

## Country Experts Survey

First, please consider the following questions:

**1. Is palliative care included in a national law on health care in your country?**

- Yes
- No
- Don't know / not sure

**2. Does your country have at least one government-backed written strategy or plan at the national level or state/territory level for the delivery of palliative care?**

- Yes
- No
- Don't know / not sure

**3. Is there a person, desk or unit in the national government responsible for palliative care and/or hospice?**

- Yes
- No
- Don't know / not sure

**4. How available are opioids for pain relief for palliative care patients throughout the country (including cancer and non-cancer patients)?**

- Not available
- Occasionally available
- Usually available
- Always available
- Don't know/not sure

**5. Is palliative care a recognized specialty or sub-specialty in your country?**

- Yes
- No
- Don't know / not sure

**6. To what degree has your country integrated palliative care into professional training for doctors, nurses, and other advanced allied health professionals (e.g., psychologists, social workers)? Please rate this between 0 (no palliative care training requirements for any health professional) to 10 (all health professionals are required to receive some training in palliative care)**

**[Include drag scale here]**

**7. What is the geographical spread of palliative care services in your country? Please rate this between 1 (no services) and 10 (widely available throughout the country). \_\_\_\_\_**

**8. Is palliative care provided free of charge perhaps as universal health coverage package, for all patients in the country?**

- Yes
- No
- Don't know / not sure

**8.A How is end-of-life care funded in your country? Select all that apply.**

- Direct payment by patients/ family,
- Donations (e.g., charities)
- Private Health insurance.
- Government funding
- Other, please specify \_\_\_\_\_
- Don't know/ not sure.

**9. Does your country systematically capture and report statistics on the quality of end-of-life care?**

- Yes, there is extensive data collection and reporting
- Yes, but on a limited basis
- Yes, but on a very limited basis
- No
- Don't know / not sure

**10. Is it common for individuals in your country to go bankrupt due to the cost of care at the end of life?**

- Very uncommon
- Uncommon
- Common
- Very common

**11. Are there resources (e.g., financial, social, or logistical) available to support informal caregivers in your country to reduce the caring burden that they face?**

- Yes, there are extensive resources available
- Yes, but limited.
- Yes, but very limited.
- No

**12. Do you agree with the following statement: End-of-life care in my country is patient-centered, meaning it is personalized care that meets patient needs, preferences, and goals of care.**

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

**13. How would you rate your country on the delivery of end-of-life care services relative to countries with similar levels of economic development?**

- Excellent
- Good

- Fair
- Poor
- Very Poor

**Open-Ended Questions**

1. **[If Q13=Excellent or Good] What are the key factors that your country does well in terms of the delivery of end-of-life care services that led you to choose this rating?**
2. **[If Q13=Fair, Poor or Very poor] What are the key factors that your country does poorly in terms of the delivery of end-of-life care services that led you to choose this rating?**
3. **What do you see as the most important action your country could take to improve the quality of end-of-life care services in your country?**

A focus of this survey is to understand differences in patient and caregiver end-of-life experiences around the world and to learn more about delivery of end-of-life care in different countries. Please tell us how much you agree or disagree with each of the statements.

Next, we will ask you to consider health-care providers' interactions with patients in your country who have a life limiting illness. We later will ask you to consider health-care providers interactions with caregivers.

Please tell us how much you agree or disagree with each statement **as it applies to patients in your country.**

Consider whether health-care providers generally present information in a way that patients can easily understand. Also, consider whether health-care provider share the information with patients or patients have to ask for this information.					
<b>1. Health-care providers generally deliver clear and timely information so patients can make informed decisions.</b>					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

Health-care providers can be inattentive and insensitive or caring and sympathetic when dealing with patients. Consider whether health-care providers mostly are kind to patients and try to put themselves in their position.

**2. Health-care providers generally treat patients kindly and sympathetically.**

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

For many people, preparing for death can be a spiritual or cultural experience as well as a physical experience. Some health-care providers understand better than others the importance of this aspect of preparing for death. Consider whether health-care providers are generally accepting and give patients enough help for their spiritual, religious, and cultural needs.

**3. Health-care providers generally support patients' spiritual, religious, and cultural needs.**

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

Some hospitals and other care facilities give more access to friends and family than others. Contact can include phone or internet access as well as visits. Consider whether patients are generally offered enough contact with friends and family up to the time of death.

**4. When possible, health-care providers generally encourage patients' contact with friends and family.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Some health-care providers try harder than others to understand what is important to the patient. Consider whether providers make efforts to get enough information from patients and caregivers to understand what patient needs or want from their treatments.

**5. Health-care providers generally ask enough questions to understand patient needs.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Sometimes health-care providers can give patients too much treatment to try to extend their lives. Other times they provide too little treatment. Providers also sometimes give patient low-quality treatments that can cause unnecessary suffering. Consider whether patients feel they are given too much treatment, too little treatment or low-quality treatment.

**6. Health-care providers generally provide appropriate levels and quality of life extending treatments.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Health-care providers use medicines and other methods to help people deal with pain and discomfort. Some of these can limit patients' ability to stay alert and to talk with people around them. Consider whether patients want more or less treatment for their pain and other physical symptoms.

**7. Health-care providers generally control pain and discomfort to patients' desired levels.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Approaching the end of life can be a stressful and emotional experience. Health-care providers sometimes help people cope with their natural feelings during this difficult time. Consider whether patients receive appropriate help from health-care providers.

**8. Health-care providers generally help patients cope emotionally.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

In addition to quality of care, some hospitals and clinics are more comfortable and attractive than others in terms of facilities, equipment and general atmosphere. Consider what you think of the facilities, equipment and general atmosphere where patients receive care.

**9. The places where health-care providers provide care generally are clean, safe, and comfortable.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know



Patients often are seen by many health-care providers. Understanding what treatments each provider is doing is important to coordinate health care decisions and avoid unnecessary tests. Consider how well different health-care providers share information about treatments and tests without involvement of the patients or their caregivers.

**10. Care generally is well coordinated across different health-care providers.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

People who approach death can need help with things unrelated to medical concerns. For example, some might need help getting a will or organizing their finances. Others might need help attending a special family event, like a wedding or graduation. Consider whether health-care providers help with patients' non-medical concerns.

**11. Health-care providers generally help with patients' non-medical concerns.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Not all options for care at the end of life are covered or covered completely by insurance. Consider whether enough money is available or subsidies provided to patients so that costs does not limit the care they receive.

**12. Costs generally are not a barrier to patients getting appropriate care.**

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

Some patients feel strongly about being cared for or dying at home where they can be in a familiar setting with their loved ones. Others prefer to stay at a clinic or a medical facility, where pain and other symptoms can be treated better. Consider whether health-care providers do all they can to honor patients' preferences about where patients die.

**13. Patients generally are able to be cared for and die at their place of choice.**

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

Now we would like you to consider different kind of questions. In these questions, we will ask you to think about choosing between different groups of providers.

We would like to know **which provider group you would choose at the end of life** if all you knew about them were ratings given by caregivers based on some of the questions like those you answered before.

To help you understand how caregivers rated these Provider Groups we will use a star system like the one below. This box shows how we will use stars to indicate how caregivers rated their experience with these provider groups.

Strongly agreed: ★★★★★

Neither agreed nor disagreed: ★★★


Strongly disagreed: ★

If the caregivers strongly agreed with the statements, they gave the Provider Group 5 stars.

If the caregivers neither agreed nor disagreed with the statements, they gave the Provider Group 3 stars.





If the caregivers strongly disagreed with the statements, they gave the Provider Group 1 star.

For example, most caregivers **strongly agreed** that providers in Provider Group X delivered clear and timely information to patients, so they gave that experience 5 stars.

Patients' experience over last 6 weeks of life	Provider Group X
Received clear and timely information so patients can make informed decisions	 Strongly agreed

The provider groups we show you later in the survey may have good ratings for some experiences and bad ratings for others. Please consider the ratings for all experiences shown and think about **which provider group would you choose** if you had to go to one of these provider groups.

Suppose many people rated Provider Group A and Provider Group B below as shown in this table and everything else about them was the same.

Caregiver's experience over last 6 weeks of patient's life	Provider Group A	Provider Group B
Received clear and timely information so patients can make informed decisions	 Neither agree nor disagree	 Strongly Disagree
Mostly treated kindly and sympathetically	 Strongly Agree	 Neither agreed nor disagree

1. Based on these ratings, which Provider Group provided better information to patients near the time of death?







- 1 Provider Group A
- 2 Provider Group B
- 3 Don't know / Not sure

2. Based on these ratings, which Provider Group would you choose?

- 1 Provider Group A
- 2 Provider Group B

3 Don't know / Not sure

This choice has 3 options instead of 2

Caregiver's experience over last 6 weeks of patient's life	Provider Group A	Provider Group B	Provider Group C
Received clear and timely information so patients can make informed decisions	 Strongly Disagree	 Neither agree nor disagree	 Strongly Agree
Mostly treated kindly and sympathetically	 Strongly Agree	 Neither agree nor disagree	 Strongly Disagree

3. If these were the only options, which Provider Group would you choose based on these ratings?

We will ask you to think about three more choices. The same three Provider Group features will be shown in each question, but the ratings for these features will change for each question. Please think about what **you actually would do if you had to choose a Provider Group to be cared for during the last 6 weeks of life.**



Patient's experience over last 6 weeks of life	Provider Group A	Provider Group B	Provider Group C
Received clear and timely information so patient could make informed decisions	★	★★★	★
Mostly treated kindly and sympathetically	★★★★	★★★★★★	★
Received support for spiritual, religious, and/or cultural needs	★	★★★	★★★★★★
Were able to contact their friends and family	★★★★★★	★	★★★

1. If these were the only options, which Provider Group (A, B or C) would you choose based on these ratings?

Patient's experience over last 6 weeks of life	Provider Group D	Provider Group E	Provider Group F
Received clear and timely information so patient could make informed decisions	★	★★★	★★★★★
Mostly treated kindly and sympathetically	★★★★	★★★★	★
Received support for spiritual, religious, and/or cultural needs	★★★★	★★★★★★	★
Were able to contact their friends and family	★★★★★★	★	★★★★

2. If these were the only options, which Provider Group (D, E or F) would you choose based on these new ratings?

[Note the change in indicators]

Patient's experience over last 6 weeks of life	Provider Group G	Provider Group H	Provider Group I
Providers asked enough questions to understand patients' needs	★	★★★	★
Health care providers provided appropriate levels and quality of life extending treatments.	★★★★	★★★★★★	★
Were able to control pain and discomfort as well as they wanted	★	★★★	★★★★★★
Received support to cope emotionally	★★★★★★	★	★★★

1. If these were the only options, which Provider Group (G, H or I) would you choose based on these ratings?

Patient's experience over last 6 weeks of life	Provider Group J	Provider Group K	Provider Group L
Providers asked enough questions to understand patients' needs	★	★★★	★★★★★
Health care providers provided appropriate levels and quality of life extending treatments.	★★★★	★★★	★
Were able to control pain and discomfort as well as they wanted	★★★★	★★★★★	★
Received support to cope emotionally	★★★★★	★	★★★

2. If these were the only options, which Provider Group (J, K or L) would you choose based on these new ratings?

[Note the change in indicators]

Patient's experience over last 6 weeks of life	Provider Group M	Provider Group N	Provider Group O
Care was provided in a clean, safe, and comfortable location.	★	★★★	★
Care was well coordinated among different providers	★★★★	★★★★★★	★
Health care providers helped with patients' non-medical concerns	★	★★★	★★★★★★
Patients were cared for and died at their place of choice	★★★★★★	★	★★★★

1. If these were the only options, which Provider Group (M, N or O) would you choose based on these ratings?

Patient's experience over last 6 weeks of life	Provider Group P	Provider Group Q	Provider Group R
Care was provided in a clean, safe, and comfortable location.	★	★★★	★★★★★
Care was well coordinated among different providers	★★★★	★★★	★
Health care providers helped with patients' non-medical concerns	★★★★	★★★★★	★
Patients were cared for and died at their place of choice	★★★★★	★	★★★★

2. If these were the only options, which Provider Group (P,Q or R) would you choose based on these new ratings?

## AGREEMENT QUESTIONS

Now consider health-care providers' interactions with **caregivers** of patients who have a life-limiting illness in your country.

Please tell us how much you agree or disagree with each statement **as it applies to caregivers**.

Consider whether health-care providers generally give caregivers enough information to help them manage patients' medical needs near the time of death. Also, consider whether providers share this information on their own or do caregivers have to ask for this information.

**1. Health-care providers generally give caregivers clear and timely information on how to care for patients near the time of death.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Health-care providers can help family and friends cope with the stress and sadness associated with losing a loved one. Consider whether health-care providers generally offer this help to caregivers in the time before patients' death.

**2. Health-care providers generally help caregivers cope emotionally before death of their loved one.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Health-care providers can be cold and insensitive or caring and sympathetic when dealing with caregivers. Consider whether the health-care providers are mostly kind to caregivers and try to put themselves in their position.

**3. Health-care providers mostly treat caregivers kindly and sympathetically.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

After a patient's death, health-care providers can help family and friends cope with their natural feelings during this difficult time. Consider whether health-care providers generally offer enough help after a patient's death.

**4. Health-care providers generally offer grief services to caregivers after patients' death.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Health-care providers sometimes offer caregivers information about decisions that need to be made after a patient dies, such as how to make funeral arrangements. Consider whether health-care providers generally give clear and timely information to help with the process after a patient's death.

**5. Health-care providers generally give caregivers information on what to do after patients' death.**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know



## VIGNETTES

Listed below is a story describing what happened to a patient as he approached his end of life. We want you to think about this story as if it was your own and answer the following questions.

Taylor had advanced cancer and recently died at home surrounded by friends and family. In the months prior to death, he saw many different health-care providers. All treated him with compassion, but some providers recommended he keep trying new treatments to extend his life whereas others recommended he seek palliative care and look to get his affairs in order. Feeling increasingly tired and confused he eventually gave up on treatment. In the last weeks of life his pain was well managed, but he was anxious and depressed wondering if he should have stopped treatment earlier.

**Health-care providers provided appropriate level and quality of life extending treatments to Taylor:**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

**Health-care providers asked enough questions to understand Taylor's needs and wants from treatment:**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

For the next few questions, suppose you were responsible for a loved one at the end of life who needs care from providers. We would like to know which group of health-care providers you would choose if all you knew about them were **ratings on how caregivers were treated by health-care providers**.

As before, we will use stars to help you understand how caregivers rated these providers. Please consider the ratings for all experiences shown and think about which group of health-care providers would you choose if your loved one had to go to one of these groups.

Caregiver's experience over last 6 weeks of patient's life	Provider Group A	Provider Group B	Provider Group C
Received clear and timely information on how to care for patients	★★★★★	★★★	★★★
Helped to cope emotionally	★★★	★★★★★	★
Mostly were treated kindly and sympathetically	★	★★★	★★★★★

1. If these were the only options, which Provider Group (A, B or C) would you choose based on these ratings?

Caregiver's experience over last 6 weeks of patient's life	Provider Group D	Provider Group E	Provider Group F
Received clear and timely information on how to care for patients	★	★★★★	★★★★★★
Helped to cope emotionally	★★★★	★★★★★★	★
Mostly were treated kindly and sympathetically	★★★★★★	★	★★★★

2. If these were the only options, which Provider Group ( D, E or F) would you choose based on these new ratings?

[Note the change in indicators]

Caregiver's experience over last 6 weeks of patient's life	Provider Group G	Provider Group H	Provider Group I
Mostly treated kindly and sympathetically by health care providers	★	★★★	★
Offered grief services (after patient's death)	★	★★★	★★★★★
Received information on what to do after the patient's death	★★★★★	★	★★★

1. If these were the only options, which Provider Group (G, H or I) would you choose based on these ratings?

Caregiver's experience over last 6 weeks of patient's life	Provider Group J	Provider Group K	Provider Group L
Mostly treated kindly and sympathetically by health care providers	★	★★★	★★★★★
Offered grief services (after patient's death)	★★★★	★★★★★★	★
Received information on what to do after the patient's death	★★★★★★	★	★★★★

2. If these were the only options, which Provider Group (J, K or L) would you choose based on these new ratings?