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Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-16 17:22:47

Consent

1 The Committee for Health would like your permission to publish your response as part of the survey results. Please indicate your preference.

Consent:
Publish response.

Who are you?

2 What is your name?

Name:
Bernie Torley

3 What is your email address?

Email:
[redacted]

4 Are you a healthcare professional?If yes, what is your role:If no, what is your interest in palliative care services:

Yes

1500 Characters:

ANP trainee in Palliative Care based in Southern Area Hospice
I have been qualified as a nurse for almost 22 years and have worked in palliative care for the last 20 years

5 What is your organisation?

Organisation:
Southern Area Hospice Services

6 Do you currently work in palliative care services?If Yes, in what capacity?

Yes

1500 characters:

ANP trainee in Palliative Care based in Southern Area Hospice

current state of palliative care services

7 In your view what is the current state of palliative care services in Northern Ireland?

Poor

8 Do you think there is an understanding by the public of what palliative care is?If no, what are the main barriers to the public understanding palliative care?

No

1500 Characters:

Public knowledge of palliative care varies, and accurately gauging it requires a robust scoping exercise. In my opinion, public knowledge is poor, with many people still believing palliative care is only for the last few weeks of life. Many do not understand that it can be beneficial much earlier in the disease trajectory or the difference between generalist and specialist palliative care. Generalist palliative care can be provided by multidisciplinary staff in acute and community settings, but many people believe it can only be provided by those working in specialist palliative care. One of the main barriers is that professionals lack understanding about palliative care and fail to recognise the benefits it can bring much earlier in the disease trajectory. Additionally, some professionals do not realise they are delivering generalist palliative care and fail to recognise when they should refer to Specialist Palliative Care. Education and information for professionals and the public have not been standardised, and there has not been a public messaging campaign to ensure structured delivery. Consequently, the public and some professionals are not fully aware of the available services or support.

Access to services

9 Are palliative care services equally accessible to all who need them?

No

10 From your experience where are the gaps in the provision of service?

1500 characters:

Lack of a regionally agreed model supported by commissioning
Lack of integration and standardisation between different palliative care services
Lack of an updated strategy that aligns to the rest of the United Kingdom and the Republic of Ireland
Lack of multidisciplinary specialist workforce planning
Lack of intelligence to identify the gaps in service delivery
Lack of coordination and sustainable services as funding is often non recurrent

11 Do you believe barriers exist that prevent equitable access to these services?If yes, please provide examples in the box provided.

Yes

1500 characters:

There is a lack of awareness among professionals and the public about the support palliative care can provide to individuals with a palliative condition, which in turn prevents access to services. Access to palliative care services is inequitable, often depending on a person’s postcode. There is also a lack of understanding of the need for palliative care services in areas of social deprivation, prisons, among the homeless, and for those with learning disabilities or mental health issues. Additionally, there is a shortage of trained and supported domiciliary care workers, which is crucial for helping people remain in their own homes (often their preferred place for end-of-life care) or facilitating discharge from hospital.

12 What additional services could/should be provided?

1500 Characters:

This is difficult to quantify without a robust needs assessment to evidence the service gaps.
Standardised education and training in palliative care for all disciplines both pre and post registration.
Standardised education and public messaging to support self-management and reduce reliance on services were possible
Palliative care Hubs should be available within an appropriate geographical distance from the patient. People living in rural areas often must travel long distances to access inpatient services and they not well supported by public transport to access or visit relatives in inpatient beds. They also have distances to travel to access palliative care hubs however these are not available in all areas.
There is a need for standardised 24/7 service provision in community. Outreach services need to be progressed in a standardised manor to support integration and equitable palliative care services across all sectors.
There is an inability to rapidly respond to the need for symptom management in community during the out of hours this is often a barrier to a patient returning home especially in rural areas.

Integration of Services

13 How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

1500 characters:

While there is some integration, it is not standardised and needs improvement. Quality indicators should be developed for acute services, similar to those in community services, to monitor care delivery. Communication between services needs to be enhanced to improve coordination and efficiency. Hospices and GPs need greater access to Encompass, as the current limited access poses a barrier to full integration and communication.

14 Should palliative care be a regional service?Please outline your reasons in the box provided.

Yes

1500 characters:

Yes, a regional service should be established to ensure equitable access to services and enhance governance structures. This initiative would aid workforce planning, boost efficiency, and attract investment. Additionally, it could improve response times and facilitate resource sharing. By integrating care pathways that connect hospitals, hospices, and community services, the coordination of acute and community care would be enhanced, leading to more seamless transitions of care. Currently, there are significant disparities across Northern Ireland for patients in long-term care facilities. Regional services allow for the consolidation of specialised resources such as palliative Medicine consultants, AHP’s, Counsellors, Nursing (ANP’s / Consultant Nurses etc). A regional structure would act as a hub for regional education, training and research. Regions could tailor services to the specific cultural demographic and health needs of their population to ensure people receive the required level of palliative care depending on their level of need. The Northern Ireland Statistics and Research Agency reported that the older population in Northern Ireland has grown by nearly 25% in the past decade, mirroring the trend across the UK. As the ageing population continues to rise rapidly, the demand for PC services will increase, but the workforce cannot keep up with the growing caseloads.

15 What can be done to improve integration?

1500 characters:

To improve integration, a structured and standardised model with sustained investment is essential. This model should include education and public awareness campaigns, supported by an up-to-date policy that prioritises palliative care within regional healthcare planning. A regional framework with robust governance structures is necessary to ensure accountability and coordination of palliative care services. Service design should be informed by the voices of service users and key stakeholders. Enhanced communication systems and centralised data, such as the Encompass system, should support this integration, with improved access for hospices and GPs. Needs-based funding is crucial to ensure underserved areas receive adequate support. Deploying outreach multidisciplinary palliative care services in order to reach rural communities. Quality indicators should be used across all care settings (generalist and specialist) to assess performance and measure patient outcomes.

Best Practice

16 Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

1500 Characters:

There are many examples of good practice and pilot programs in palliative care that effectively meet the needs of patients and their families/carers. However, an evidence-based, standardised approach is needed to ensure consistency and quality across the board. Currently, there is still a tendency towards siloed working, which can hinder the widespread adoption of best practices across Northern Ireland. A new OOHrs End of Life Nursing service has been developed by Southern Area Hospice; this runs 365 nights of the year from 10pm to 8am for patients in the Newry City area and BT35 postcode area. The feedback from service users, families, and our community health professional colleagues has been extremely positive. We aim to expand this service; however, this will require sustained funding.

17 Do you think that families receive sufficient support when accessing services?Please outline your reasons in the box provided.

Not sure

1500 Characters:

Effective communication between healthcare providers and families is crucial. The involvement of GPs, district nurses, community specialist palliative care teams, and other healthcare professionals, such as voluntary services (hospices), ensures that families are well-informed and supported. Overall, while there is a strong framework in place to support families, ongoing efforts are needed to ensure that all families receive the necessary support when accessing palliative care services. This approach needs to be standardised to ensure equitable care of the highest standard.

Funding and Strategy

18 Do you think the current funding for palliative care is sufficient?Please outline your reasons in the box provided.

No

1500 characters:

No, the current funding for palliative care is insufficient. In Northern Ireland, palliative care services have largely relied on charitable trust funds. While there are occasional investments, they are generally non-recurrent, which does not provide the stable and consistent funding needed for sustainable and comprehensive palliative care services.

19 Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future?Please outline your reasons in the box provided.

No

1500 characters:

No, the current funding model for hospices, including hospice at home, community care, and rapid response support, is neither sustainable nor sufficient to meet present and future needs. Palliative care should be recognised as an essential service within the overall healthcare system, and funding should reflect this to ensure true integration with other healthcare services. The funding model for hospices needs to be increased to 100%, as essential palliative care services should not rely on charitable funds for service delivery. Securing funding is challenging, making it difficult to attract and retain a skilled workforce. Additionally, regional evidence is needed to identify current gaps and future needs in services, ensuring a comprehensive career pathway for those in the palliative care sector.

20 Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not?Please outline your reasons in the box provided

Yes

1500 characters:

Yes, Northern Ireland needs a new Palliative Care Strategy with sustainable funding to support service development and address the population's needs. This strategy should involve a thorough review of palliative care services to identify current gaps and plan for future improvements. Public and patient involvement should be central to all levels of strategy development and implementation. The strategy should emphasise strong governance structures to oversee both generalist and specialist palliative care, ensuring it is forward-thinking, inclusive, and adaptable. It should prioritise equitable access for everyone, regardless of condition, and gather data on the current workforce to support its development and sustainability through proactive education and training. The strategy should aim to enhance service integration through improved communication and performance indicators, optimise the use of technology for better service provision and efficiency, and increase public awareness and engagement. Ultimately, a new strategy will help Northern Ireland improve the coordination of palliative care services, ensuring high-quality care that aligns with standards in other parts of the UK and the Republic of Ireland.

Any other comments

21 Any other comments

1500 characters:

The publication of the Irish Government's strategy starkly underscores the disparity in approaches to palliative care across the island of Ireland. While our counterparts in Southern Ireland benefit from 100% state funding for palliative care services, hospices in Northern Ireland are compelled to rely on local community fundraising to provide care for our dying patients. The annual operational costs of these hospices amount to approximately £34 million, with only approximately 35% of this amount covered by government funding.

Across the rest of the UK, your Ministerial and Health Committee colleagues in England, Scotland, Wales, and the Isle of Man have chosen to invest in strategic planning for the palliative care crisis that we face as our elderly population rapidly increases.

A strategy alone is insufficient; we need a guarantee of investment in affordable, accessible, and equitable palliative care. This commitment would enable individuals to experience dignified end-of-life care in their preferred setting, with the majority expressing a preference for care in their own homes.

We recognise there are pressures on our health care budget. However, the long-term costs of ignoring the need for a strategic approach to ensuring that the dying (irrespective of postcode or financial status) can receive compassionate and professional end-of-life care are huge.