







STUDY PROTOCOL

# Recalibrating the ‘world map’ of palliative care development

[version 1; peer review: 2 approved]

Nicole Baur <sup>1</sup>, Carlos Centeno <sup>2</sup>, Eduardo Garralda<sup>2</sup>, Stephen Connor <sup>3</sup>,  
David Clark <sup>1</sup>

<sup>1</sup>School of Interdisciplinary Studies, University of Glasgow, Dumfries Campus, Dumfries, DG1 4ZL, UK

<sup>2</sup>Institute for Culture and Society, Health Research Institute of Navarra (IDISNA), University of Navarra, Pamplona, 31009, Spain

<sup>3</sup>Worldwide Hospice and Palliative Care Alliance, Fairfax, Virginia, 22039, USA

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## Abstract

**Background:** Despite growing interest from policy makers, researchers and activists in the global development of palliative care, there is still little science to underpin it. This study presents the methods deployed in the creation of a ‘world map’ of palliative care development. Building on two previous iterations, with improved rigour and taking into account reviewers’ feedback, the aim of this recalibrated version of the study is to determine the level of palliative care development in 198 United Nations recognised countries in 2017, whilst ensuring comparability with previous versions. We present methods of data collection and analysis.

**Methods and analysis:** Primary data on the level of palliative care development in 2017 was collected from in-country experts through an online questionnaire and, where required, supplemented by published documentary sources and grey literature. Data relating to the total population of each country as well as per capita opioid consumption were derived from independent sources. Data analysis was conducted according to a new scoring system and algorithm developed by the research team.

**Ethics and dissemination:** The study was approved by the University of Glasgow College of Social Sciences Research Ethics Committee. Findings of the study will be disseminated in peer-reviewed journals, as a contribution to the second edition of the Global Atlas of Palliative Care at the End-of-Life, and via social media, including the Glasgow End of Life Studies Group blog and the project website.



**Limitations of the study:** There are potential biases associated with self-reporting by key in-country experts. In some countries, the identified key expert failed to complete the questionnaire in whole or part and data limitations were potentially compounded by language restrictions, as questionnaires were available only in three European languages. The study relied in part on data from independent sources, the accuracy of these data could not be verified.

## Keywords

Palliative care, global development, hospice, mapping

## Open Peer Review

Reviewer Status  

	Invited Reviewers	
	1	2
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- 1 **Liz Grant**, University of Edinburgh, Edinburgh, UK
- 2 **Philip Larkin**, University of Lausanne, Lausanne, Switzerland

Any reports and responses or comments on the article can be found at the end of the article.

**Corresponding author:** David Clark ([david.clark.2@glasgow.ac.uk](mailto:david.clark.2@glasgow.ac.uk))

**Author roles:** **Baur N:** Conceptualization, Formal Analysis, Investigation, Methodology, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Centeno C:** Formal Analysis, Methodology, Resources, Validation, Writing – Review & Editing; **Garralda E:** Formal Analysis, Resources; **Connor S:** Conceptualization, Resources, Writing – Review & Editing; **Clark D:** Conceptualization, Formal Analysis, Funding Acquisition, Project Administration, Supervision, Writing – Review & Editing

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## Introduction

The need for palliative care is increasing around the world and has recently been estimated at over 61 million patients per year<sup>1</sup>. The World Health Assembly has called on all its member states to develop strategies to integrate palliative care into policies for health and social care across the lifespan<sup>2</sup>. Whilst interest in the global development of palliative care is growing, there remains little science to underpin it.

In an effort to advance methodological understanding of the challenges in conducting research on global palliative care development and how they may be overcome, we present here the methods deployed in producing a third ‘world map’ of palliative care development, allocating all 198 countries recognised by the United Nations to one of six categories, based on 10 key indicators. The chosen method for the study builds on previous iterations of the world map but is significantly improved in rigour and replicability. It also takes into account feedback and commentary received on previous versions from

within the global palliative care community and from a small number of published works<sup>3,4</sup> (Figure 1). The improvements made to the methodology lead us to a recalibration of the world map. Comparability with the results of the earlier studies has been an enduring consideration, although not at the expense of improving the underlying method.

There is growing engagement from policy makers, researchers and activists in the development of palliative and end-of-life care in a global context<sup>5-8</sup>. This builds on discussions about how palliative care began as a social and medical movement in the West and over time expanded its scope and influence<sup>9</sup>. Palliative care has been recognized as a public health issue<sup>10</sup>. Closely linked to this, palliative care availability and access have also been acknowledged as a matter of ‘human rights’ in recent years<sup>11</sup>, in a context where 80% of the need for palliative care is in low and middle-income countries. At the same time, comparative research on palliative care between countries remains challenging due to enormous inequity in the

Critique of previous methods and response

Protocol	
An explicit study protocol describing the study design in detail should be developed	Based on the experiences of using study methods in 2006 and 2011 as well as similar mapping exercises (e.g. the Latin American and European regional atlases) a detailed study protocol has been prepared.
Protocol should be developed in cooperation with international collaborators	The protocol was developed in collaboration with the Worldwide Hospice and Palliative Care Alliance (WHPCA) and the ATLANTES group at the Universidad de Navarra in Pamplona.
Protocol should be included in the final report, available on request from the authors, or published separately	The protocol and a detailed account of methods of data collection and analysis are published separately
Protocol should be based on a solid theoretical background relevant to the evaluation of health care, such as Donabedian's model of structure, process, and outcome indicators	The new study follows the WHO public health model.
Use of experts as source of information	
Expert research must follow strict guidelines	Detailed guidelines have been developed on the recruitment of key informants, the design of the survey questionnaire and validation of resulting data.
Standard ethics approval procedure should be followed	The study was submitted to and approved by the research ethics committee of the College of Social Sciences at the University of Glasgow.
Involving more than one expert from each country, ideally from different settings (hospital, university, hospice, non-governmental organization, government).	Where possible, two key informants from different institutions were identified for each country. For some countries identifying more than one expert proved impossible and for a small number of countries, no expert could be identified
Grey literature	
Methods of search and analysis of grey literature to be described in detail	The process of searching and finding grey literature has been detailed in the study protocol.

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Ranking and rating	
Results must be accompanied by appropriate information on their validity and must highlight any limitations	Data have been validated according to their accuracy and consistency and divided into data of low/medium/high strength of evidence. Limitations regarding data collection and validation have been acknowledged in the study protocol and will be acknowledged in any publications resulting from this study.
A rating approach is suggested as it leads to more careful reading of results	Based on the experience of using the ‘categories approach’ used in the previous studies, we are confident that the ranking method is the most appropriate and feasible for this study. With distinct and clear descriptions of what each category stands for the responses on development indicators will be much more precise.
Aging of data on provision	
Longitudinal collection of data, for example, on an annual basis is recommended and the data should be continuously available for researchers and policy makers	The current study aims to provide a detailed account of the global development of palliative care which helps compare the development between different countries at a given time. Given that this is the third study with approximately a five-year interval, it also enables assessment of a particular country's status over five years.  It would be ideal to have annual data collection reporting on global palliative care development hosted by one of the global palliative care agencies. However, currently, such provisions are not available.
Primary research	
Research collaboration between developed and developing countries at the primary level is strongly recommended	In this study we collaborate with the Worldwide Hospice and Palliative Care Alliance (WHPCA) and the ATLANTES group at the Universidad de Navarra in Pamplona with a vision towards co-production of publications and visual outputs.

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Figure 1. Critique of previous methods.

provision of services<sup>12</sup> as well as varying policy contexts and implementation practices<sup>13</sup>. Comparative data about the distribution of services remain difficult to obtain, yet these are vital in informing global palliative care policy and in monitoring policy impacts.

Since 2006, the last author (DC) has been engaged in efforts to categorize palliative care development country by country throughout the world and to depict this development in a series of world and regional maps.

For the first ‘world map’<sup>14</sup>, data about palliative care development from 2006 were collected from published articles in peer-reviewed and professional journals, books and monographs, palliative care directories and related websites, relevant reviews and databases, grey literature and conference presentations. These were then synthesised in order to allocate each country to one of the categories of development. Expert opinion was also used as a substitute for documentary sources where these were not available to inform the classification. The methods were weak, but nevertheless allowed a first foray into research of this scope and scale.

The four-part typology categorisation for the first world map was initially constructed for a review of palliative care in Africa<sup>15</sup>. The four categories were:

- (1) No identified hospice-palliative care activity
- (2) Capacity building activity but no service
- (3) Localized palliative care provision
- (4) Palliative care activities approach integration with mainstream service providers

The second world map<sup>16</sup> involved a more systematic approach to the identification of in-country experts or ‘champions’ who were asked to give an opinion on the level of development of palliative care in their country in 2011, based on a refined six category classification:

- (1) No known hospice-palliative care activity
- (2) Capacity-building activity
- (3a) Isolated palliative care provision
- (3b) Generalized palliative care provision
- (4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision
- (4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision.

The palliative care ‘champions’, with their extensive knowledge of both national and international development, were identified from published and grey documentary sources of information provided by 66 national palliative care associations and international palliative care agencies (International Association of

Hospice and Palliative Care, Help the Hospices, Worldwide Hospice Palliative Care Alliance). Where no palliative care ‘champion’ could be identified for a country, regional palliative care associations (Asia Pacific Hospice Palliative Care Network, African Palliative Care Association, European Association for Palliative Care, Latin American Palliative Care Association) acted as ‘proxies’ for named countries within their jurisdiction. Where this was not possible, published and grey literature and data contained in regional palliative care ‘atlases’ from Europe and Latin America which had appeared since the publication of the first world map, also provided material on which the researchers made a classification. Data from the second world map were in turn used to support the production of the first global atlas of palliative care, published jointly by the Worldwide Hospice Palliative Care Alliance and the World Health Organization<sup>17</sup>.

The protocol and methods reported here for the third iteration of the world map of palliative care development build on the earlier work but go significantly beyond it. In a major departure from the earlier studies, the third world map is based primarily on an online survey of in-country experts, in which the questionnaire they were asked to complete was constructed to measure levels of development against 10 indicators drawn from the emerging literature. Where these data could not be obtained or were incomplete, they were enhanced by systematic searches of the published and grey literature for the countries in question. In addition, data on levels of opioid consumption, a well-established indicator of the level of palliative care development and delivery, and population were taken for all countries from reliable global sources. Additionally, the included jurisdictions were restricted to those recognised by the United Nations (UN) as sovereign states and excluded those classed as associated territories, some of which had been included in previous iterations.

### Protocol

The present study, to produce a third iteration of the world map of palliative care development, forms part of a Wellcome Trust Investigator Award. It has benefitted from greater funding support than previous iterations and from fuller collaboration between project partners.

The objectives of the study are:

- 1) To establish the level of palliative care development in UN countries in 2017.
- 2) To implement methodological improvements, based on recent progress in the field and commentaries relating to the previous ‘world map’ studies.
- 3) To monitor development in global palliative care since 2006 and 2011.

### Recruitment and sampling of participants

For the third world map, we sought to recruit at least two palliative care expert respondents from each UN recognised country (n=198). For this we created a database of key informants in collaboration with our project partners Worldwide Hospice Palliative Care Alliance (WHPCA) and ATLANTES

research group (Universidad de Navarra). This enabled us to make use of published named contacts in countries where regional mapping of palliative care had been undertaken, i.e. Africa, Europe, Latin America and the Eastern Mediterranean region, as well as to capitalise on the partners' wider networks. We also worked with the regional palliative care associations African Palliative Care Association (APCA), Latin American Association of Palliative Care (ALCP), Asia Pacific Hospice Palliative Care Network (APHN) and European Association for Palliative Care (EAPC), as well as the International Association for Hospice and Palliative Care (IAHPC), to identify key experts in areas where no atlas or mapping had taken place. Further contact details were obtained through authorship of peer-reviewed articles as well as posts and recruitment calls on social media. Names, workplaces and contact details of experts were collated in an electronic database and organised by World Health Organization (WHO) region and country.

Based on this database, sampling then took place according to the following algorithm, which listed preferred categories of informant in declining order of preference:

- I) Representatives of the national in-country hospice-palliative care association or nearest professional association (e.g. society for palliative medicine or hospice forum). The person should have an established administrative and/or leadership role in the organisation, making them a reliable source of information. They will also play an important part in identifying further key informants within the country.
- II) Academic experts with known interests and research experience in hospice-palliative care development in-country and/or beyond, as evidenced by peer-reviewed publications. The person should have an established academic role in hospice-palliative care research or education, making them a reliable source of information.
- III) Policy specialists (in or outside government) with experience of and/or responsibility for hospice-palliative care delivery in-country. The person should have an established policy role relating to hospice-palliative care, making them a reliable source of information.
- IV) Palliative care representatives, academics or policy specialists from outside the country but with direct knowledge of its hospice-palliative care provision, making them a reliable source of information.

Despite best efforts, we were unable to identify contacts for 19 UN countries. We surveyed 560 individuals from 180 countries in total. Contacts from 179 countries agreed to participate. Their distribution can be seen in [Table 1](#).

#### Data collection

Data collection focussed primarily on the questionnaire which in-country contacts were asked to complete. This was supplemented where required, as explained below, by published

**Table 1. Numbers of contacts per country.**

No of contacts per country	No of countries
Countries with 1 contact	33
Countries with 2 contacts	48 <sup>i</sup>
Countries with 3 contacts	37
Countries with 4 contacts	26
Countries with 5 contacts	16
Countries with 6 contacts	4
Countries with 7 contacts	8
Countries with 8 contacts	2
Countries with 9 contacts	2
Countries with ≥ 10 contacts	3

Figure excludes Timor L'este where originally two contacts were identified, but both did not feel that they were the right people to complete the questionnaire, i.e. we have no contact in Timor L'este

documentary sources and grey literature. Opioid consumption and population data came from independent sources.

**Online questionnaire.** Between September 2017 and January 2018, a questionnaire was developed collaboratively by the project team (For a copy of the questionnaire see Extended data)<sup>18</sup>. In January and February 2018, the questionnaire was piloted for content by 8 palliative care experts from 6 countries. In addition, technical piloting was carried out by 2 technical experts. The final version of the questionnaire consisted of 28 questions, constructed according to the four dimensions of the WHO 'Public Health Model for Palliative Care': policy, access to medicines, palliative care education and implementation of palliative care services<sup>19</sup>.

The questionnaire was subdivided into eight sections:

- Consent for participation in the study (Questions 1-4)
- Demographic information about the respondent and their organisation (Questions 5-14)
- Service provision and funding for palliative care (Questions 15-18)
- Palliative care policy, legislation and 'vitality', captured by the existence of national strategies or plans, clinical guidelines and laws relating to palliative care, as well as the existence of a national palliative care association, regular conferences, a national journal and evidence of co-operation with other specialities (Questions 19-20)
- Access to medicines for pain relief (Questions 21-22)
- Palliative care education / training (Questions 23-25)
- Palliative care provision for children (Questions 26-27)

- Usefulness of the world map in promoting palliative care development (Question 28)

To facilitate completion of the questionnaire in a multi-lingual environment, as well as to facilitate data analysis, the majority of the questions were either multiple-choice or had pre-defined answers in a drop-down menu.

SurveyMonkey was used to host the English language questionnaire and it was anticipated that the questionnaire could be completed in approximately 20 minutes. The questionnaire was designed in a way that participants could skip questions and also pause and return to it at a later stage, in anticipation that this would reduce the number of partially complete questionnaires.

A Word version of the questionnaire was produced in March 2018 for participants with limited access to the online questionnaire. In April 2018, a professional company, 'Language Insight', was contracted to translate the Word version into French and Spanish in order to facilitate completion for participants in French- and Spanish-speaking countries. Completed paper questionnaires received by email were then inputted into SurveyMonkey by the research team.

The survey was opened on 20 February 2018, when an email letter of invitation containing a link to the questionnaire was circulated to contacts in the WHO regions of Africa, Eastern Mediterranean and Europe. Similar emails to contacts in WHO regions for the Americas, South-East Asia and Western Pacific were sent the following day. This two-step approach was applied to facilitate dealing with large numbers of potential queries and problems from email recipients, should these arise. In order to maximise response rate, a system of personalisation was used, i.e. participants were individually addressed in the email which was also signed by NB in order to initiate a personal relationship between researcher and participant, which we could later build on when sending out reminders. Additionally, contacts were reminded that their anonymity would be preserved in the study.

One month was given to complete the questionnaire and an Excel spreadsheet was designed to monitor incoming returns. By the end of this period, we had received questionnaires from 75 countries. For 13 countries we had received more than one questionnaire. As a number of questionnaires had only been partially completed, we decided to adjust the questionnaire formatting to allow respondents to skip questions.

First reminders were circulated on 20 March 2018 and second reminders on 24 April 2018. Reminder emails, which were again personalised, stressed the importance of the study and the participant's response to the overall project. By mid-May 2018, we had received completed questionnaires from 111 countries, with 35 countries providing more than one questionnaire. In an effort to increase response rates further, we started to keep weekly statistics and circulate weekly updates to our project partners. Contacts who had still failed to respond were contacted by DC and other team members in May, June and July 2018

and a slow increase in response rates was evident, as Table 2 shows. The survey was closed on 31 August 2018, although two fully completed questionnaires were subsequently included that arrived in early September as these particular countries had been granted an extension.

**Collection of secondary data (May to December 2018).** Secondary data were collected for countries where no contact could be identified, as well as to supplement information for countries where no complete questionnaire was returned.

To begin, data were extracted from the published atlases of palliative care for the Eastern Mediterranean and African WHO regions. Further relevant peer-reviewed items were identified through PubMed and Google Scholar using the MeSH search terms 'palliation' OR 'palliative care' OR 'end of life care' OR 'terminal care' AND 'country' (inserting the name for each individual country). Returns were selected using filtering by title and abstract. Information was selected from published literature according to the WHO dimensions and the 10 indicators described below.

Inclusion criteria were: reference to at least one of the dimensions of the WHO palliative care public health strategy (education, policy, implementation of palliative care services, medicine availability) plus vitality / country-level data / published in English, French, German or Spanish between 2014 and 2018 and not reliant on data published in any of the regional palliative care atlases or the previous two world maps.

**Table 2. Response rates to the survey over time.**

Date	Countries with complete surveys		Countries with partially complete surveys	
	1 survey	>1 survey	1 survey	>1 survey
11 May	111	35	34	0
18 May	114	39	33	0
25 May	123	44	35	0
01 June	124	50	33	3
08 June <sup>#</sup>	125	53	34	3
29 June	132	58	34	3
06 July	136	61	34	3
13 July	137	63	34	3
20 July	138	64	35	3
27 July	138	64	35	3
03 Aug	138	64	35	3
10 Aug	138	64	35	3
17 Aug	138	64	35	3
24 Aug	140	64	35	3
31 Aug	141	64	35	3

<sup>#</sup>No updates were circulated on 15 and 22 June, as the primary researcher was on annual leave



In addition to peer-reviewed items, 'grey literature' identified on the internet was used to fill gaps, including governmental websites, ehospice, EAPC blogs, conference presentations and policy statements.

### Data entry, cleansing and storage

Using SurveyMonkey as an online survey tool meant that most data arrived in electronic form, but 23 questionnaires were returned by email. Of these, 15 were English language questionnaires, four were French and four were Spanish. In order to facilitate data analysis, these were printed and entered into SurveyMonkey by the research team at the University of Glasgow. Afterwards, the printed copies of these questionnaires were stored in a locked cabinet in the PI's office.

Once the survey closed, all data were downloaded into an Excel spreadsheet and cleansed for accuracy and completeness. As the number of responses was manageable, this task was carried out manually at the University of Glasgow. Cleansing included the removal of duplicate responses which resulted from participants abandoning a questionnaire and starting a new one after receiving a reminder email as well as checking for 'illegal values', i.e. values that were outside the definition of accepted values. In a further step, any missing values were flagged for completion with supplementary data from other sources at a later stage. Special attention was given during the cleansing

process to data that had been entered from paper questionnaires, as respondents frequently presented information that could not be captured in the online system and which did not meet the entry criteria but had to be entered manually into the Excel spreadsheet.

After the cleansing process, every record was given a code before personal data were removed from the spreadsheet and stored separately in a password protected file. The file containing the research data was also stored on a password protected computer and accessible only to the primary researcher at the University of Glasgow.

### Data analysis

Data analysis started in September 2018 and priority was given in the first instance to the survey returns.

**a) Analysis of data obtained from questionnaires.** Data analysis built on a scoring system developed by the research team. Based on the four dimensions detailed in the WHO 'Public Health Model for Palliative Care', the following table of ten qualitative and quantitative indicators had been created collaboratively in November 2017 (see [Figure 2](#)), with each of the indicators relating to one or more questions/sub-questions. The final questions had thus been shaped by the agreed indicators, shown in [Table 3](#).

Indicators of Palliative Care Development

Score		Categories					
WHO Dimension	Indicator	0 Category 1 No known PC activity	1 Category 2 Capacity-building PC activity	2 Category 3a Isolated PC provision	3 Category 3b Generalised PC provision	4 Category 4a PC services at preliminary stage of integration	5 Category 4b PC services at advanced stage of integration
Services (Q15)	Provision of services <sup>1</sup>	No evidence / Don't know	No evidence	0-0.49 per 100,000	0.5-0.99 per 100,000	1.0-1.49 per 100,000	1.5 and more per 100,000
(Q17)	Geographical spread of services	No evidence / Don't know	In progress	1-4	5-6	7-8	9-10
Funding (Q18)	Range of available funding sources for palliative care	No evidence / Don't know	Direct payments	Direct payments, Donor	Donor, institutions & partial NHS (pilot projects)	NHS participates in the funding on a regular basis	Mainly by NHS or health finance system
Strategy or National Plan (Q19 a/e/f/g/k)	Existence of national strategy or plan for palliative care	No evidence / Don't know	No reference	Reference to PC in national strategies for cancer, AIDS and/or other non-communicable diseases	Strategy or national plan specific to PC	PC strategy implemented & evaluated	PC Strategy implemented & updated OR Desk at Ministry of Health
Law (Q19 b/c/d)	Existence of legal provision to support palliative care	No evidence / Don't know	No reference	Establishment in progress of any reference (decrees / norms) but not national law – could be regional law (e.g. Germany)	Any reference (decrees / norms) but not national law – could be regional law (e.g. Germany)	References to PC in national laws	Standalone PC law or recognition of PC as a right in top law or the constitution of the country
Medicine (Q21/22)	Availability of morphine and other strong opioids	No evidence / Don't know	Not available	Morphine <b>occasionally</b> available	Morphine <b>usually</b> available	Morphine <b>always</b> available, other opioids <b>usually</b> available	Any kind of strong opioids <b>always</b> available
	Country consumption of morphine per capita (2015)	No evidence / Don't know	0.0001-0.2399 (Quartile 1)	0.2400-1.0387 (Quartile 2)	1.0388-3.9857 (Quartile 3)	>3.9857 (Quartile 4)	>3.9857 (Quartile 4) and any kind of strong opioids <b>always</b> available
Education (Q23)	Training programmes for professionals in palliative care	No evidence / Don't know	Professionals receive training abroad, basic courses are available in the country	Informal process of training for palliative care professionals available in the country	<b>Establishment</b> of official process of palliative medicine specialisation in the country in <b>progress</b>	Official process of palliative medicine specialisation <b>available</b> in the country	Substantial number of professionals certified
(Q24/25)	Education for pre-qualification doctors / nurses	No evidence / Don't know	Teaching by non-profit sector and/or hospice organisations	Teaching is available at hospitals / medical centres / university hospitals or through Ministry of Health	Teaching is available in the primary care sector	Universities provide PC training	Universities provide PC training and palliative medicine is a recognised medical speciality or sub-speciality
Vitality (Q19 h/i/j/l/m/n/o)	Existence of meetings, associations, journals, conferences, guidelines, collaborations in palliative care	No evidence / Don't know	Evidence of PC professional or political meetings	Existence of a national PC association or establishment in progress	Existence of <b>at least one</b> of the following: a national journal, palliative care directory, standards or guidelines and national conference <b>AND</b> a national PC association	Existence of <b>at least two</b> of the following: a national journal, palliative care directory, standards or guidelines and national conference <b>AND</b> a national PC association	Existence of <b>at least two</b> of the following: a national journal, palliative care directory, standards or guidelines and national conference <b>AND</b> a national PC association <b>as well as</b> evidence of professional co-operation with other specialities outside PC (national or international)

<sup>1</sup> This indicator relates to the total number of palliative care services operating a country. These include, but are not limited to: free standing hospices with or without inpatient beds, hospices that are a part of public or NGO hospitals, home care teams, palliative care support teams in hospitals, palliative care inpatient and outpatient facilities, paediatric palliative care hospices and services. The focus is on services that are providing specialised / specialist palliative care as their *primary mission*. A palliative care service provider organisation may have more than one local service in operation, so the number of palliative care services in a country may be greater than the number of provider organisations. (This definition was included in the questionnaire)

**Figure 2. Indicators of Palliative Care Development.**

Each indicator was then assigned a range of characteristics representing the six categories used in the second world map, now expanded, as shown in [Table 4](#).

In order to facilitate quantitative analyses and categorisation of countries, a scoring matrix was created, assigning each category

a value between 0 (Category 1) and 5 (Category 4b), with all 10 indicators weighted equally at 10%. This way, each country was allocated a weighted score (between 0% and 100%) based on the category for each indicator. Pilot scoring and moderation of three countries took place between the Glasgow team and ATLANTES and subsequently, the scoring matrix was

**Table 3. Relation of indicators in the questionnaire to the WHO 'Public Health Model for Palliative Care'.**

WHO Dimension	Indicator of choice	Question(s)
Implementation	Provision of services per 100,000 population	15
	Geographical spread of services	16
	Source(s) of funding	18
Policy	Strategy / national plan	19a/e/f/g/k
	PC law	19b/c/d
	Vitality	19h/i/j/l/m/n/o
Access to medicine	Availability of opioids	21/22
	Opioid consumption (mg per capita)	data from INCB <sup>iii</sup>
Education	Training for professionals	23
	Education for future doctors/nurses	24/25

<sup>iii</sup>International Narcotics Control Board

**Table 4. Expanded categories of palliative care development (2018).**

<b>Category 1:</b> No known palliative care activity	A country in this category is one where current research reveals no evidence of any palliative care activity.
<b>Category 2:</b> Capacity-building palliative care activity	A country in this category shows evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for the development of palliative care services, although no service has yet been established. Developmental activities include attendance at, or organisation of, key conferences, personnel undertaking external training in palliative care, lobbying of policy makers and Ministries of Health and emerging plans for service development.
<b>Category 3a:</b> Isolated palliative care provision	A country in this category is characterized by the development of palliative care activism that is still patchy in scope and not well-supported; sources of funding that are often heavily donor-dependent; limited availability of morphine; and a small number of palliative care services that are limited in relation to the size of the population.
<b>Category 3b:</b> Generalised palliative care provision	A country in this category is characterized by the development of palliative care activism in several locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; several hospice-palliative care services from a range of providers; and the provision of some training and education initiatives by the hospice and palliative care organizations.
<b>Category 4a:</b> Palliative care services at a preliminary stage of integration to mainstream health care services	A country in this category is characterized by the development of a critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health professionals and local communities; a palliative care strategy that has been implemented and is regularly evaluated; the availability of morphine and some other strong pain-relieving drugs; some impact of palliative care on policy; the provision of a substantial number of training and education initiatives by a range of organizations; and the existence of a national palliative care association.
<b>Category 4b:</b> Palliative care services at an advanced stage of integration to mainstream health care services	A country in this category is characterized by the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities, and society in general; a palliative care strategy that has been implemented and is regularly updated; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of palliative care on policy; the existence of palliative care guidelines; the existence of recognized education centres and academic links with universities with evidence of integration of palliative care into relevant curricula; and the existence of a national palliative care association that has achieved significant impact.



circulated again to the collaborators for feedback in May and June 2018.

When starting the analysis, priority was given to countries where only one completed questionnaire was available. For countries with more than one completed questionnaire that showed discrepancies in the responses, the above-mentioned algorithm of sampling key experts was applied to decide on an 'index questionnaire' for this country that would form the basis of the analysis. Information obtained from additional questionnaires from this country was then used as complementary material where required. [Table 5](#) shows the number of questionnaires returned by country.

[Figure 3](#) shows that countries where no contact respondent had been identified were immediately entered into a literature review process. Countries from which we received at least one fully completed questionnaire were processed through the algorithm in [Figure 4](#). Countries which provided incomplete questionnaires or failed to respond to our reminders went into a review process involving the research team. For these countries, missing data were supplemented by information gathered from published literature, including the most recent regional atlases for the African (APCA) and Eastern Mediterranean (EMRO) regions. If sufficient information could be gathered in this way, these countries proceeded to the above-mentioned algorithm. If only insufficient or no information at all could be identified, the countries were assigned to category 1.

An algorithm was also developed to establish the level of palliative care development for each country in the study ([Figure 4](#)). The algorithm was applied to all countries for which sufficient data could be gathered from either the questionnaires alone or the questionnaires and supplementary secondary sources combined. The mode of the 10 indicators, the most repeated value, and the mean, the measure of central tendency, were then used to determine the level of development for each country as follows:

- a) When the mode and median of the 10 indicators were coincident, the most repeated value was also in the middle of the distribution of the 10 values. This then determined the country's level of categorization of palliative care.

- b) When the mode and the median were not coincident, we took the categorical view that the most significant indicators for judging palliative care development are the existence of essential medicines for pain control and the provision of palliative care services. In our survey, we employed two indicators on medicines (concerned with the availability and consumption of opioids) and two indicators on services provision (the total number of services per population and the distribution of these services). We therefore included these four indicators in the algorithm as the 'most consequential indicators' of palliative care development. Thus:

- i. When the mode of the 10 indicators was coincident with the median of the most consequential indicators, that number was used to determine the level of categorization, meaning that the most consequential indicators (services and medicines) were jointly coincident with the most repeated position of the other indicators.
- ii. When the mode was to the left-hand side of the median of the most consequential indicators (i.e. the mode was less than the median for services and medicines), then the indicators for services and medicine were used to moderate the level by taking the mode slightly to the right and assigning mode + 1 as the level of development.
- iii. When the mode was to the right-hand side of the median of the most consequential indicators (i.e. the mode was greater than the median for services and medicines), then the indicators for services and medicine were used to moderate the level by taking the mode slightly to the left and assigning mode -1 as the level of development.

**b) Third party sources.** The analysis relied, for some items, on third-party information. In order to calculate the number of services per 100,000, for example, population figures from the [2017 World Population Data Sheet](#) were used. Data regarding the per capita opioid consumption were obtained by DC from the University of Wisconsin Pain and Policies Study Group through personal communications with Professor James Cleary (now of the Walther Supportive Oncology Program at Indiana University School of Medicine).

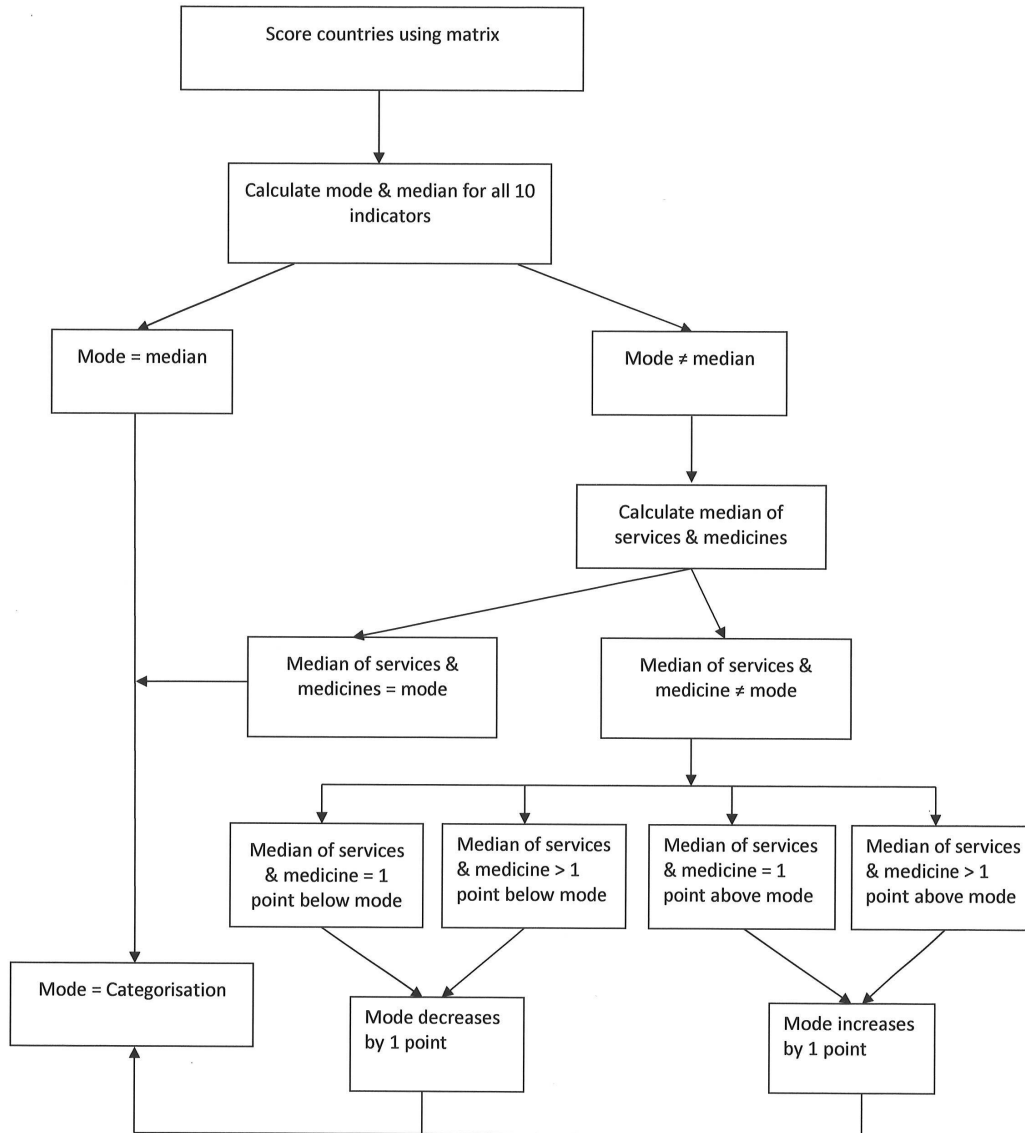
**c) Analysis of secondary data.** Analysis of secondary data was applied to countries with no contact respondent or countries where contacts failed to reply and was used to supplement information for countries which returned only a partially complete questionnaire. Although we searched for secondary data to match the indicators as closely as possible, the nature of such information made it impossible to include four of these countries in the scoring matrix. Instead, they were assigned a world map category by the research team, based on expert judgement and contextual knowledge.

Most of the data analysis was completed from September to November 2018 by the research team in Glasgow, where regular moderation meetings between the researcher and the PI ensured

**Table 5. Number of returned questionnaires per country.**

No of returned questionnaires per country	No of countries
Countries with 1 questionnaire	98
Countries with 2 questionnaires	59
Countries with 3 questionnaires	20
Countries with 4 questionnaires	1
Countries with 5 questionnaires	0
Countries with 6 questionnaires	1
Countries with 7 questionnaires	1

### Analysis algorithm to determine categories of palliative care development



**Figure 3.** Data analysis process.

accuracy and consistency. Further moderation took place with ATLANTES, which culminated in a face-to-face meeting in Dumfries in December 2018. In a small number of cases, respondents had to be contacted again in order to clarify answers.

#### Ethical considerations

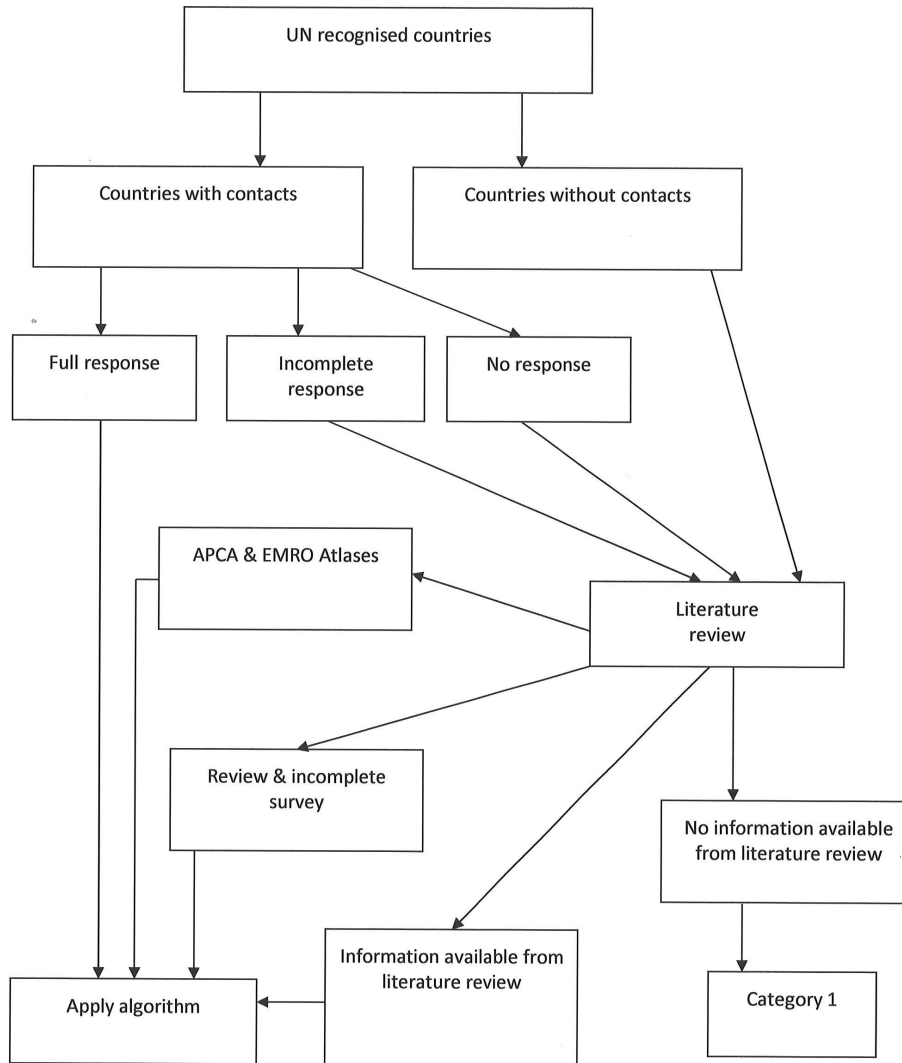
The study was subject to review by the University of Glasgow College of Social Sciences Research Ethics Committee. Approval was granted on 15 January 2018 (Application No: 400170065). Prior to data collection, the purpose of the study was explained to all participants (see [Figure 5](#)) and written consent for participation in the study was obtained from each participant

before access to the questionnaire was granted. Participants were informed that they had the right to withdraw from the study at any point in time, without any repercussions.

#### Confidentiality and data protection

Paper questionnaires were stored in a secure location at the University of Glasgow. All electronic research data were stored as de-identified data (i.e. identifiers have been replaced by a code) in a password protected file.

Personal data on the respondents were collected for administrative purposes. As soon as the questionnaires were returned, the respondents were assigned a unique code that was linked to the

**Data sourcing process**

**Figure 4. Algorithm determining WM3 categories.**

respondent in a password-protected Excel database and will not be used in any publications. The Excel database was stored separately from the questionnaire and personal data will not be disclosed either orally or in writing to any unauthorised party. Personal data will only be retained for the length of the data collection period. Afterwards the electronic file containing personal data will be permanently deleted.

Participants have been made aware that a copy of the final manuscript of their data is available to them upon request.

#### Data dissemination and resource sharing

Following the wide interest and high citation levels of publications about the first two world maps of palliative care development, it is anticipated that interest in the results of this study will be high. Our publication and dissemination strategy include:

1. The current paper detailing the study protocol and methods used.
2. A 'headline' paper on the third iteration of the 'world map of palliative care development', supported by the current paper as an account of the protocol and methods.
3. A paper specifically focussed on the global development of children's palliative care.
4. A paper on the linear ranking of palliative care development.
5. Contribution to material for inclusion in the 2<sup>nd</sup> edition of the Global Atlas of Palliative Care at the End-of-Life. The Global Atlas includes summary results of the mapping as part of a larger publication depicting all aspects of palliative care globally. Being a co-publication with the WHO, it receives a high level of attention; the first edition has been downloaded over 70,000 times.
6. Findings from the study and related commentary will also be available on social media, including the Glasgow



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Sciences

## Participant Information Sheet

### The third iteration of the 'World Map' of palliative care development

David Clark, Nicole Baur

School of Interdisciplinary Studies, University of Glasgow, Dumfries campus, Dumfries, Scotland in collaboration with ATLANTES and the WHPCA

We would like to invite you to take part in the above research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study is to produce the third iteration of world maps on palliative care development. You can find out about the previous two world maps here: [www.glasgow.ac.uk/worldmapofpalliativecare](http://www.glasgow.ac.uk/worldmapofpalliativecare). From this third study we are hoping to gain an understanding of the development of palliative care in each country of the world in 2017 – which can be compared with the results of previous studies from 2006 and 2011.

Participation in this study is voluntary. Your participation will involve completing an online survey (approx. 20 min).

Copies of the completed surveys will be stored at the University of Glasgow in a locked facility or in computers secured by passwords.

We will maintain the confidentiality of all research data, all participants will remain anonymous in publications, and all data will be destroyed in ten years' time.

We will inform you by email once the project has been completed, providing you with information on how to access findings. This email will also contain contact details for further enquiries.

This study is part of the Glasgow End of Life Studies Group's 'Global Interventions at the End of Life project' funded by the Wellcome Trust. The Wellcome Trust Grant Number is 103319/Z/13/Z.

This project has been considered and approved by the Research Ethics Committee of the College of Social Sciences, University of Glasgow.

❖ For further information, please email **Dr Nicole Baur**: [nicole.baur@glasgow.ac.uk](mailto:nicole.baur@glasgow.ac.uk) or call +44 (0) 1387 702015

❖ To pursue any complaint: please contact the College of Social Sciences Ethics Officer, **Dr Muir Houston**, email: [Muir.Houston@glasgow.ac.uk](mailto:Muir.Houston@glasgow.ac.uk)

Figure 5. Participant Information Sheet.

End of Life Studies Group blog, ehospice.com, and the project website -<https://www.gla.ac.uk/research/az/endoflifestudies/projects/worldmapofpalliativecare/>

ArcGIS, Version 10.5, was used to create the map for this study. In addition, a special geoprocessing tool was added to ArcMap in order to create cartograms according to the Gastner-Newman method. This technique allowed us to generate maps which make countries visually comparable by modifying their geographical size according to our specific data.

### Strengths and limitations

Figure 1 lists our summary of commentaries and concerns about the methodology of the previous world map studies, together with our responses to these issues in the present study.

The present study suffers from potential biases associated with key informants. Such self-reported data cannot be independently verified and we are aware that some respondents might have deliberately underrated or overrated levels of development in their country for their own reasons. For countries where more than one questionnaire was returned, the research team had to moderate discrepancies between the answers. Although the use of key informants from the field of palliative care has its drawbacks, we are not convinced that 'government sources' can necessarily provide a more detailed report of palliative care provision in a given country and we remain committed to the use of in-country specialists, who by their involvement also help to build capacity for the wider effort of palliative care mapping.

In some instances, we were unable to identify two palliative care experts in-country and in other countries, where only one eligible person was identified, they failed to complete the questionnaire. Data limitations were compounded by language constraints. Questionnaires were only available in three European languages. Whilst this impeded communication with reluctant respondents, it might also have added to the barriers for non-native speakers willing to complete the questionnaire. Furthermore, not all data provided in the questionnaires relates to the year 2017 and, as the research team was reliant on third-party data for some information, some minor data gaps exist.

### Study status

At the time of publication of this article, all data for the study has been collected and analysed and all visuals have been prepared. The study is currently unpublished with a draft article being prepared by the PI who will be the first author.

### Conclusions

The first and second 'world maps' of palliative care development created in 2006 and 2011 have become important tools for presenting the global process of palliative care development

in the world through an international comparative analysis. Allocating each country to one of six levels of palliative care development has enabled us to chart progress over time.

The third world map will allow us to assess global palliative care development over the period 2006–17. Taken together, the three maps will form a valuable tool for advocacy, in a context where the study results are relevant to governments, policy makers, palliative care activists, service providers and the wider public.

The ultimate beneficiaries of increased understanding and measurement of palliative care development are the patients and families that need palliative care but are unable to access the care they require. The enormous unmet need for palliative care, particularly in low and middle-income countries, is a largely unrecognized matter of public health urgency. This work will help to highlight the continuing gaps that exist in palliative care development around the world.

### Data availability

#### Underlying data

No underlying data are associated with this article.

#### Extended data

Enlighten: Research Data: Recalibrating the 'world map' of palliative care development. <https://doi.org/10.5525/gla.researchdata.779><sup>18</sup>

This project contains the following extended data:

- Questionnaire.pdf (Copy of online consent and questionnaire form)
- World\_map\_of\_palliative\_care\_development\_drop\_down\_menus (Drop-down answer options for sections 3, 4 and 5 of the questionnaire)
- Participant\_Information-World\_Map\_revised.pdf (Participant information sheet)

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](#) (CC-BY 4.0).

### Grant information

This work was supported by the Wellcome Trust [103319], a Wellcome Trust Investigator Award to DC, with NB employed on an Enhancement Award to this grant at the time of this work.

*The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.*

### Acknowledgements

We would like to thank all the participants in the study for taking the time to respond to our questionnaire.



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# Open Peer Review

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## Version 1

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### Philip Larkin

Lausanne University Hospital (CHUV), Faculty of Biology and Medicine, University Institute of Training and Research in Patient Care (IUFERS), University of Lausanne, Lausanne, Switzerland

This is an important paper written by a group with strong credibility in the field of palliative care and with regard to this level of global mapping. It is useful to have a 'methods' paper as this is often overlooked in the haste to present the data and in fact, this paper demonstrates the complexity of such an undertaking. It is largely well written but I would suggest an overall review for grammar and spelling. I note, for example, on pg 12 that the tense moves from the past to the future and I believe that if indexed, it should be written in the past tense as far as possible.

I do wonder if pg 12 (Information leaflet) adds to this paper and unless essential to the discourse, I would suggest it is either excluded or placed as an appendix. I am not sure what added value it brings.

The scoring system is complex and rather well explained. I think the algorithms would benefit from some style editing. They are clear but perhaps could be presented in a better visual format. One comment is noted on page 6 where the development of the questionnaire refers to the possibility to 'skip questions' but it is not clear to me if this was designed initially (which I thought on pg 5) but seems to have been an adaptation later. I think that could be clarified.

Other than these minor points, I would commend the authors for a comprehensive and well proportioned paper.

**Is the rationale for, and objectives of, the study clearly described?**

Yes

**Is the study design appropriate for the research question?**

Yes

**Are sufficient details of the methods provided to allow replication by others?**

Yes

**Are the datasets clearly presented in a useable and accessible format?**

Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Palliative Care, Nursing, Education,

**I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 24 May 2019

<https://doi.org/10.21956/wellcomeopenres.16485.r35435>

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### Liz Grant

Global Health Academy and the Primary Palliative Care Research Group, the Usher Institute, University of Edinburgh, Edinburgh, UK

This is the third world map of palliative care. It builds on two previous ones (2006 and 2011) developed by Clark and colleagues introducing a more complex and comprehensive analysis of the reach, quality and coverage in each country.

The first map provided a basic matrix looking at four categories: No identified hospice-palliative care activity; Capacity building activity but no service; Localized palliative care provision; Palliative care activities approach integration with mainstream service providers. The second map, recognising the gaps in the data collection of the 1<sup>st</sup> process especially with regards to reliance on published literature, worked with in-country experts who commented on the level of palliative care engagement using a refined set of six categories which included the following: No known hospice-palliative care activity; Capacity-building activity; Isolated palliative care provision; Generalized palliative care provision; Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision; Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision.

This third mapping project has sought to improve the rigour of the methods of data collection, and the quality of data collected

It had the following objectives:

1. To establish the level of palliative care development in UN countries in 2017.
2. To implement methodological improvements, based on recent progress in the field and commentaries relating to the previous 'world map' studies.
3. To monitor development in global palliative care since 2006 and 2011.

The work was extensive in its analysis. Recognising the value of experts a new database was established of experts who were able to provide a much more nuanced summary of the state of palliative care in their country. The study also linked to the various networks and Associations of Palliative care to increase the number of people with considered opinions on palliative care.

An algorithm was established to enable sampling to take place with a list of preferred categories

These included four separate categories:

1. Representatives of the national in-country hospice-palliative care association or nearest professional association
2. Academic experts with research experience in hospice-palliative care development in-country
3. Government and Civil Society Policy specialists with knowledge of palliative care
4. Palliative care representatives, academics or policy specialists from outside the country who have knowledge of the country

Data was collected using an online questionnaire (In English speaking countries this was Survey Monkey – no data given of what it was in other countries) in 179 UN countries.

No experts could be located in 19 countries. 560 people were interviewed. Information about these categories is very important as these sources are the ones who have shaped the constructs.

Data on the total country population and per capita opioid consumption were derived from a set of different independent sources. More information on these would be helpful.

Interview data was analysed using a scoring system developed by the researchers. This leads to a minor limitation which the authors identified. A weighting system was also developed by the group.

Other limitations that the authors identified were the challenges of self reported summaries especially when experts were involved in the setting up and development of country services and where their future income from external donors depended on good results, internal moderation of the discrepancies between different country perspectives.

The authors do note that though there are most certainly challenges in relying on country experts because of their biases they noted that ‘government sources’ could also be unreliable – sometimes out of data, capturing urban public sources. Data is only as good as the carefulness of those who have inputted it and the quality of what was inputted.

Further limitations were that the questionnaires were only available in three European languages and this could have significantly affected the feedback and the accuracy of the feedback from those who only spoke local languages.

There is also concern about the years that the data relate to – the respondents note that not all countries had data that went up to 2017 so there is a danger that comparisons across are false.

More information is needed on the comprehensiveness of the academic expert conversations especially as a number of academics in countries expressed a lack of awareness about the 1<sup>st</sup> and 2<sup>nd</sup> maps and about the processes.

However despite the multiple challenges the map has provided a very important step forward in a) demonstrating that we need to understand coverage, b) in profiling the importance of multi country analysis of palliative care in a way that corresponds to the effort and significance that other diseases and other health system services such as maternal health, have had.

The three maps demonstrate the changes in societal understanding of palliative care in different countries. This work will help to highlight the continuing gaps that exist in palliative care development around the world. As such it is an exceptionally important piece of work.

### **Is the rationale for, and objectives of, the study clearly described?**

Yes

**Is the study design appropriate for the research question?**

Yes

**Are sufficient details of the methods provided to allow replication by others?**

Yes

**Are the datasets clearly presented in a useable and accessible format?**

Yes

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** palliative care and global health

**I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

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