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1 **Engagement of specialized palliative care services with the general public: a**  
2 **population-level survey in three European countries**

3 Aline De Vleminck<sup>1</sup>, Sally Paul<sup>2</sup>, Maria Reinius<sup>3</sup>, Libby Sallnow<sup>4,5</sup>, Carol Tishelman<sup>6,7</sup>, Joachim Cohen<sup>1</sup>

4 <sup>1</sup> Vrije Universiteit Brussel (VUB) & Ghent University, End-of-life Care Research Group, Laarbeeklaan 103, 1090  
5 Brussels, Belgium

6 <sup>2</sup> School of Social Work and Social Policy, University of Strathclyde, Glasgow, Scotland

7 <sup>3</sup> Medical Management Centre, Department of Learning, Informatics, Management and Ethics, Karolinska  
8 Institutet, S-17177, Stockholm, Sweden

9 <sup>4</sup> St Christopher's Hospice, London, UK

10 <sup>5</sup> Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, London,  
11 UK

12 <sup>6</sup> Division of Innovative Care Research, Department of Learning, Informatics, Management and Ethics,  
13 Karolinska Institutet, Stockholm, Sweden

14 <sup>7</sup> Center for Health Economics, Informatics and Health Care Research (CHIS) Stockholm Health Care Services  
15 (SLSO), Region Stockholm, Stockholm, Sweden

16

17

18 **Corresponding author:**

19 Joachim Cohen

20 End-of-life care research group

21 Vrije Universiteit Brussel (VUB) & Ghent University

22 Laarbeeklaan 103,

23 1090 Brussels – BELGIUM

24 Tel. +32 477 47 10

25 Email: jcohen@vub.be

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32

1 **Abstract**

2 **Background:**

3 There is growing recognition of a need for community capacity development around serious illness,  
4 dying and loss, complementary to strategies focusing on health services. Hitherto, little is known  
5 about how and to what extent palliative care services in different countries are adopting these ideas  
6 in their practices.

7 **Aim:** To examine views towards and actual involvement in community engagement activities as  
8 reported by specialized palliative care services in Belgium, Sweden and the UK.

9 **Design, setting, participants:** Cross-sectional survey among all eligible specialized palliative care  
10 services in Flanders (Belgium) (n=50), Sweden (n=129) and the UK (n=245). Representatives of these  
11 services were invited to complete an online questionnaire about their actual activities with the  
12 general public and their attitudes regarding such activities.

13 **Results:** Response rates were 90% (Belgium), 71% (Sweden) and 49% (UK). UK services more often  
14 reported engaging with the general public to develop knowledge and skills through a range of  
15 activities (80-90%) compared to Belgian (31-71%) and Swedish services (19-38%). Based on a  
16 combination of engagement activities 74% of UK services could be labeled as extending their focus  
17 beyond the clinical mandate compared to 16% in Belgium and 7% in Sweden. Services' dependency  
18 on charitable donations was strongly associated with increased engagement with the general public.

19 **Conclusion:** An expansion of the mandate of specialized palliative care services beyond a traditional  
20 clinically-oriented focus towards one inclusive of community capacity building around serious illness,  
21 dying and loss is occurring in different countries, albeit to different degrees and with different  
22 intensities.

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25 **Key words:** palliative care, hospices, Belgium, United Kingdom, Sweden, survey, community  
26 participation, social participation

27

1 **Key statements**

2

3 **What is already known about the topic?**

- 4 • *There is an increasing interest internationally in public health approaches to palliative care*  
5 *that aim to develop community capacity around serious illness, dying and loss*  
6 • *Community engagement activities by palliative care services have been demonstrated in the*  
7 *UK and New Zealand*  
8 • *It is not known to what extent palliative care services in different countries are adopting*  
9 *these ideas in their practices*

10

11 **What this paper adds**

- 12 - *Palliative care services in Belgium, UK and Sweden report community engagement activities*  
13 *indicating an expansion of their traditional clinically-oriented focus*  
14 - *The degree of community engagement seems to be considerably larger in the UK compared*  
15 *to in Belgium and even more so to Sweden*  
16 - *Services' orientation towards community engagement is found to be associated with their*  
17 *dependency on charitable donations for their functioning*

18

19

20 **Implications for practice, theory or policy**

- 21 • *Palliative care services' priorities and activities regarding community engagement seem to*  
22 *be shaped by different traditions, health care systems and cultural norms in different*  
23 *countries*  
24 • *Normative ideas about the role of palliative care services in the development of community*  
25 *capacity, therefore, need to be avoided and a variety of ways to achieve this need to be*  
26 *considered*  
27 • *The fact that at least some palliative care services are expanding their mandate may need to*  
28 *be more fully recognized and supported by health policy makers*

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## 1 Introduction

2 Specialized palliative care services developed in many countries in response to complex needs and  
3 problems associated with serious illness, dying, death and grief<sup>1</sup>. These services traditionally focus on  
4 assessing and relieving biopsychosocial problems of individual patients and their family members, and  
5 in supporting care providers in doing so<sup>2-4</sup>. However, there is growing realization of the limitations of  
6 traditional service-led models, with increasing interest on broader impacts of palliative care services,  
7 beyond clinical service provision<sup>1-6</sup>. This involves expanding the reach and effectiveness of palliative  
8 care services by collaborating with the public to: increase awareness about death, dying and loss and  
9 thereby death literacy; empower communities in caring for their own at the end-of-life (here used to  
10 include bereavement); and address social, existential and psychological issues that are better dealt  
11 with within existing social networks than by health services<sup>1,7</sup>.

12 This expanding mandate is articulated in a paradigm first referred to over 20 years ago by Kellehear  
13 as health-promoting palliative care<sup>8,9</sup> and more recently as public health palliative care<sup>4,10</sup>, derived  
14 from the Ottawa Charter for Health Promotion<sup>11</sup>. Such models are based on the premise that while  
15 end-of-life care can require professional and medical support, it is predominately a universal  
16 experience entailing social responses<sup>4,10,12</sup>. They aim to resituate community and family responses by  
17 empowering them alongside, and in partnership with, professional services through community  
18 engagement<sup>13</sup>.

19 A research base about public health palliative care is gradually developing<sup>14-17</sup>, although little prior  
20 research has explored specialized palliative care services' community engagement initiatives. A 2013  
21 survey of >200 specialized palliative care services in the United Kingdom (UK), found that 60%  
22 prioritized community engagement initiatives to support those facing end-of-life issues, with  
23 professionals working closely with communities to support this<sup>18</sup>. A 2016 study found similar results  
24 for 15 hospices in New Zealand<sup>19</sup>. These studies indicate that some specialized palliative care services  
25 had begun to rethink how they could work with broader communities to improve end-of-life  
26 experiences. Such approaches are dependent on norms and cultural influences in local contexts as  
27 well as the history and structure of health and social care systems.

28 However, existing data about specialized palliative care services' community engagement derives  
29 nearly exclusively from English-speaking countries, although community engagement in palliative care  
30 is gaining momentum internationally. Ongoing discussions among the authors pointed to a need to  
31 update extant knowledge by exploring differing settings, needs and potentials, beginning with their  
32 own contexts in Belgium, Sweden and the UK. These three countries vary in terms of types of health  
33 care systems, organization of palliative care within the countries, and the differences in the extent  
34 and role of volunteering activities within palliative care, with Belgium and the UK having a longer  
35 tradition of volunteerism in palliative care compared to Sweden<sup>20-24</sup>. Belgium, Sweden and the UK are  
36 generally also mapped as having different shared values<sup>25</sup> (see Table A1 in Appendix for a more  
37 detailed description). Cross-national comparisons can help to understand similarities and differences  
38 across countries at the intercept of community engagement and specialized palliative care provision,  
39 and support mutual learning. In this article, we therefore aim to examine views towards and actual  
40 involvement in community engagement activities as reported by specialized palliative care services in  
41 Belgium, Sweden and the UK.

42

43

## 1 **Methods**

2 We conducted an online cross-sectional survey among specialized palliative care services in Flanders  
3 (Belgium), Sweden and the UK ~~that might feasibly engage with the surrounding community.~~  
4 Presentation follows STROBE guidelines <sup>26</sup>.

### 5 **Participants**

6 Survey respondents were representatives of specialized palliative care services. A specialized palliative  
7 care service was defined as a service dedicated to providing palliative care by professionals either  
8 trained in or working predominately within palliative care. In Flanders (Belgium), services were  
9 identified through up-to-date listings of services from the Flemish Federation of Palliative Care for  
10 Flanders in 2018 (n=50). In Sweden, all adult services voluntarily registered with the 2018 national  
11 Palliative Guide were included (n=129). In the UK, services were identified through 2018 listings of  
12 services on the Hospice UK online database (n=245). Given the aims of this study, we wanted to  
13 include services that might feasibly engage with the surrounding community and therefore excluded  
14 services acting only as consultants for other professionals, e.g. hospital-based palliative support teams  
15 who mainly have an intramural support function, as these would not be expected to engage directly  
16 with the community. For each included service, one person identified as well-placed to know the  
17 activities of the service (e.g. coordinators, directors or chairs of the service) received an email  
18 invitation, with instructions to forward it if another person within the service was better suited to  
19 respond to the survey.  
20

### 21 **Questionnaire**

22 Existing questionnaires and instruments were initially perused but deemed inappropriate for our aims.  
23 The questionnaire for this survey was in part inspired by Paul & Sallnow's 2013 UK questionnaire<sup>18</sup> but  
24 further developed collaboratively within the research team to ensure appropriate operationalization  
25 of community activities across countries. 'Community engagement activities' were defined as  
26 "*activities that your service does with the general public*". The community engagement activities  
27 surveyed were structured according to Sallnow & Paul's model of power sharing in palliative care  
28 (2004) that presents a spectrum of engagement activities with communities, ranging from informing  
29 through consulting, to involving, collaborating, and empowering<sup>13</sup>. This spectrum aims to represent  
30 increasing engagement, capable of more penetrating health and social outcomes.  
31

32 A first version of the questionnaire was developed in English and subsequently translated to Swedish  
33 and Dutch. In order to reach equivalence across countries we followed previously published guidance  
34 on translation and cultural adaptation<sup>27, 28</sup> and performed cognitive interviews, using a 'think aloud  
35 approach'<sup>29</sup> with palliative care team members in Flanders, Belgium (n= 6), Sweden (n= 3) and the UK  
36 (n= 4) to explore the interpretation of items and concepts. During these interviews, respondents were  
37 asked to complete a printed copy of the questionnaire in the presence of a researcher, while voicing  
38 their thought process out-loud and remarking on questions, terms or concepts that were unclear or  
39 difficult to answer. Based on the results of the cognitive interviews, the questionnaire was further  
40 adapted through several meetings with the research team. From the interviews, it became clear that  
41 certain key terms in the questionnaire such as 'general public' needed to be defined more explicitly  
42 (see Appendix 2 for the English questionnaire). We also specified what was meant with 'full-time  
43 equivalent professional care providers employed by the service' and 'volunteers', and used the  
44 Swedish expression commonly used for bereavement care, literally translated as "support for  
45 survivors" since there is no established phrase in Sweden for "bereavement care". Lastly, space for  
46 additional comments and reflections of respondents was included, and an explanatory cover letter to  
47 respondents defining the purpose and key terms of this study was added.  
48  
49

1 The final questionnaire consisted of 11 questions in three modules: 1) characteristics of the services;  
2 2) community engagement activities with the general public - following Sallnow & Paul's conceptual  
3 model<sup>13</sup> this was further differentiated as: information provision about the service; public education  
4 about palliative care-related aspects; collaborating with other organizations to develop end-of-life  
5 skills and knowledge among the general public; and developing new networks together with  
6 communities); and 3) attitudes regarding specialized palliative care services' role in engaging with the  
7 general public (see Appendix 2 for the English questionnaire).  
8

### 9 **Data collection**

10 The online tool LimeSurvey was used to create electronic questionnaires for all three countries.  
11 LimeSurvey enables secure, anonymous data collection and ensures confidentiality. After approval  
12 from the Ethical Review Board of Brussels University Hospital (ref B.U.N. 143201837115) and in  
13 accordance with research ethics regulations in each respective country, respondents were contacted  
14 in January 2019 (Belgium and Sweden) and February 2019 (UK) via email with an invitation to  
15 participate in the online survey. The questionnaire was accessed through a unique link in the email,  
16 which allowed the program to monitor survey response. An information sheet prefaced each survey,  
17 stating that survey response was considered as provision of informed consent. Respondents without  
18 a recorded response to the questionnaire received an automated reminder email, at timepoints  
19 determined by the response rate and praxis in each country: two and four weeks after the first  
20 invitation in Belgium, after one, two and four weeks in Sweden, and after one, two, three, five, six and  
21 eleven weeks in the UK. In Belgium, a data collector telephoned non-responders one week after the  
22 second reminder, to ask if support filling out the questionnaire was desired. Likewise, in the UK a data  
23 collector called non-responders in week six. Participants' responses were stored anonymously on the  
24 password-protected survey website. After completed data collection (May 2019), individual responses  
25 were transferred to SPSS for analysis.  
26

### 27 **Statistical analyses**

28 Statistical analyses were performed using IBM SPSS Statistics version 26. Descriptive data were  
29 aggregated by country and differences in distribution between countries examined with Kruskal  
30 Wallance Test. Two-step Cluster Analysis identified clusters of services in relation to community  
31 engagement activities. Cluster membership was then used as a grouping variable for further analyses.  
32 Chi-square tests were performed to check for statistical differences in service characteristics and  
33 cluster membership. Thereafter, multivariable binary logistic regression analyses were performed  
34 with cluster membership as the dependent variable and service characteristics as independent  
35 variables. Analyses were performed both across and within countries. Models were built hierarchically  
36 and multicollinearity between independent variables was avoided. Odds ratios (OR) and 95%  
37 confidence intervals (CI) are presented. A Principal Component Analysis (PCA)(Varimax rotation) was  
38 performed using data about participants' attitudes towards community engagement to investigate  
39 underlying attitudinal structures. Components were selected based on theoretical consistency of  
40 items and statistical criteria (e.g. explained variance, eigenvalues, component loadings of the items).  
41 Thereafter, one-way ANOVA tests were carried out to explore associations between mean scores for  
42 identified attitude-components and relevant service characteristics. Additionally, multivariable  
43 analyses were performed to correct for possible confounding factors.  
44

## 1 **Results**

2 Response rates were 90% for Belgium, 70.5% for Sweden and 49.4% for the UK. An overview of service  
3 characteristics by country is shown in Table 1. Approximately 75% of the UK services offer day hospice  
4 care, in contrast to 9% of the Belgian services and 12% of the Swedish services. While <20% of Swedish  
5 services involve volunteers, 93% do so in Belgium, with 100% in the UK. Ninety-one percent of Swedish  
6 services reported that they could function well without donations, whereas 98% of the UK services  
7 indicated that they could not function at all without donations; in Belgium 75% indicated that at least  
8 some aspects of their work would not be possible without donations.

### 9 **Community engagement activities**

10 In all countries, only a minority of services reported that they planned to initiate activities they were  
11 not currently engaged in, in the coming year. However, planned and present engagement in all  
12 community activities, with the exception of government collaboration, differed significantly between  
13 countries (Table 2). In general, the UK services reported strong community engagement (80-90%) to  
14 educate the general public, with moderate activity among Belgian services (31-71%) and least among  
15 those in Sweden (19-38%). Approximately 20% of services in Belgium and Sweden reported having  
16 built or helped build informal end-of-life support or care networks, whereas in the UK, ~77% of  
17 services engaged in building end-of-life networks.

### 18 **Factors associated with community engagement**

19 A Two-Step cluster analysis created a typology of services based on their community engagement  
20 activities, with three clusters of services we labelled “expanding services” (i.e. extending their focus  
21 beyond a clinical mandate; N= 88; 38.4%), “selective engagement services” (i.e. engaging in some  
22 community activities but not in general; N= 62; 27.1%), “clinically-oriented services” (i.e. focusing  
23 predominantly on direct care provision itself; N= 79; 34.5%). See Appendix 3 for more detail.

24 The univariable analyses (Table 3) indicate that community engagement differs significantly between  
25 services in Belgium, Sweden and the UK. Most UK services (73.5%) are located in the cluster  
26 “expanding services” with only one service in the clinically-oriented cluster, while most (69.9%)  
27 Swedish services are located in “clinically-oriented services”; only 7.2% are ‘expanders’. For Belgium,  
28 15.9% of services were in the “expanders” cluster and 45.5% in the “clinically-oriented” cluster.  
29 Services unable to function at all without voluntary donations are significantly more often in the  
30 “expanding services” cluster (n= 52; 75.4%), while services not at all dependent on donations (n= 64;  
31 72%) were generally found in the “clinically-oriented” cluster. Services working with volunteers are  
32 also in the “expanding services” cluster (n=83; 52.5%) significantly more than in other clusters.

33 A cross-country multivariable logistic regression analysis with the cluster ‘Expanding services vs the  
34 rest’ as dependent variable, showed that differences between countries remained large, even after  
35 controlling for dependency on donations which explained a substantial portion of country differences  
36 in cluster membership (see in Appendix 4, Tables A3.1-2).

### 37 **Attitudes towards community engagement activities**

38 Table 4 presents attitudes to community engagement by country, highlighting notable differences in  
39 perception of knowledge among the general public, reported mandate, available resources, and role  
40 of the public in bereavement care. Principal Component Analysis (PCA) was performed on all attitude  
41 items to explore their underlying structure, resulting in three components (Table 5; see Appendix 5  
42 for details). The multivariable models showed that respondents from services that function well  
43 without donations appear most convinced that the general public is sufficiently informed about end-  
44 of-life issues. Swedish respondents supported the statement that specialized palliative care services  
45 have a mandate to engage with the general public to a significantly lesser degree than UK respondents  
46 (p<0.001). Services in the expanding and selective engagement clusters, and those predominately

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1 serving rural populations showed more support for this mandate. Respondents from Swedish services  
2 endorsed the importance of informal networks significantly more compared to respondents from the  
3 UK ( $p=0.03$ ), while respondents from services that work with registered nurses were less likely to  
4 endorse this ( $p=0.004$ ).

5



## 1 Discussion

### 2 *Summary of main findings*

3 This three-country survey indicates considerable country-variation in specialized palliative care  
4 services' degree of engagement with the general public, with those in the UK particularly expanding  
5 their focus beyond a clinical mandate, compared to those in Belgium and even more so than those in  
6 Sweden. The findings suggest that this may partly be due to services' dependency on charitable  
7 donations; the majority of specialized palliative care services in the UK indicated they could not  
8 function well without donations. It also corresponds with the different attitudes held by services in  
9 the three countries about the importance of community engagement for palliative care services and  
10 their interpretation of their mandate.

11

### 12 *Strengths and limitations*

13 There are some strengths and limitations to consider when interpreting these results. While the  
14 results showed high degrees of community activity, the UK response rate was notably lower than  
15 that in Paul and Sallnow's previous 2013 survey<sup>18</sup>. The reasons for this are unclear, and may possibly  
16 represent a selection bias in favor of those involved in community engagement activities or,  
17 alternatively, be due to a satiation effect as community engagement activities are more common in  
18 the UK. However, the UK survey findings are in line with expectations based on the 2013 survey that  
19 had a high response rate and also showed a high degree of community engagement<sup>18</sup>. Although the  
20 response rate in the UK was lower than the high rates obtained in Belgium and Sweden, it is still  
21 acceptable and relatively high compared to other surveys among healthcare professionals<sup>30</sup>.

22 By targeting the entire population of those specialized palliative care services that could feasibly  
23 engage with the greater community selection bias was limited. Reliance on one representative of  
24 the service as respondent is a potential bias as perspectives may differ within services. Additionally,  
25 reported past activities may be subject to recall bias. While we conducted a thorough translation  
26 practice to obtain content validity across the three countries, lack of existing culturally appropriate  
27 and familiar terminology to cover the areas in focus in both Flemish and Swedish may have affected  
28 interpretation of items. Despite written instructions defining key terms, the extent to which terms  
29 such as 'community' and 'general public', as well as underlying assumptions in public health  
30 palliative care, are understood similarly is unclear<sup>31</sup>.

31

### 32 *What this study adds*

33 This study is the first to compare specialized palliative care services' engagement with the general  
34 public across countries. The findings indicate that services in all three countries are expanding their  
35 traditional clinically-oriented focus to include community engagement to educate the general public  
36 or raise awareness about palliative, end-of-life and bereavement care, to some degree. They not  
37 only promote their service, but also develop societal capacity by organizing events to reach a broad  
38 audience as well as through collaboration with businesses and schools. Such collaborations have  
39 various forms of capacity-building potential, for example impacting school curricula, developing new  
40 knowledge and skills in different groups, and facilitating networking between different community  
41 organizations<sup>32</sup>.

1 The interest in community engagement from specialized palliative care services' is likely driven both  
2 by realization that they reached only a limited group through clinical practice and that working  
3 further 'upstream' may be needed to more effectively impact the health and wellbeing of those  
4 experiencing serious illness, dying and grief as well as a desire to make a relevant societal  
5 contribution to those beyond their formal service clientele<sup>3</sup>. Yet, the findings suggest that the need  
6 to expand the reach and mandate of specialist palliative care services is not universally accepted.  
7 The striking differences between the three studied countries in the degree to which specialized  
8 services engage with communities and hold the view that this is their responsibility is notable.  
9 Swedish palliative care services were more restrictive than their Belgian counterparts, who in their  
10 turn were more restrictive than services in the UK.

11 Several factors may underlie the differences between countries. First, the UK has a longer history of  
12 both palliative care and public health palliative care, which is also supported by national end-of-life  
13 care policies and strategies<sup>2, 33, 34</sup>. It may thus be that specialized palliative care services in the  
14 different studied countries are in different phases of expanding their mandate to engage with  
15 communities. Second, the funding of specialized palliative care services can play an important role.  
16 In Sweden palliative care is generally funded and run by the state, whereas funding to services is  
17 more limited in the UK<sup>35</sup>. The extent to which services in the three countries depend on charitable  
18 donations indeed varied strongly in our findings. Dependency on charitable donations from  
19 individuals and organizations compared to full reliance on state funding can drive an orientation  
20 towards the wider community. Third, the role of volunteerism in palliative care likely plays a role.  
21 Belgium<sup>21, 22</sup> and the UK<sup>20</sup> have stronger traditions of volunteerism in palliative care compared to  
22 Sweden<sup>23, 24</sup>. Previous research has identified that volunteers occupy a liminal space between the  
23 purely medical domain and the community<sup>36</sup>. Therefore, extensive involvement of volunteers both  
24 brings the community into the service more explicitly while also enabling services to expand their  
25 activities beyond purely clinical work with clients. Fourth, differential organization may also support  
26 different views among palliative care services in different countries, not about the usefulness of  
27 building capacity across society in dealing with serious illness, dying and grief per se, but rather  
28 about the role of palliative care services in achieving this.

## 29 **Conclusion**

30 The results from this survey indicate that an expansion of the mandate of specialized palliative care  
31 services beyond a traditional clinically-oriented focus, is occurring in Belgium, Sweden and the UK,  
32 albeit to different degrees and with different intensities. While services generally appear to view  
33 community networks as important partners in end-of-life and bereavement care, the extent to  
34 which they view palliative care services as having a role in supporting this engagement relates to  
35 healthcare organization and funding, as well as culturally-specific views, traditions and  
36 responsibilities related to community engagement. While UK hospices and palliative care services  
37 demonstrate a driving role in public health palliative care approaches, this study suggests that  
38 normative ideas about how similar results can be achieved in other countries are best avoided.  
39 Exploring and developing different contextually-relevant ways to achieve broad coalitions of societal  
40 actors to meet community end-of-life care needs appears a constructive alternative.

41

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43

1 **Authorship statement**

2 All authors made substantial contributions to the concept and design of the study, the drafting and  
3 testing of the main questionnaire, and the acquisition of data in their countries. Analyses were led  
4 by ADV and JC but all authors contributed to refinements in the analyses and interpretation of data.  
5 All authors contributed to the drafting and revising of the article, approved the final version and  
6 have participated sufficiently in the work to take public responsibility for appropriate portions of the  
7 content.

8  
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14  
15 **Declaration of conflicts of interest**

16 The authors declare that there is no conflict of interest.

17  
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21 contributions to the study design, and Joanne Harman (St Christopher's Hospice) for helping with  
22 survey dissemination. Olav Lindqvist contributed to the initial, conceptual, phases of this project,  
23 prior to his death in 2018.

24  
25 **Data management and sharing**

26 Pseudonymized data are stored on a secure server at the Vrije Universiteit Brussel. Access to  
27 aggregated data can be provide by the corresponding author upon request after applying measures  
28 to minimize risk of reidentification and approval from the responsible data protection officer.

29

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Engagement of specialized palliative care services with the general public: a population-level survey in three European countries

1 Table 1: Characteristics of the specialized palliative care services surveyed in Belgium, Sweden and  
2 UK, 2019

	BE	SE	UK
	N (%)	N (%)	N (%)
Survey sent out	50	129	245
Respondents (response rate)	45 (90.0)	91 (70.5)	121 (49.4)
<b>Characteristics of the SPCS*</b>			
<i>Population served</i>			
Mainly rural	7 (15.9)	9 (10.0)	15 (12.8)
Mainly urban	7 (15.9)	23 (25.6)	27 (23.1)
Mixed	30 (68.2)	58 (64.4)	75 (64.1)
<i>Type of service†</i>			
Inpatient beds	27 (60.0)	48 (52.7)	97 (80.2)
Home care	18 (40.0)	56 (61.5)	90 (74.4)
Day hospice	4 (8.9)	11 (12.1)	91 (75.2)
Consultancy (network in Sweden)	/	56 (61.5)	/
Outpatient care	/	/	78 (64.5)
<i>Disciplines connected to the service</i>			
Physicians	43 (95.6)	90 (98.9)	100 (82.6)
Registered nurses	43 (95.6)	91 (100.0)	113 (93.4)
Other nursing staff	8 (17.8)	54 (63.7)	103 (85.1)
Psychologists and/or counsellors	41 (91.1)	4 (4.4)	95 (78.5)
Social workers	23 (51.1)	81 (89.0)	87 (71.9)
Occupational therapists	3 (6.7)	75 (82.4)	91 (75.2)
Physiotherapists	22 (48.9)	75 (82.4)	97 (80.2)
Spiritual workers/chaplain	24 (53.3)	36 (39.6)	95 (78.5)
Dietician	13 (28.9)	62 (68.1)	31 (25.6)
Complementary therapist	/	10 (11.0)	104 (86.0)
<i>Full-time equivalent employed care providers</i>			
<3	3 (6.7)	4 (4.4)	0 (0.0)
3-10	21 (46.7)	10 (11.0)	9 (8.1)
11-20	18 (40.0)	21 (23.1)	1 (0.9)
21-30	2 (4.4)	18 (19.8)	3 (2.7)
31-40	1 (2.2)	10 (11.0)	5 (4.5)
41-50	0 (0.0)	9 (9.9)	9 (8.1)
51-100	0 (0.0)	6 (6.6)	38 (34.2)
101-200	0 (0.0)	12 (13.2)	35 (31.5)
>200	0 (0.0)	1 (1.1)	11 (9.9)
<i>Having volunteers working in the service</i>	42 (93.3)	18 (19.8)	113 (100.0)
<i>Importance of voluntary donations for the functioning of the service</i>			
We can function well without these donations	11 (24.4)	83 (91.2)	2 (1.8)
Some parts of what we do as a service would not be possible without these donations	25 (55.6)	5 (5.5)	8 (7.0)
Substantial parts of what we do as a service would not be possible without these donations	8 (17.8)	1 (1.1)	34 (29.8)
Without these donations we could not function at all	1 (2.2)	2 (2.2)	70 (61.4)

\*Belgian, Swedish, and UK respondents who filled out the questionnaire through question 8 were included in the analysis. Other incomplete returned questionnaires were considered as non response

† Numbers do not add up to total because some services offered more than one type of service. In Belgium the category home care include the palliative care networks.

Percentages are column percentages. Missing values characteristics SPCS: Population served: n=6 (2.3%); Type of service: none, Disciplines connected to the service: none; Full-time equivalent employed care providers: n=10 (3.9%); Having volunteers working in the service: n=8 (3.1%); Importance of voluntary donations for the functioning of the service: n= 7 (2.7%).

Engagement of specialized palliative care services with the general public: a population-level survey in three European countries

1 Table 2: Community engagement activities by specialized palliative care services in Belgium, Sweden  
2 and UK, 2019

	BE (n= 45)			SE (n= 91)			UK (n= 121)			p- value*
	To date %	No, but in future plans %	No future plans %	To date %	No, but in future plans %	No future plans %	To date %	No, but in future plans %	No future plans %	
<b>Community engagement activities</b>										
<b>Activities for raising awareness about your service to the general public</b>										
Using mainstream printed media	55.6	2.2	42.2	46.2	3.3	50.5	96.5	1.7	1.7	<0.001
Using social media	53.3	6.7	40.0	39.6	3.3	57.1	100.0	0.0	0.0	<0.001
Disseminating printed information	77.8	2.2	20.0	48.4	2.2	49.5	95.7	2.6	1.7	<0.001
Inviting the general public to meet the service	37.8	2.2	60.0	30.8	6.6	62.6	95.7	1.7	2.6	<0.001
Giving talks and lectures	75.6	4.4	20.0	53.8	8.8	37.4	95.7	0.9	3.5	<0.001
<b>Activities to educate and raise awareness among the general public about end-of-life care and bereavement issues</b>										
Using mainstream printed media	33.3	2.2	64.4	33.7	1.1	65.2	83.6	6.4	10.0	<0.001
Using social media	31.1	4.4	64.4	24.7	5.6	69.7	88.2	6.4	5.5	<0.001
Disseminating printed information	71.1	2.2	26.7	38.2	2.2	59.6	90.0	3.6	6.4	<0.001
Events organized by your service alone	48.9	0.0	51.1	19.1	6.7	74.2	82.7	10.0	7.3	<0.001
Events organized by your service together with other civil society organizations	71.1	0.0	28.9	31.5	5.6	62.9	80.0	12.7	7.3	<0.001
<b>Whether the service has been or plans to be engaged with one or more of the following organizations to develop skills and knowledge in the general public</b>										
Schools (preschools to secondary school)	68.9	0.0	31.1	25.6	4.7	69.8	79.4	9.3	11.2	<0.001
Colleges or universities	68.9	2.2	28.9	52.3	10.5	37.2	76.6	4.7	18.7	0.003
Businesses	24.4	0.0	75.6	8.1	1.2	90.7	79.4	4.7	15.9	<0.001
Community education programs (adult education)	68.9	0.0	31.1	33.7	4.7	61.6	38.3	8.4	53.3	0.001
Media organizations	33.3	0.0	66.7	15.1	4.7	80.2	72.0	5.6	22.4	<0.001
Religious groups	33.3	0.0	66.7	16.3	3.5	80.2	68.2	4.7	27.1	<0.001
Philosophy groups	28.9	6.7	64.4	3.5	1.2	95.3	29.9	10.3	59.8	<0.001
Patient or informal carer organizations	60.0	0.0	40.0	36.0	16.3	47.4	75.7	10.3	14.0	<0.001
Local regional or national governments	46.7	0.0	53.3	53.5	9.3	37.2	64.5	3.7	31.8	0.069
Other public interest groups or non-profit organizations	68.9	0.0	31.1	22.1	7.0	70.9	83.2	2.8	14.0	<0.001
<b>If the service ever built or helped to build informal end-of-life support or care networks, and/or plan to do so</b>	18.2	11.4	70.5	21.4	9.5	69.0	76.9	6.7	16.3	<0.001

## Engagement of specialized palliative care services with the general public: a population-level survey in three European countries

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\*Kruskal Wallis test

Percentages are column percentages (% within country).

Missing values for the different community engagement activities are ranging from 2.3% to 9.7%

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Engagement of specialized palliative care services with the general public: a population-level survey in three European countries

1 Table 3: Types of community engagement by characteristics of specialized palliative care services in  
2 Belgium, Sweden and UK, 2019

	Clusters of services in terms of their community engagement			p-value†
	Expanding services	Selective engagement services	Clinically-oriented services	
	N (%)*	N (%)*	N (%)*	
Total	88 (38.4)	62 (27.1)	79 (34.5)	
<b>Country</b>				<b>&lt;0.001</b>
Belgium	7 (15.9)	17 (38.6)	20 (45.5)	
Sweden	6 (7.2)	19 (22.9)	58 (69.9)	
UK	75 (73.5)	26 (25.5)	1 (1.0)	
<b>Population served</b>				0.439
Mainly rural	11 (37.9)	10 (34.5)	8 (27.6)	
Mainly urban	24 (45.3)	15 (28.3)	14 (26.4)	
Mixed	52 (35.9)	37 (25.5)	56 (38.6)	
<b>Type of service</b>				
Inpatient beds	69 (44.5)	38 (24.5)	48 (31)	<b>0.023</b>
Home care	69 (46.9)	41 (27.9)	37 (25.2)	<b>&lt;0.001</b>
Day hospice	62 (65.3)	26 (27.4)	7 (7.4)	<b>&lt;0.001</b>
Consultancy (only for SE)	2 (3.8)	10 (18.9)	41 (77.4)	0.099
Outpatient care (only for UK)	53 (79.1)	14 (20.9)	0 (.00)	0.113
<b>Disciplines connected to the service (yes vs no)</b>				
Physicians	81 (37.9)	55 (25.7)	78 (36.4)	<b>0.046</b>
Registered nurses	87 (38.5)	61 (27)	78 (34.5)	0.968
Other nurses	76 (50)	37 (24.3)	39 (25.7)	<b>&lt;0.001</b>
Psychologists	74 (58.3)	34 (26.8)	19 (15.0)	<b>&lt;0.001</b>
Social workers	67 (38.5)	40 (23)	67 (38.5)	<b>0.020</b>
Occupational therapists	69 (45.1)	38 (24.8)	46 (30.1)	<b>0.012</b>
Physiotherapists	71 (40.3)	42 (23.9)	63 (35.8)	0.136
Spiritual workers	72 (50.7)	28 (19.7)	42 (29.6)	<b>&lt;0.001</b>
Dietician	27 (28.1)	22 (22.9)	47 (49.0)	<b>&lt;0.001</b>
<b>FTE employed care providers</b>				<b>&lt;0.001</b>
<3	1 (14.3)	2 (28.6)	4 (57.1)	
3-10	5 (13.5)	20 (54.1)	12 (32.4)	
11-20	5 (12.8)	7 (17.9)	27 (69.2)	
21-30	3 (14.3)	4 (19)	14 (66.7)	
31-40	5 (31.3)	2 (12.5)	9 (56.3)	
41-50	7 (46.7)	5 (33.3)	3 (20)	
51-100	29 (78.4)	6 (16.2)	2 (5.4)	
101-200	22 (51.2)	13 (30.2)	8 (18.6)	
>200	8 (72.7)	3 (27.3)	0 (0)	
<b>Depending on charity</b>				<b>&lt;0.001</b>
We can function well without these donations	6 (6.7)	19 (21.3)	64 (71.9)	
Some parts of what we do would not be possible without these donations	7 (20.0)	14 (40.0)	14 (40.0)	
Substantial parts of what we do would not be possible without these donations	23 (63.9)	12 (33.3)	1 (2.8)	
Without donations we could not function at all	52 (75.4)	17 (24.6)	0 (0.0)	
<b>Volunteers</b>				<b>&lt;0.001</b>
Yes	83 (52.5)	46 (29.1)	29 (18.4)	

3 \*Percentages are row percentages

4 †Chi<sup>2</sup> Test

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Engagement of specialized palliative care services with the general public: a population-level survey in three European countries

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2 Table 4: Attitudes towards community engagement held by representatives (e.g. coordinators,  
3 directors, chairs) of specialized palliative care services in Belgium, Sweden and UK, 2019

	BE (n=45)	SE (n=79)	UK (n=105)	
Agree/completely agree				
Attitude items*	N (%)	N (%)	N (%)	p-value†
a) For the most part, the general public is sufficiently informed about our service	10 (22.2)	30 (38.0)	21 (20.0)	<b>0.018</b>
b) For the most part, the general public has sufficient knowledge about end-of-life care	3 (6.7)	14 (17.9)	3 (2.9)	<b>0.002</b>
c) For the most part, the general public has sufficient knowledge about bereavement care	5 (11.1)	11 (14.3)	7 (6.7)	0.236
d) As a service, part of our responsibility is to promote the general public to take care of themselves and each other when faced with a life-threatening illness in the future	33 (73.3)	46 (59.7)	88 (83.8)	<b>0.001</b>
e) Our service does not have the time or resources to engage in activities aimed at the general public	19 (42.2)	46 (59.0)	14 (13.3)	<b>&lt;0.001</b>
f) Our service should focus on providing care; working with the general public is not our job	10 (22.2)	37 (47.4)	4 (3.8)	<b>&lt;0.001</b>
g) People's own social networks are at least as important providers of end-of-life care as professionals	32 (71.1)	68 (86.1)	83 (79.0)	0.129
h) People's own social networks are at least as important providers of bereavement care as professionals	34 (75.6)	76 (96.2)	88 (83.8)	<b>0.003</b>

\*Percentages are column percentages  
†Kruskall wallace test  
Missing values: item a): n=28 (10.9%); item b) n=30 (11.7%); item c) n=30 (11.7%); item d): n=30 (11.7%); item e): n=29 (11.3%); item f) n=29 (11.3%); item g) n=28 (10.9%); item h): n=28 (10.9%)

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Engagement of specialized palliative care services with the general public: a population-level survey in three European countries

1 Table 5: Associations between attitudes towards community engagement and specialized palliative  
 2 care service characteristics in Belgium, Sweden and the UK, 2019

Items	Component 1: Extent to which the public is informed		Component 2: Mandate to engage with communities		Component 3: Importance of informal networks	
	Coefficient b (95%CI)	p- value	Coefficient b (95%CI)	p- value	Coefficient b (95%CI)	p- value
<b>Intercept</b>	-0.18 (-0.41 to 0.06)	0.15	-0.46 (-0.80 to -0.13)	0.007	-0.04 (-0.22 to 0.15)	0.68
<b>Country</b>						
Belgium			-0.16 (-0.47 to 0.16)	0.33	-0.24 (-0.58 to 0.09)	0.16
Sweden			-0.59 (-0.91 to -0.27)	<b>&lt;.001</b>	0.32 (0.03 to 0.60)	<b>0.03</b>
UK (ref)			ref		ref	
<b>Dependence on donations</b>						
We can function well without	0.39 (0.07 to 0.71)	<b>0.02</b>				
Parts would not be possible	0.09 (-0.24 to 0.42)	0.59				
Without we cannot function (ref)	ref					
<b>Cluster assignment</b>						
Expanding services			1.12 (0.77 to 1.46)	<b>&lt;.001</b>		
Selective services			0.65 (0.36 to 0.93)	<b>&lt;.001</b>		
Clinically-oriented services (ref)			ref			
<b>Population served</b>						
Mainly rural			0.34 (0.04 to 0.63)	<b>0.03</b>		
Mainly urban			0.06 (-0.18 to 0.29)	0.64		
Mixed (ref)			ref			
<b>Disciplines connected</b>						
Registered nurses (No vs Yes)					-1.63 (-2.74 to -0.52)	<b>0.004</b>

3 Coefficient b values are standardized mean differences

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## **Appendix**

### **Engagement of specialized palliative care services with the general public: a population-level survey in three European countries**

Aline De Vleminck, Sally Paul, Maria Reinius, Libby Sallnow, Carol Tishelman, Joachim Cohen

**Appendix 1: Supplemental table A1: Description of health care system, palliative care and cultural characteristics for Belgium, Sweden and UK**

	<b>Belgium</b>	<b>Sweden</b>	<b>UK</b>
Health care system characteristics	<p>Belgium has a social health insurance system, where registration to a health insurer is mandatory for all residents. Health care insurance is organized through seven competing private non-profit national sickness funds. Health care payments are based on a co-payment financing system, in which the costs for health care are split between the patient and the insurer. The latter part is funded through general taxation. Co-payments apply for services provided by general practice, specialist physician care, inpatient hospital care, and for pharmaceuticals. Annual ceilings exist on the out-of-pocket costs for low-income, chronically ill and disabled, and children based on household income.<sup>1</sup></p>	<p>Sweden's universal health system covers all legal residents. The system is decentralized, with the Ministry of Health and Social Affairs determining overall health policy, regulation and financing in concert with 8 other national government agencies. Twenty-one regions finance and deliver health care services through 7 university hospitals, ~ 70 council driven hospitals, 6 private hospitals and ~ 1100 public and private primary care facilities. Municipalities (n=290) are responsible for care of the elderly and disabled by both public and private providers. These care needs are evaluated and resources granted by Social Services. Funding comes primarily from regional- and municipal-level taxes with some subsidies and grants provided by the national government; there is low out-of-pocket costs and ceilings on payments by the individual. National insurance coverage is automatic, with about 13% of the population aged 16-64 having supplemental private insurance.</p>	<p>The UK has a universal health care system, called the National Health Service (NHS). All people who are ordinarily resident in the UK are entitled to free public health care through the NHS. This includes hospital, physician, and mental health care, as well as access to free and/or subsidized prescription drugs, optometry, and dental care for special groups (e.g., children, the elderly, certain medical conditions and low income). The NHS budget is primarily funded through general taxation and National Insurance Contributions. It is governed by the Department of Health but administration and organization are devolved across the four nations. NHS England, NHS Scotland, NHS Wales and NHS Northern Ireland organize health care services via clinical commissioning groups or health boards who plan, commission and deliver health services that address</p>

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		Services covered by national insurance include inpatient, outpatient, mental health, and long-term care, as well as subsidized prescription drugs and dental care. <sup>2</sup>	local need. Private health care is also available throughout the UK, with about 10.5% of the population having voluntary private insurance. <sup>3</sup>
Palliative care characteristics	<p><b>National legislation to regulate palliative care provision:</b></p> <ul style="list-style-type: none"> <li>-National law specific to palliative care</li> <li>-National legislation or decrees relating to palliative care</li> <li>-National legislation related to end-of-life issues</li> <li>-National general law on health care with reference to palliative care</li> </ul> <p><b>Organization of palliative care in Belgium</b></p> <p><b>Palliative networks:</b></p> <p>In Belgium, palliative networks were created in 1997. A palliative network is a partnership regarding palliative care between different care providers and care facilities in a certain region. The</p>	<p><b>National Guidance and Guidelines for palliative and end-of-life care:</b></p> <ul style="list-style-type: none"> <li>-Prioritization Inquiry (SOU 1995: 5) highlighted palliative care as having the same priority as life-threatening acute illness, although this had limited effect</li> <li>-"Death concerns us all - dignified care at the end of life" (SOU 2001: 6), a parliamentary investigation specifically related to palliative care and end-of-life care with proposals for further development for equal access</li> <li>-In 2009, the National Board of Health and Welfare was commissioned to design national knowledge support for good palliative care<sup>1</sup></li> <li>-In 2012, the 1<sup>st</sup> national program for palliative care provision was first published; this was revised in 2016.</li> </ul>	<p><b>National Guidance and Strategy:</b></p> <ul style="list-style-type: none"> <li>- National Framework and/or strategy for Palliative Care.</li> <li>- National Standards for Palliative Care</li> </ul> <p><b>Organization of palliative care in the UK</b></p> <p><b>National Palliative Care Networks<sup>7</sup></b></p> <p>The Help the Hospices charity (now Hospice UK) was established in 1984 to share and promote good practice around end-of-life care across the UK. In 1991, in England, Wales and Northern Ireland, the National Council for Hospice and Specialist Palliative Care Services was established as a national umbrella charity to organise services and promote innovation. In</p>

<sup>1</sup> In Sweden, a distinction is made between national guidelines from the national government agency, the National Board of Health and Welfare, referred to as *guidance*, and clinical practice guidelines developed by healthcare professionals, referred to as *guidelines*.

	<p>network provides advice, information, support and coordination to all healthcare providers involved in palliative care. These networks cover the entire Belgian territory (15 networks in Flanders, 1 bilingual network in Brussels, 8 networks in Wallonia and 1 network in the German-speaking community).</p> <p><b><u>Provision of Palliative Care</u></b></p> <p><b><u>Home care services:</u></b></p> <p>1) <i>Multidisciplinary palliative home care teams:</i> support regular care providers at home, usually as a second line consulting team but they also frequently take over some aspects of care.</p> <p><b><u>Inpatient services:</u></b></p> <p>1) <i>Palliative care units in hospital:</i> separate wards with 6-12 beds reserved for inpatient PC. Some of these label themselves as hospices.</p> <p>2) <i>Palliative support teams in hospital:</i> support regular caregivers in the different wards of the hospital with PC provision. These teams are compulsory for every hospital in Belgium.</p>	<p>-In 2013, the National Board of Health and Welfare published “National knowledge support for good palliative care at the end-of-life. Guidance, recommendations and indicators: Support for control and management. The impact of this document was evaluated in 2016, and in 2018 a clarification of terms and concepts was developed by the National Board of Health and Welfare, entitled “Palliative Care—Clarification and concretization of concepts”</p> <p>- 2021: Publication of a third revised national program for palliative care provision, with one document for care of adults and one for children &lt;18 yrs old, as well as support for implementation</p> <p><b>Organization of palliative care in Sweden</b></p> <p><b>National networks for palliative care</b> are primarily based on different professions, with the non-profit National Council for Palliative Care (in Swedish NRPV, Nationella Rådet för Palliativ Vård) constituted in 2004 as an</p>	<p>2004 it subsequently changed its name to the National Council for Palliative Care and, in 2017, merged with Hospice UK to expand the research its work. Hospice UK brings together key stakeholders to improve experiences of and access to palliative care, sharing best practices and learning. It also provides a directory of palliative care services across the UK.</p> <p>In Scotland, the Scottish Partnership Agency for Palliative and Cancer Care (now the Scottish Partnership for Palliative Care, SPPC) was established in 1991. It is a collaboration of organisations, including NHS health boards, hospices, social care providers, working together to improve experiences of palliative care. Their work involves, but is not limited to, advocacy, information sharing, raising public awareness, sharing good practice and facilitating networks across the sector.</p> <p><b><u>Provision of Palliative Care</u></b><sup>8,9</sup></p> <p>Palliative care is integrated into the NHS but is also provided by an</p>
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	<p><b><u>Outpatient services:</u></b></p> <p>1) <i>Palliative day care centres</i>: provide ambulatory palliative support usually as a form of respite care. There are 5 in total in Flanders.</p> <p>References: <sup>4,5</sup></p>	<p>umbrella organization comprised of different professional organization and other networks. NRPV works for better coordination of palliative care and end-of-life care in Sweden.</p> <p>Another network is the non-profit Swedish Palliative Network, which began to write and disseminate a newsletter to all interested in 2002. The newsletter is still disseminated today, in digital form</p> <p><b><u>Provision of Palliative Care</u></b></p> <p>The development of palliative care provision in Sweden has occurred to a large extent via enthusiasts and local initiatives, rather than in a coordinated or organized manner. This has led to notably different circumstances and access to specialized palliative care or end-of-life care in different regions and municipalities. Care provision is often described as occurring on two levels, specialized palliative care devoted solely to palliative and end-of-life care, and Generalized palliative care.</p> <p>Specialized palliative care is carried out by palliative home care teams, in patient palliative care facilities, hospices</p>	<p>established independent hospice movement. The hospice movement emerged in the 1960's in the voluntary sector and although it has received some government funding since the 1970's hospices remain charitable organizations, receiving up to 50% of their operational costs from the NHS. Due to the funding and history of hospice care, hospices have a long history of volunteerism and fundraising. This has resulted in a diverse range of service provision and activity across the UK.</p> <p>Specialist palliative care is usually provided by in-patient clinics (hospice/specialist palliative care units), outpatient clinics, Hospital support teams, Home Care teams, Day Care Centre's and community settings, such as nursing and residential homes. Most hospital and Home Care Teams work as advisory services with patients remaining under the care of their primary health-care team.</p> <p>References: <sup>4,7-9</sup></p>
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		<p>and by consulting teams who advise other professionals rather than providing direct care. Generalized palliative care is carried out in other care facilities on regional and municipal levels, although the educational level of staff can vary greatly. The lack of a central organization or coordinating body means that there are limited statistics available about the number of palliative care facilities, providers, etc.</p> <p>NRPV collects information about specialized palliative care providers, which is now available in digital form, rather than in the earlier printed Palliative Guide, published in 2010. However, not registration is not automatic, and it is unclear how complete and correct the guide is, nor when it has been recently updated.</p> <p>References: <sup>4,6</sup></p>	
<p>Cultural characteristics (according to the Inglehart-Welzel World Cultural Map2020)<sup>10</sup></p>	<p>According to the Inglehart-Welzel World Cultural Map (2020), Belgium belongs to the cluster “Catholic Europe”.</p>	<p>Sweden belongs to the cluster “Protestant Europe”, representing societies with very high scores in secular-rational values and self-expression values* (and both higher than in UK and Belgium).</p>	<p>UK belongs to the cluster “English speaking” countries. The UK scores higher on the self-expression values and secular values compared to Belgium, but lower than Sweden*.</p>

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	Compared to Sweden and the UK, Belgium scores lower on the self-expression values*.		
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\*: Self-expression values refer to prioritizing environmental protection, participation in decision-making concerning economics and politics, and values of equality regarding gender, sexuality, and ethnicity. Secular-rational values refer to placing less importance on religion, traditional family values, and authority.

### References:

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9. Burbeck R, Low J, Sampson EL, Bravery R, et al. Volunteers in Specialist Palliative Care: A Survey of Adult Services in the United Kingdom. J Palliat Med. 2014.568-574.
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**Appendix 2: Original questionnaire (English version)**

The following questions ask about some characteristics of your service		
<p>1. Does your service serve mainly a rural, urban or mixed population?</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Rural</li> <li><input type="radio"/> Urban</li> <li><input type="radio"/> Mixed population</li> </ul>	
<p>2. What type of services does your organization offer? (more than 1 answer possible)</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Inpatient beds → How many beds?.....</li> <li><input type="radio"/> Home care → How many patients in the last week?.....</li> <li><input type="radio"/> Day hospice</li> <li><input type="radio"/> (UK: Outpatient care)</li> <li><input type="radio"/> (Sweden: Consultancy)</li> <li><input type="radio"/> Others:...</li> </ul>	
<p>3. Which of the following professional care disciplines are connected to your service? (Please check any and all that apply to your service)</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Physicians</li> <li><input type="radio"/> Registered nurses</li> <li><input type="radio"/> Other nursing staff</li> <li><input type="radio"/> Psychologists and/or counselors</li> <li><input type="radio"/> Social workers</li> <li><input type="radio"/> Occupational therapists</li> <li><input type="radio"/> Physiotherapist</li> <li><input type="radio"/> Spiritual workers</li> <li><input type="radio"/> Complementary therapist</li> <li><input type="radio"/> Dieticians</li> </ul> <p>Other: .....</p>	
<p>4. How many full-time equivalent professional care providers are approximately employed by your service? (By this we mean only the professional caregivers such as doctors, nurses, psychologists, occupational therapists, speech therapists, physical therapists, etc.)</p>	<ul style="list-style-type: none"> <li><input type="radio"/> &lt;3</li> <li><input type="radio"/> 3-10</li> <li><input type="radio"/> 11-20</li> <li><input type="radio"/> 21-30</li> <li><input type="radio"/> 31-40</li> <li><input type="radio"/> 41-50</li> <li><input type="radio"/> &gt;50</li> </ul>	
<p>5. Do you have volunteers working in your service? (With volunteers we mean: non-paid persons helping you with certain aspects of the functioning of your service)</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Yes</li> <li><input type="radio"/> No</li> </ul>	
<p>6. How important are financial donations/charitable donations for the functioning of your service?</p>	<ul style="list-style-type: none"> <li><input type="radio"/> We can function well without these donations</li> <li><input type="radio"/> Some parts of what we do as a service would not be possible without these donations</li> </ul>	

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	<ul style="list-style-type: none"> <li>○ Substantial parts of what we do as a service would not be possible without these donations</li> <li>○ Without these donations we could not function at all</li> </ul>	
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**The following questions ask about activities your service has organized to make the service known among the general public.**  
*(With 'the general public' we mean people who you would not normally come into contact with through clinical and patient care)*

<b>7. Please indicate whether your service has been involved in any of the following activities to make the service known among the general public, and/or has plans to do so in the future? (more than 1 answer possible)</b>	we have done this in the past 5 years	we are currently doing this	we have plans to do this in the next year	we have no plans to do this in the coming year	Add comments
Using mainstream printed media (e.g. newspapers) to make your service known among the general public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Using social media to make your service known among the general public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Disseminating printed information (e.g. leaflets, books) to make your service known among the general public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Inviting the general public to meet the service: e.g. open days (e.g. for Belgium eating events)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Giving talks and lectures (e.g. to community groups, or through radio or tv) to make your service known among the general public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Please indicate here whether you organize any other activities to make your service known among the general public, and if so, what activities.	.....				

**The following questions ask about activities your service has organized to educate the public on aspects related to the end of life and bereavement care.**

<b>8. Please indicate whether your service has been involved in any of the following activities to educate the public on aspects related to the end of life and bereavement care, and/or has plans to do so in the future? (more than 1 answer possible)</b>	we have done this in the past 5 years	we are currently doing this	we have plans to do this in the next year	we have no plans to do this in the coming year	
Using mainstream printed media (e.g. newspapers) to educate the public on aspects related to the end of life and bereavement care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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Using social media to educate the public on aspects related to the end of life and bereavement care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Disseminating printed information (e.g. leaflets, books) to educate the public on aspects related to the end of life and bereavement care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Events to educate the public on aspects related to the end of life and bereavement care organized <i>by your service alone</i> (e.g. lectures or seminars, death cafes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Events to educate the public on aspects related to the end of life and bereavement care organized by your service <i>together</i> with other civil society organizations (e.g. lectures or seminars in schools, on markets or festivals,...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Please indicate here whether you organize any other activities to educate the general public about end-of-life care and bereavement care, other than information about your service, and if so, what activities?	.....				

**The following questions refer to activities to develop certain knowledge and skills in the general public about loss, death, dying and/or end-of-life care. We are referring to activities to improve the general public's competence and capacity in dealing with issues related to loss, death, dying and/or end-of-life care.**

<b>9. Has your service been, and/or plans to be, engaged with one or more of the following organizations to develop skills and knowledge in the general public (more than 1 answer possible)</b>	we have done this in the past 5 years	we are currently doing this	we have plans to do this in the next year	we have no plans to do this in the coming year	
... schools (from preschools to secondary school)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... colleges or universities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... businesses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... community education programs (adult education)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... media organizations (e.g. TV, radio or written media, podcasts)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... religious groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... philosophy groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... patient or informal carer organizations (e.g. patient advocacy groups or self-help groups)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
... local, regional or national governments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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.. other public interest groups or non-profit organizations (e.g. volunteer organizations, community groups)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Please indicate here whether your service has been, or plans to be, engaged with any other organizations to develop skills and knowledge in the general public. Please specify.

<p>.....</p>
--------------

**The following question refer to any new structures or organisations set up by your service to support informal end-of-life care**

**10. Has your service built or helped to build informal EOL support or care networks, and/or does it plan to do so?** (e.g. setting up a neighbour network, compassionate neighbours, compassionate cities)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Please specify which informal EOL support or care networks your service has built or helped to build, and/or plans to do so.

<p>.....</p>
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**The following questions relate to your opinion as an individual**

11. Please indicate the extent to which you agree or disagree with the following statements	Completely disagree	Disagree	Neither Agree or disagree	Agree	Completely agree
For the most part, the general public is sufficiently informed about our service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For the most part, the general public has sufficient knowledge about EOL care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For the most part, the general public has sufficient knowledge about bereavement care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
As a service, part of our responsibility is to promote the general public to take care of themselves and each other when they would be faced with a life-threatening illness in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our service does not have the time or resources to engage in activities aimed at the general public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Our service should focus on providing care; working with the general public is not our job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People's own social networks are more meaningful providers of EOL care than professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People's own social networks are more meaningful providers of bereavement care than professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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If you have any thoughts or reflections about the role of Specialised Palliative Care services in *relation to* the general public or about this study that you would like to add, you can do so here

We anticipate following up a small number of responses to find out more about the ways in which services work with communities. If you are happy to be contacted again in the future please leave your name, service, contact telephone number and email below

Only if they leave their email address, the 'tick the box' will not appear

- Please tick this box if you would also like to receive a copy of the findings from this survey  
(Optional)

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### **Appendix 3: Community engagement activities: Cluster analysis**

We performed a Two-Step cluster analysis including the following variables:

- Activities for raising awareness about your service to the general public: using printed media; using social media; disseminating printed info; inviting the public to meet the service (e.g. open days); giving talks and lectures
- Activities to educate and raise awareness among the general public about EOL care and bereavement issues: using printed media; using social media; disseminating printed info; organizing events by the service alone; organizing events together with other civil organizations
- Whether the service has been or plans to be engaged with one or more of the following organizations to develop skills and knowledge in the general public: schools; companies; media organizations; religious groups; secular groups; patient organizations; governments; non-profit organizations
- If the service ever built or helped to build informal EOL support or care networks, and/or plan to do so (Yes/no)

This Two-Step Cluster analysis revealed three clusters of services in terms of community engagement, with a fair cluster quality (see Figure A2.1). We named the 3 clusters: “expanding services” (i.e. extend the focus beyond clinical mandate)” (N= 88; 38.4%), “selective engagement services” (N= 62; 27.1%), and “strongly clinically oriented services” (N= 79; 34.5%) (see Figure A2.2). The predictor importance of the included variables for defining the clusters is shown in Figure A3.3.

Figure A3.1: Cluster analysis community engagement activities – Model summary

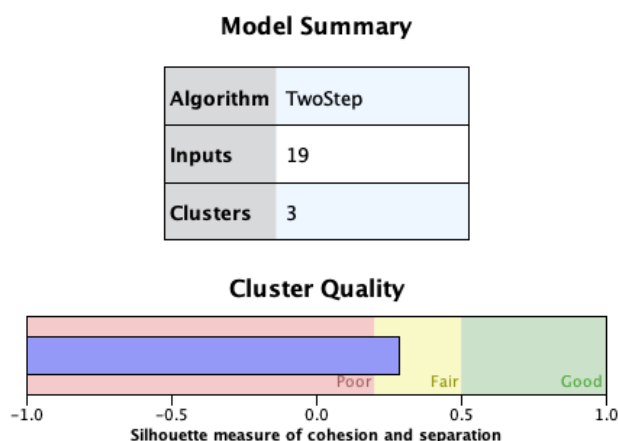
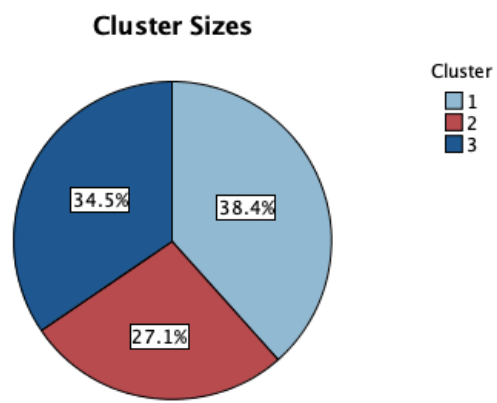


Figure A3.2: Cluster sizes



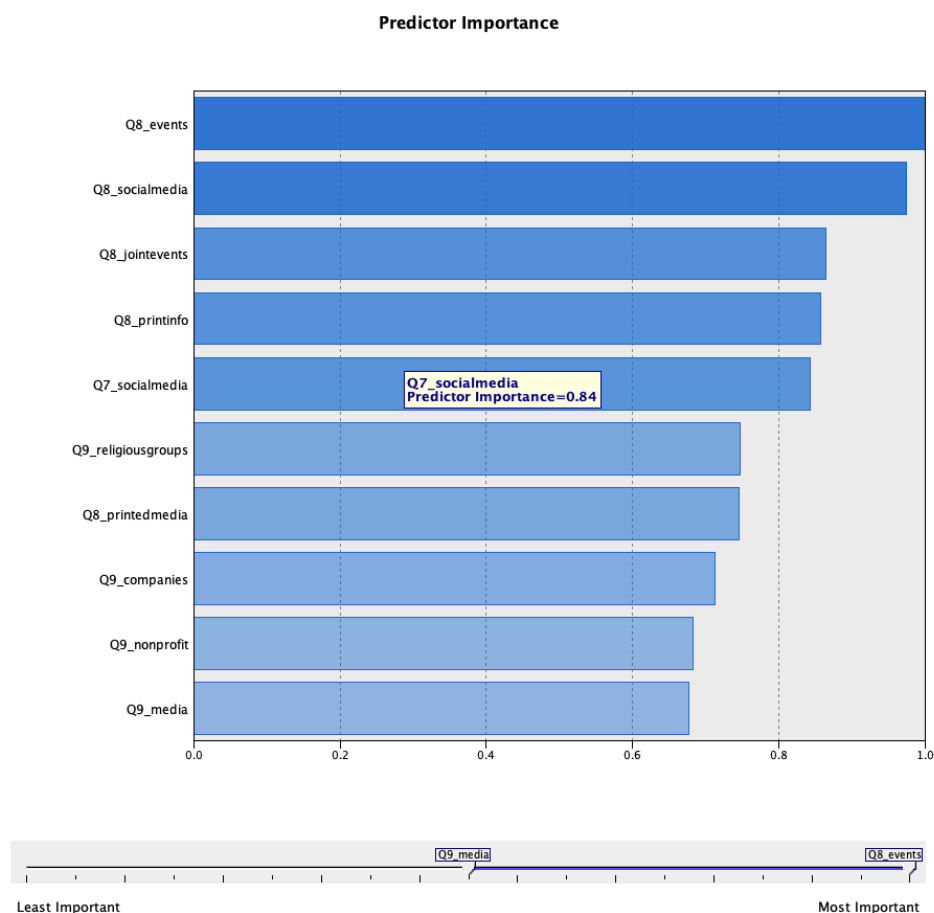
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<b>Size of Smallest Cluster</b>	62 (27.1%)
<b>Size of Largest Cluster</b>	88 (38.4%)
<b>Ratio of Sizes: Largest Cluster to Smallest Cluster</b>	1.42

Figure A3.3: Predictor importance

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**Appendix 4: Multivariable logistic regression analysis**

Table A4.1: Cross-country multivariable logistic regression analysis

	OR (95% CI) for <b>Expanding services vs. rest</b>	
	Model 1	Model 2
<b>Country</b>		
Belgium (reference category)	(ref)	(ref)
Sweden	0.41 (0.13-1.31)	0.82 (0.18-3.84)
UK	14.68 (5.85-36.84)	5.74 (1.79-18.35)
<b>Depending on charity</b>		
We can function well without these donations (reference category)		(ref)
Some parts of what we do would not be possible without these donations		2.14 (0.44-10.35)
Substantial parts of what we do would not be possible without these donations		6.06 (1.25-29.32)
Without donations we could not function at all		7.57 (1.59-35.97)

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Table A4.2: Cross-country multivariable logistic regression analysis

	OR (95% CI) for <b>Clinically-oriented services vs. rest</b>	
	Model 1	Model 2
<b>Country</b>		
Belgium (reference category)	(ref)	(ref)
Sweden	2.78 (1.31-5.93)	3.87 (1.67-8.93)
UK	0.01 (0.00-0.09)	0.02 (0.00-0.13)
<b>Type of service</b>		
Home care (Yes vs No)		0.31 (0.14-0.70)

Table A4.3: Within-country multivariable logistic regression analysis - BELGIUM

	OR (95% CI) for <b>Expanding services vs. rest</b>
<b>Type of service</b>	
Home care (Yes vs No)	12.5 (1.35-115.79)

Table A4.4: Within-country multivariable logistic regression analysis - BELGIUM

	OR (95% CI) for <b>Clinically-oriented services vs. rest</b>
<b>Type of service</b>	
Home care (Yes vs No)	0.06 (0.01-0.30)

Table A4.5: Within-country multivariable logistic regression analysis - UK

	OR (95% CI) for <b>Expanding services vs. rest</b>
<b>Disciplines connected to the service</b>	
Psychologists and/or counsellors (Yes vs No)	4.93 (1.69-14.38)

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## **Appendix 5: Principal Component Analysis**

Table A5: Principal component analysis - component loadings

	<b>Extent to which the public is informed</b>	<b>Mandate to engage with communities</b>	<b>Importance of informal networks in care/bereavement</b>
a) For the most part, the general public is sufficiently informed about our service	<b>0.828</b>	0.007	-0.072
b) For the most part, the general public has sufficient knowledge about EOL care	<b>0.883</b>	0.079	-0.081
c) For the most part, has sufficient knowledge about bereavement care	<b>0.835</b>	0.113	0.63
d) As a service, part of our responsibility is to promote the general public to take care of themselves and each other when faced with LL illness	0.093	<b>0.536</b>	-0.301
e) Our service does <u>not</u> have the time or resources to engage in activities aimed at the general public	0.019	<b>-0.850</b>	-0.085
f) Our service should focus on providing care; working with the general public is <u>not</u> our job	-0.123	<b>-0.855</b>	0.038
g) People's own social networks are at least as important providers of EOL care as professionals	-0.053	-0.148	<b>0.891</b>
h) People's own social networks are at least as important providers of bereavement care as professionals	-0.007	0.024	<b>0.912</b>
Chronbach's alpha	0.802	0.652	0.797

\*Items loading on a component higher than 0.5 were retained in that component

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