

## Consent for Participation in the Study

The research team at the University of Glasgow End of Life Studies Group under the leadership of Professor David Clark, collaborating with the Worldwide Hospice Palliative Care Alliance (WHPCA) and the University of Navarra (ATLANTES), requests your consent for involvement in a study about the development of palliative care across the world. The study is funded by the Wellcome Trust. This consent form asks you to allow the research team to use your responses to enhance understanding of the topic.

Participation in this study is completely voluntary. If you decide not to participate there will be no negative consequences. Please be aware that if you decide to participate, you remain free to stop participating at any time.

The research team will maintain the confidentiality of the research data, all participants will remain anonymous in publications, and all data will be stored in password-protected files and destroyed in ten years' time.

By completing and returning the questionnaire you are indicating that you have read the description of the study provided on the Participant Information Sheet emailed to you, you are over the age of 18, and that you agree to the terms as described above.

Results of the study will be made widely available and we will keep you informed about this.

If you have any questions, or would like a copy of this consent letter, please contact me at [nicole.baur@glasgow.ac.uk](mailto:nicole.baur@glasgow.ac.uk).

Thank you in advance for your participation!  
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\* 1. I agree to participate in the research study.

Yes

No

\* 2. I understand the purpose and nature of this study and I am participating voluntarily. I understand that I can withdraw from the study at any time, without any penalty or consequences.

Yes

No

\* 3. I grant permission for the data generated from this survey to be used in the research team's publications on this topic.

Yes

No

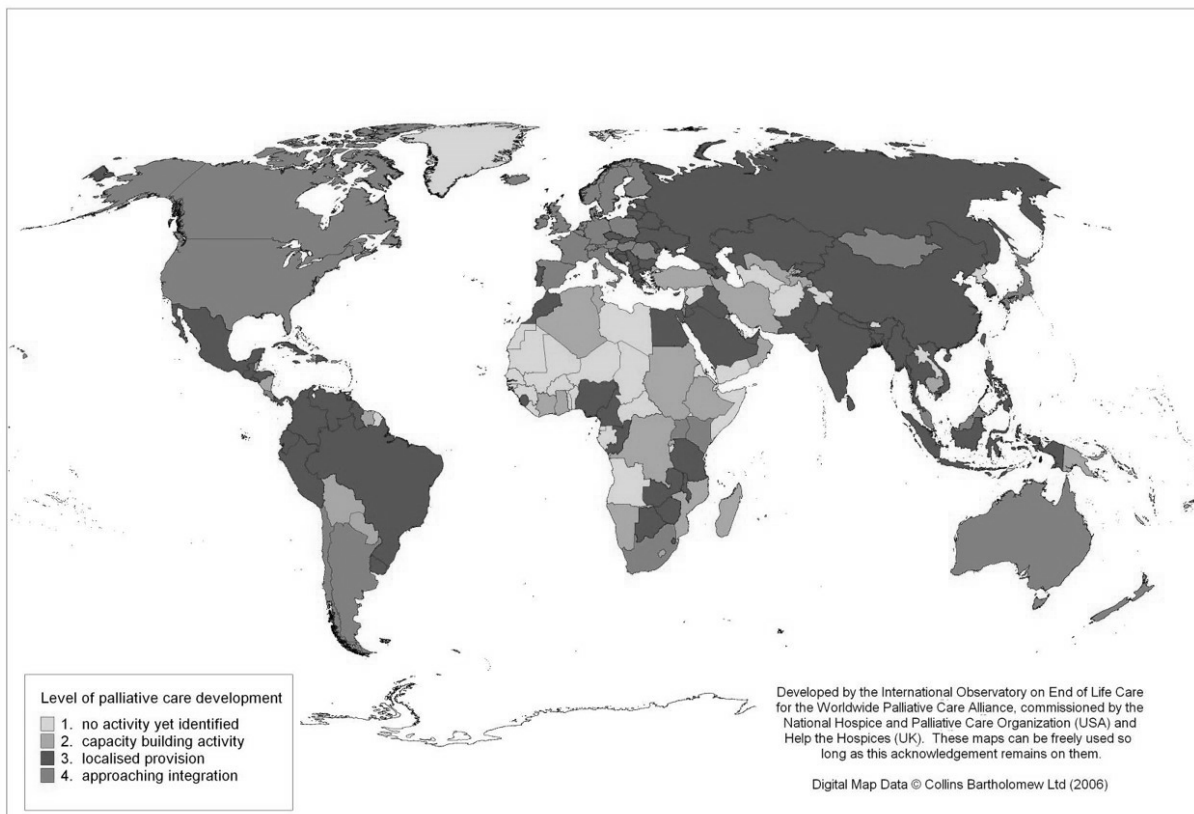
I grant permission under the following conditions:

\* 4. Please type your name in the box below to indicate agreement to participate in this study.

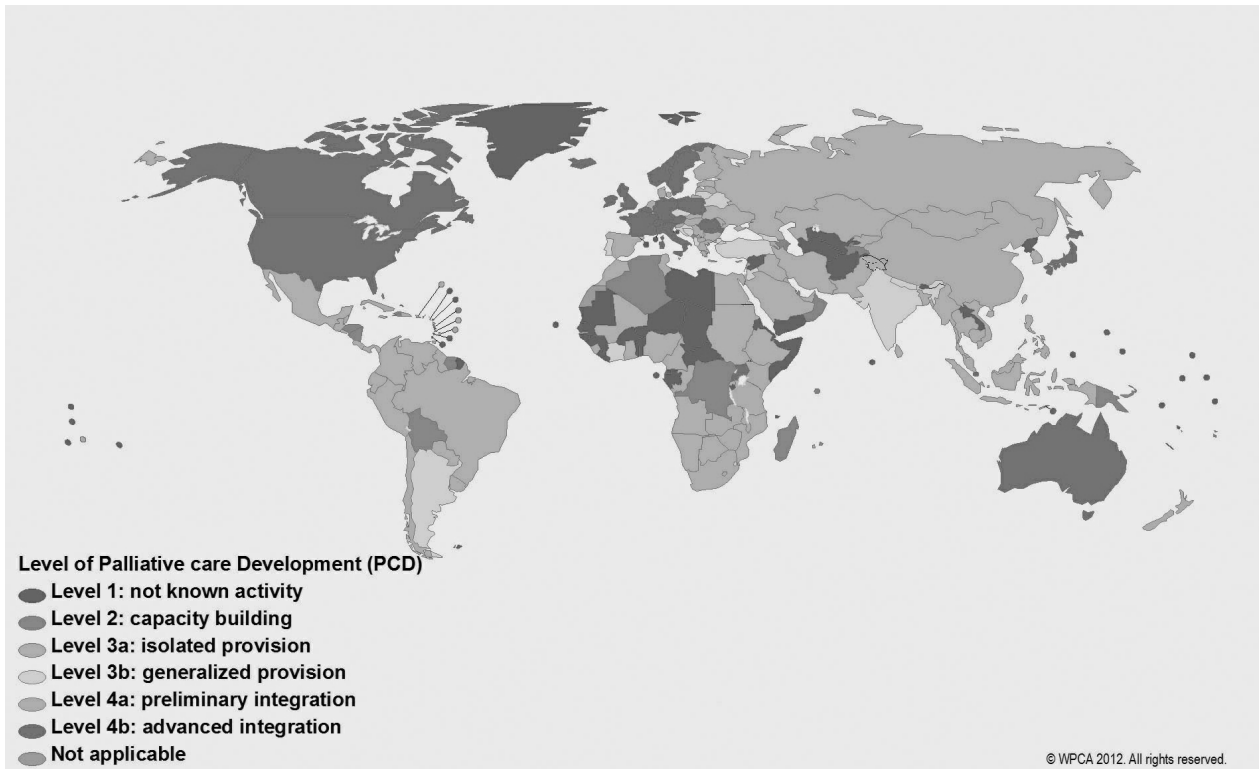
Welcome to our survey on palliative care development across the globe.

**Thank you for taking the time to complete this survey, which will take approximately 20 minutes. The ‘world map’ of palliative care is an important tool for assessing the progress of palliative care development in each country of the world. It enables us to chart progress over time and also provides a valuable tool for advocacy. The first world map appeared in 2006 and the second in 2012. They were published in the Journal of Pain and Symptom Management in 2008 and 2013 respectively. You can see each of these below. These maps have been widely used by many organisations to support national and international palliative care development. Thank you for being willing to help us create a third map, based on the situation in your country in 2017. Your contribution is extremely valuable to us.**

### First World Map of Palliative Care Development (2006)



## Second World Map of Palliative Care Development (2012)



**Section 1: Demographic Information**

\* 5. Your first name

\* 6. Your last name

\* 7. Name of your institution

\* 8. Postal address

\* 9. City / Town

\* 10. Country

\* 11. Contact telephone

\* 12. Contact email

13. Website

\* 14. Type of organisation

Palliative care association

Government

Hospital

Affiliate to international palliative care association

Hospice

World Health Organisation focal point

University

Voluntary

Other, please specify

## Section 2: Service Provision and Funding

In this section we would like to ask you about the palliative care services provided in your country

**DEFINITION:** For the purpose of this questionnaire we are interested in the total number of palliative care *services* operating in your 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.

Our focus is on services that are providing specialised / specialist palliative care as their *primary mission*.

We also note that a palliative care service provider organisation may have more than one local service in operation. Please therefore report information on the number of palliative care *services* in your country, recognising that this is likely to be greater than the number of provider organisations.

\* 15. What was the total number of palliative care services operating in your country in 2017?

\* 16. Is the above figure your personal estimate?

Yes

No - please give the source of the figure

\* 17. In your opinion, what is the geographical spread of palliative care services in your country?

(Please click and slide below)

Highly restricted to very few locations (1)

Widely available across the country (10)

**\* 18. How is palliative care funded in your country?**

Please select all applicable options.

- Direct payment by patients / their relatives
- Costs met by non-profit organisations (e.g. NGOs, charities, civil society)
- Government-funded
- Health insurance or national pension schemes
- Other (please specify)



### Section 3: Palliative Care Policy, Legislation, and Vitality

In this section we would like to ask you about palliative care policies and legislation in your country.

\* 19. Does your country have any of the following?

Please select

A reference to palliative care in national strategies for cancer, AIDS and / or other non-communicable diseases

A reference to palliative care in decrees / norms other than in a national law

A reference to palliative care in a national law

A specific (stand-alone) palliative care law or recognition of palliative care as a right in the constitution

A national strategy or plan specific to palliative care

A national palliative care strategy that has been implemented and is regularly evaluated

A national palliative care strategy that has been implemented and is regularly evaluated and updated

National standards for operating a palliative care service

National clinical guidelines for management of symptoms

A palliative care association or equivalent

Please select

A person / desk / unit in a government department (e.g. the Ministry of Health) with palliative care responsibility

A directory of palliative care services that is updated regularly

A national journal of palliative care

A national palliative care conference once every year or once every two years

Evidence of professional co-operation with other specialities outside palliative care

\* 20. How would you assess the strength of palliative care research capacity in your country?

- No evidence of any palliative care research activity
- Isolated individuals undertaking small projects
- A small number of informal groups working on specific studies
- Some officially recognised centres within academic institutions undertaking planned research programmes

Please expand on your answer choice

## Section 4: Access to Drugs for Pain Relief

In this section we would like to ask you about access to pain medication according to the WHO Cancer Pain Ladder for adults in your country.

\* 21. Please tell us to what extent patients in need of palliative care in your country have access to each step of the ladder.

	Select access
Step 1 of the ladder (e.g. paracetamol, aspirin)	<input type="text"/>
Step 2 of the ladder (e.g. codeine, tramadol)	<input type="text"/>
Step 3 of the ladder (e.g. morphine, fentanyl)	<input type="text"/>

\* 22. Does your country have access to the following drugs?

	Select access
Injectable morphine	<input type="text"/>
Oral morphine	<input type="text"/>

**Section 5: Palliative Care Education / Training**

**In this section we would like to ask you about palliative care training and education in your country.**

\* 23. What palliative care training is available in your country?

	For physicians	For nurses	For others involved in palliative care
No evidence of any training	<input type="text"/>	<input type="text"/>	<input type="text"/>
Basic courses available in the country, but professionals receive training abroad	<input type="text"/>	<input type="text"/>	<input type="text"/>
Basis courses & informal training for professionals available in the country	<input type="text"/>	<input type="text"/>	<input type="text"/>
Official process of palliative medicine specialisation available in the country	<input type="text"/>	<input type="text"/>	<input type="text"/>
Substantial number of professionals certified & training modules available for some other related specialities	<input type="text"/>	<input type="text"/>	<input type="text"/>
Substantial number of professionals certified & training modules available for almost all related specialities	<input type="text"/>	<input type="text"/>	<input type="text"/>

\* 24. Who provides palliative care training in your country?

Please select all that apply.

- Non-profit sector (e.g. charities, NGOs, voluntary organisations)
- Hospice organisations
- Primary care organisations
- Hospitals / medical centres / university hospitals
- Universities
- Other (please specify)

\* 25. How is palliative medicine recognised in your country?

Please select

Palliative medicine is a recognised medical specialty

Palliative medicine is a recognised medical sub-specialty

**Section 6: Children's Palliative Care Provision**

**In this section we would like to ask you about palliative care provision for children in your country.**

\* 26. Which of the following categories best describes palliative care activity related to children in your country? *Please consult the category descriptors shown below before selecting ONE of the answers below.*

- |   |   |
|---|---|
| <input type="radio"/> (1) No known palliative care activity for children          | <input type="radio"/> (3b) Generalised children's palliative care provision   |
| <input type="radio"/> (2) Capacity building palliative care activity for children | <input type="radio"/> (4a) Children's palliative care services at preliminary stage of integration into mainstream health care services |
| <input type="radio"/> (3a) Isolated children's palliative care provision          | <input type="radio"/> (4b) Children's palliative care services at advanced stage of integration into mainstream health care services    |

(1) No known palliative care activity for children

A country in this category is one where current research reveals no evidence of any palliative care activity relevant specifically to children.

(2) Capacity building palliative care activity for children

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 for children, although no service or specific program has yet been established. There are some developmental activities including 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.

(3a) Isolated children's palliative care provision

A country in this category is characterized by the development of children's 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; at least a service or program can be identified by other professionals in the country as a best practice model for palliative care for children; there are a few children's palliative care services or specific programs, but they are limited in relation to the need of the population.

(3b) Generalised children's palliative care provision

A country in this category is characterized by the development of children's 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 or programs for children from a range of providers; and the provision of some training and education initiatives by the hospice and palliative care organizations.

(4a) Children's palliative care services at a preliminary stage of integration into mainstream health care services

A country in this category is characterized by the development of a critical mass of children's palliative care activism in a number of locations; a variety of palliative care providers and types of services and programs; awareness of palliative care on the part of health professionals and local communities; the availability of strong pain relieving drugs other than morphine; 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.

(4b) Children's palliative care services at an advanced stage of integration into mainstream health care services

A country in this category is characterized by the development of a critical mass of children's palliative care activism in a wide range of locations; comprehensive provision of all types of children's palliative care by multiple service providers; broad awareness of children's palliative care on the part of health professionals, local communities, and society in general; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of children's palliative care on policy; the existence of children's palliative care guidelines; the existence of recognized education centres and academic links with universities with evidence of integration of children's palliative care into relevant curricula; and the recognition of children's palliative care by a national association that has achieved significant impact.

27. Please provide here any additional information on children's palliative care services in your country you would like us to know



**Section 7: Usefulness of the World Map in Promoting Palliative Care Development**

**Finally ... as we explained at the start, the world map of palliative care development has been published twice already, with a third version now in the making. Please comment in your own words on how useful you have found the world map in your work to promote palliative care development, either in your own country and/or internationally.**

\* 28. Please provide your comments on the usefulness of the 'world map' in promoting palliative care in your country and/or internationally

Thank you for your time and participation.

**Thank you very much for completing the survey. We are grateful to you for contributing your valuable time and offering valuable information.**