

Public Consultation Adult Palliative Care Policy Update

Survey for Organisations

Fields marked with * are mandatory.

Introduction

The Department of Health plans to update the Palliative Care Policy for Adults in 2022 and is seeking the views of the public on palliative care services in Ireland and the public's priorities for the update. The public consultation will allow the Department of Health to hear the views from a wide range of stakeholders and the findings will inform the policy update. We are asking organisations to participate in the public consultation by completing the online survey below. If you are not representing an organisation / representative body and want to complete the survey as an individual, then click [here](#).

This survey is best viewed on a larger screen (desktop, tablet, larger smartphone). If you are using a smartphone with a small screen, you may need to rotate your screen to landscape view.

Any personal information which you volunteer to this public consultation will be treated with the highest standards of security and confidentiality, strictly in accordance with the General Data Protection Regulation 2016/67 and the Data Protection Act 2018. The Department's Privacy Policy can be viewed [here](#).

Please fill in the details below on behalf of your organisation / representative body:
I confirm I am the authorised representative on behalf of an organisation/representative body.

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Section 1: Organisation's Profile

This section asks questions about your organisation, so we can look at the submissions received from different points of view. This is the only reason for collecting this information.

1.1 Please select the category that best describes your organisation.

- Health service provider

- Union/Staff representative body **X**
- Other representative body
- Academic institution
- Charity / NGO
- Community / Voluntary group
- Advocacy body
- Other
- You selected other, please specify:

50 character(s) maximum

Section 2: Views on Current Palliative Care Services

This section asks about your organisation's views on current palliative care services in Ireland for people with serious and progressive illnesses and their families / carers.

2.1 To what extent do you agree with the following statements in relation to current palliative care services in Ireland.

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Health care staff recognise the palliative care needs of people with a serious and progressive illness in all care settings.		X			
People with a serious and progressive illness and their families / carers receive the necessary information to assist them with planning for end of life care and death.		X			
People with a serious and progressive illness and their families / carers can access the appropriate type of palliative care services when they need them e.g. community palliative care, hospice care, hospital care.		X			
Families and carers are receiving the necessary support to allow the person with a serious and progressive illness die at home if that is their wish.		X			

Strongly Disagree Disagree Unsure Agree Strongly Agree

Health care staff involved in palliative and end of life care talk to each other and co-ordinate the care they provide.

X

People with a serious and progressive illness and their families / carers are involved in decisions about their treatment and end of life care.

X

Families and carers receive the appropriate support and information after their loved one has died of a serious and progressive illness.

X

2.2 What is working well in the current provision of palliative care in Ireland? i.e. What are the strengths?

2500 character(s) maximum

Palliative care is care that focuses on relief of the pain, symptoms and stress of serious illness. The goal of palliative care is to help people live more comfortably and to provide the best possible quality of life for patients with life-limiting illness and their families. Palliative care can also be beneficial to patients alongside curative treatments.

The Adult Palliative Care Services, Model of Care for Ireland provides an excellent framework for the provision of specialist palliative care services and for the integration of the palliative care approach into hospital ,community and primary care services. Over the last number of years substantial progress has been made in expanding the best-practice model of palliative care from the hospice setting to the acute hospital setting and into the community, however, there are significant regional variations in the levels of specialist palliative care services available, and there has been no increase in resources for palliative care services within General Practice.

In addition, Ireland has a growing and ageing population and the number of adults over 50 requiring palliative care is growing progressively and expected to double by 2046. Significant investment is needed in palliative care services to meet both future and current unmet need.

2.3 What is not working well in the current provision of palliative care in Ireland? i.e. What are the weaknesses?

2500 character(s) maximum

Under the model of care for Adult Palliative Care Services, level three specialist palliative care is provided by consultant led specialist multidisciplinary teams. However currently there are less than half

the number of consultant posts in palliative medicine required, which are mainly hospital based. (According to the NDTP there are 42 (WTE) consultant posts in palliative medicine, which is only 39% of the estimated requirement of 109(91 WTEs) consultants in palliative medicine required to meet demographic change, unmet demand and develop academic research in palliative medicine). The two-tier consultant pay issue and poor working conditions continue to contribute to the difficulties in recruiting and retaining consultant specialists.

Under the model of care for Adult Palliative Care Services, level two general palliative care is provided by healthcare professionals, who although not engaged full time in palliative care, have additional training and experience in palliative care. Currently the Domiciliary Palliative Care Scheme which provides a payment for GPs providing domiciliary end of life care, however the current scheme is insufficient to meet the complexity of patient needs and is limited to patients with advanced cancer, terminal HIV and progressive neurological conditions only.

Advance care planning should be made on the basis of informed decision-making and made in consultation with a medical professional who has in-depth knowledge of the relevant condition. It must be recognised that advance care planning requires substantial practitioner time and resources.

While the majority of patients express a preference to die at home, a number of patients will die in hospital or in long-term nursing home settings. An increase in the number of designated palliative single rooms in these settings is required to ensure that the privacy of patients and their families is respected.

In addition the COVID-19 Nursing Homes Expert Panel highlighted the need to ensure direct linkages from nursing homes to community palliative care teams, expansion of the hospice friendly hospital programme into the nursing home sector and that all nursing home staff should receive training in palliative care.

Section 3. Views on the Future of Palliative Care Services

This section asks for your organisation's views on the future of palliative care service in Ireland.

3.1 On a scale of 0 to 10 (Number Slider) where 0 is not at all important and 10 is very important, please rate the importance of the following priorities for the adult palliative care policy update.

Equal access to palliative care no matter where you live, your diagnosis or what age you are.

10

Better training for healthcare staff to be able to deliver palliative and end of life care across all healthcare settings.

10

Increased public awareness and discussion of palliative and end of life care, dying and death.

9

Increased support for patients to plan and organise their affairs and future care at the end of life.

9

Increased practical help and support for patients and their families / carers during end of life care e.g. home help hours, assistive equipment.

10

Increased availability of palliative care services at weekends and out of hours.

10

Improved communication between healthcare professionals, providers, patients and families.

10

Increased use of telehealth to improve access to palliative care services.

9

3.2 What changes or improvements do you suggest for inclusion in the update to the adult palliative care policy?

2500 character(s) maximum

The IMO would like to see the following included in an updated adult palliative care policy:

- Increase investment in palliative care services so that all patients approaching the end of life receive appropriate care regardless of diagnosis or place of care;
- Ensure that each CHO and cancer centre is staffed by a fully multidisciplinary specialist palliative care team comprising Consultants and SpRs in Palliative Medicine, Clinical Nurse Specialists, a Social Worker and an Occupational Therapist, supported by designated administration/clerical staff
- Increase in the number of consultant posts and higher specialist training posts in palliative medicine to meet current unmet demand and demographic change;
- Address the issues that impede the recruitment and retention of hospital specialists across the health system;
- Negotiate with the IMO an enhanced and expanded package of care for the provision of palliative care in General Practice that reflects the complexity of patient needs;
- Advance care planning should be made on the basis of informed decision-making and made in consultation with a medical professional who has in-depth knowledge of the relevant condition and should be appropriately resourced;
- Ensure that inpatient specialist palliative care units with sufficient bed capacity to cater for the population are built in each CHO
- Increase the number of single rooms designated for palliative care in acute and long-stay settings;

- Invest in telehealth where evidence shows improvements to quality of care – telehealth is not a substitute for adequate investment in palliative care services;
- All healthcare professionals should receive formal training in the principles and skills of palliative care.