0.59)
<i>Diagnostic testing</i>	27.2	63.2	0.43 (0.41-0.45)	27.2	62.1	0.44 (0.42-0.46)	21.5	56.5	0.38 (0.36-0.41)	24.7	59.6	0.42 (0.40-0.44)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

<i>Blood transfusion</i>	2.7	5.9	0.47 (0.40-0.54)	2.8	5.7	0.49 (0.42-0.58)	2.3	5.8	0.39 (0.31-0.49)	2.3	5.4	0.42 (0.34-0.51)
<i>Surgery</i>	0.5	2.8	0.19 (0.14-0.26)	0.5	2.7	0.19 (0.14-0.27)	0.3	2.6	0.13 (0.08-0.23)	0.5	2.5	0.18 (0.12-0.28)

* P<0.0001 calculated using two-sided T-test statistic.

For peer review only

Supplementary table 2: Sensitivity analyses using different intervention models to calculate healthcare costs in the last 14 days of life; presented as means (SE)

	Model: Use of allowance for palliative home patient			Model: Use of a multidisciplinary palliative home care team			Model: Use of palliative nursing care or physiotherapy for palliative patients at home		
	Yes n=7972	No n=7972	Incremental cost (95%CI)	Yes n=8216	No n=8216	Incremental cost (95%CI)	Yes n=6171	No n=6171	Incremental cost (95%CI)
Total inpatient costs	1775 (32.2)	4118 (47.6)	-2343 (2230-2456)	1585 (43.8)	3864 (66.4)	-2279 (2122-2435)	1634 (35.9)	3821 (53.1)	-2187 (2061-2313)
Total outpatient costs	1330 (12.3)	519 (9.1)	811 (781-841)	1310 (15.7)	687 (14.4)	623 (581-664)	1496 (14.0)	595 (10.7)	901 (866-935)
Total costs	3105 (29.8)	4637 (46.7)	-1532 (1423-1640)	2895 (40.9)	4551 (64.2)	-1656 (1506-1805)	3129 (32.8)	4416 (52.0)	-1287 (1166-1407)

SE = standard error ; All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.

Supplementary box 1: Determination of inpatient and outpatient care costs

Persons affiliated to the Belgian National Institute for Health and Disability Insurance are entitled to reimbursement of the cost of healthcare services· treatments and fees provided that the services in question meet certain requirements. Not every healthcare profession or service is entitled to reimbursement.

A list of reimbursable services or **acts** for each profession· the so called **nomenclature** assigns a specific code (nomenclature code) to each act that determines the financial cost and is used as a base for the reimbursement of healthcare costs. **Nomenclature codes** can be divided into acts which are assigned to ambulatory care i.e. outpatient care and institutionalized care i.e. inpatient care. There are more than 26 thousand reimbursed acts.

Inpatient or institutionalized care refers to any medical service or act that requires an hospitalization or an act which is provided during an admission and stay into a hospital. To qualify as an inpatient· a patient must be under the care of a physician while staying overnight in the hospital.

Outpatient or ambulatory care includes all acts that does not require an overnight stay in a hospital or medical facility. Outpatient care is mainly administered in a medical office· hospital· nursing home facility or at home.

The total cost is the sum of all inpatient and outpatient acts described in the nomenclature.

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	p.1	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	p.1
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported	p.3-4		
Objectives	3	State specific objectives, including any prespecified hypotheses	p.4		
Methods					
Study Design	4	Present key elements of study design early in the paper	p.4-5		
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	p.5		
Participants	6	(a) <i>Cohort study</i> - Give the eligibility criteria, and the		RECORD 6.1: The methods of study population selection (such as codes or	p.5

		<p>sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p><i>(b) Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>		<p>algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p>	<p>p.5</p>
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	p.6-7
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	p.6-7		
Bias	9	Describe any efforts to address potential sources of bias	p.6-7		
Study size	10	Explain how the study size was	p.6-7		

				level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (<i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (<i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	p.8 and p.15
Descriptive data	14	(a) Give characteristics of study participants (<i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time (<i>e.g.</i> , average and total amount)	p.8		
Outcome data	15	<i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or summary measures	p.8		
Main results	16	(a) Give unadjusted estimates	p.8		

		and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	p.8		
Discussion					
Key results	18	Summarise key results with reference to study objectives	p.9		
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	p.10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	p.9		
Generalisability	21	Discuss the generalisability (external validity) of the study results	p.11		

Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	p.12		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	

*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

*Checklist is protected under Creative Commons Attribution ([CC BY](https://creativecommons.org/licenses/by/4.0/)) license.