

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals  
Submitted on 2025-01-16 22:34:08

## 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:  
Diane Walker

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:

No

1500 Characters:

I am the Macmillan Transformational Lead for Palliative Care in Northern Ireland and have managed the regional Palliative Care in Partnership Programme (PCiP) since 2016. Prior to that I worked on the Transforming Your Palliative & End of Life Care programme from 2013.

Personally I have cared for my father, my mother and my mother-in-law in their last years of life.

5 What is your organisation?

Organisation:  
Strategic Planning & Performance Group

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

Yes

1500 characters:

Macmillan Transformational Lead for Palliative Care (Northern Ireland), Palliative Care in Partnership Programme Manager

## current state of palliative care services

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

Good

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:

Despite improvement in this area there is still a general misunderstanding that palliative care is only applicable in the last weeks or days of life and only for people with terminal cancer. Unfortunately some of these misconceptions are also evident in the staff caring for people approaching the end of their lives across care settings.

There is much which needs to be done to improve the public's understanding of how a palliative care approach can support quality of life and aid planning for a dignified death in line with the person's wishes and preferences.

I believe there needs to be a greater cross-departmental focus on a public health approach to palliative care including improving death literacy, promoting public awareness of death and dying and implementing the Regional Advance Care Planning Policy published in 2022.

## Access to services

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

Not sure

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

1500 characters:

Progress has been made in recent years to expand the reach of palliative care services to people with conditions other than cancer, across geographies and into the community (people's homes and care homes).

However, service activity and data reporting across palliative care services (systems and providers) is inconsistent and disjointed. The full implementation of encompass will seek to provide better data in the future. In the meantime, it is difficult to assess the accessibility of services without better data and a full population based needs assessment for palliative and end of life care.

From the limited data we have, we know specialist palliative care services are still predominantly being accessed by people with a cancer diagnosis and the geographical location of SPC inpatient beds may not be aligned to the local needs. Under the PCiP Programme some work has commenced looking at the specific needs of the LGBTQIA+ community, at palliative care within prisons and for people with learning disabilities but due to resource constraints limited progress has been made in these areas.

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:

In order to provide appropriate palliative care we need to identify people early enough in their disease trajectory to ensure timely intervention and meaningful planning. Early identification of palliative care needs is key to this process, often opportunities to provide palliative support and plan ahead can be missed because people's needs are not identified or communicated to them in a timely manner.

Earlier identification of palliative care needs using regionally agreed tools such as SPICT or AntiCiPal need to be built into practices in both primary and secondary care and targeted education and training for generalist healthcare staff across care settings would support improvements in people being identified earlier.

12 What additional services could/should be provided?

1500 Characters:

The SPC Workforce Planning Report developed by the PCiP Clinical Engagement Group highlighted the gaps in multidisciplinary SPC staff (AHPs, Pharmacists and Social Workers) required to meet population needs. As per recommendations from the National Audit for Care at the End of Life (NACEL) serious consideration needs to be given to 7 day SPC services and access to 24/7 SPC advice.

Social care services which support the changing needs of people who wish to be cared for in their own home (especially when they live alone) need to be considered within the context of social care reform, as too should the need for more care home beds to meet the needs of our aging population in their final years of life.

A full population based needs assessment is required to fully understand the requirements for additional services.

## Integration of Services

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

1500 characters:

Integration of palliative care services differs across HSC Trusts given the mix and range of providers (generalist and specialist) operating in each area. The Palliative Care Locality Boards set up within the Palliative Care in Partnership structure are a vehicle for the co-ordination of services in each area and again good progress has been made in the last number of years in many areas.

When patients are identified as likely to be in their last year of life they should be allocated a palliative care keyworker (usually the District Nurse) who will co-ordinate their care. A QI Project running regionally within District Nursing has shown steady improvement in patient outcomes when a palliative care keyworker is involved with a high majority of people achieving their preferred place of care at the time of death.

Where co-ordination of care is known to struggle is when patients change care settings (i.e. admitted to a hospital or care home or discharged from a hospital or hospice) and also during the out of hours periods where fewer services are available and when patients and those important to them feel most vulnerable.

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

Not sure

1500 characters:

The majority of palliative care is provided by core (generalist) healthcare professionals working locally across care settings and is an inherent part of their roles. This level of care is not specifically commissioned and nor should it be. However, these staff would ultimately benefit from regionally agreed standardised and accessible training in supporting people with palliative and end of life care needs.

Currently there are a range of specialist palliative care and enhanced services operating across Northern Ireland. These services have evolved over time responding to local needs but without regional strategic overview. A number of these services were already in place prior to the Living Matters, Dying Matters Strategy and as the strategy did not have an accompanying funding stream there has been limited opportunity since its launch for a strategic review which could lead to system change.

Generalist palliative care will always be delivered at a local level however SPC as a specialist service has the potential for a regional delivery model but in order to inform a position on this further data is required with regards to current SPC service activity and performance and a population- based health needs assessment.

15 What can be done to improve integration?

1500 characters:

1. Regionally agreed service specification for palliative and end of life care
2. Agreed protocols for identifying people likely to be in their last year of life in primary care and when admitted or discharged from hospital.
3. Improved data sharing and systems across providers (which encompass will hopefully support in the future)
4. Improved reporting, monitoring and accountability across providers

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:

- Just in Case (Anticipatory Medications) initiative implemented across the Western Trust, now spread to Southern Trust and being piloted/ considered elsewhere.
- Regional District Nursing Palliative Care Keyworker QI Project being led by PHA
- Belfast Community Palliative Care Hub project being led by Belfast Trust to co-ordinate SPC services across the Trust
- Work by the Southern Trust SPC Team to identify when patients known to their service are admitted to ED and support pathways to get them back home as soon as possible where practical..

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

Not sure

1500 Characters:

If a person is appropriately identified and has a palliative keyworker or is under the care of an SPC service then yes I believe in the majority of cases the patient and those important to them receive good support from services.

Unfortunately, many people are not identified in a timely manner or are not adequately communicated with about the progress of their disease trajectory and therefore opportunities to provide support or access services are often missed.

The public perspective and understanding of what palliative care is can often lead to miscommunication so improving death literacy and public willingness to talk about death and dying is key to empowering people (or those important to them) to take more responsibility in shaping their own end of life care

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:

The Living Matters, Dying Matters Strategy did not have an accompanying budget and there has been no significant Departmental investment into palliative and end of life care since it was published. Despite this progress has been made in developing the services but these have been supported in the main by charities either through new services brought about by our hospices or the pump-priming of SPC posts into our Trusts funded by Macmillan.

The regional Palliative Care in Partnership programme staff infrastructure was funded in full by Macmillan from 2017- 2024 and my role as Programme Manager for the programme continues to be funded fully by Macmillan.

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:

The promised Regional Review of Specialist Palliative Care Services needs to be progressed to fully understand the existing activity and performance of SPC services across the system including hospices. The hospice sector has a key role to play in the provision of SPC services to the population of NI but the current commissioning arrangements and contracts were made historically when the landscape of SPC services from other providers was very different.

A full strategic review with input from all partners is required to inform a new model of SPC delivery which will meet the needs of our population where they want to be cared for and inform future commissioning decisions.

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

Not sure

1500 characters:

The Living Matters, Dying Matters Strategy is officially out of date but many of its recommendations are still valid and with accompanying investment could be actioned. The work of the Palliative Care in Partnership programme and its priorities are live and keenly aligned to the strategic direction of Living Matters, Dying Matters and palliative care frameworks and strategies from elsewhere (including Scotland, England and ROI). The PCIIP Programme has a robust infrastructure and is well supported by key partners, however, the majority of the regional palliative care workplan is being progressed with zero budget.

Whilst I think a new strategy is an key ambition for the future, I also believe a co-produced strategic and costed Action Plan for palliative and end of life care would enable the partnership to continue to improve support and services for people with palliative and end of life care needs and those important to them in the meantime.

Any other comments

21 Any other comments

1500 characters: