Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-16 17:27:56

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 my response but keep it anonymous.

Who are you?

2 What is your name?

Name:
[redacted]

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:

[redacted]

5 What is your organisation?

Organisation:
[redacted]

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

Yes

1500 characters:

[redacted]

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:

You would need a 'Death literacy' study to ascertain current Northern Irish general public's understanding of words and phrases associated with 'palliative' care to appreciate this
Barriers include language used
- Lack of clarity on definitions professionally – euphemisms frequently used.
- Tendency to want to ‘soften’ palliative to avoid WHO definition relating to 'life-threatening disease'. (EG using phrases like lift-limiting which is untrue and unhelpful). Knowing the 'would you be surprised if this person died in the next year' question is helpful.
- ‘End of life care’ is a vague statement without consensus. ‘Last days’ care is more helpful.

Other barriers include huge number of charities involved in providing care and patients and families are unclear of what is available and who can help with what aspect of care.

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:

- Huge regional variations in NHS and charitable funding/services/staffing available in various regions.
- Variation in accessibility for patients with malignant verses non-malignant diagnoses.
NHS co-ordination is the major gap! Allowing non-NHS charitable services to open services as the charity decides rather than being guided by the needs of the population.
- Medical charities need to self-promote and so services often driven by what is considered popular or fashionable at a time rather than needed or science driven.
- Gaps most pronounced in Northern, Western and Southern Trust 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:

POLITICAL BARRIERS
At a very basic level, the political blocking of Regional progress on a simple, INDIVIDUAL LAST DAYS CARE PLAN which general staff can use to improve last days care for patients dying in hospital, is a huge barrier. Why does the Northern Ireland Assemble not call for this? This is a simple core tool which would support good last days care in hospitals. Training could be provided online on HSC learning to relevant staff (as many other training modules are).

SPECIALIST PC
- Inadequate funding. But also, where is the funding going to? Does anyone know how much is spent by the NHS and charities combined on Palliative Care in Northern Ireland? Where is it spent? How is it spent? Is it spend by people who have a clear understanding of what the palliative health needs are? Is the funding spent fairly across the province?
- Why isn't Specialist Pall Care commissioned and co-ordinated?

12 What additional services could/should be provided?

1500 Characters:

- Clear regional commissioning of services.
- NHS run inpatient palliative care beds (similar to Antrim Unit or Omagh Pall Care Unit). It would be helpful to run a cost analysis on cost of our current NHS run inpatient units compared with privately run hospices.
- NHS run Specialist Palliative Care Community Team services – Southern Trust only Specialist Community Palliative Care MDT run by NHS.
- Clear regional commissioning of services.
- NHS run inpatient palliative care beds (similar to Antrim Unit or Omagh Pall Care Unit). It would be helpful to run a cost analysis on cost of our current NHS run inpatient units compared with privately run hospices.
- NHS run Specialist Palliative Care Community Team services – Southern Trust only Specialist Community Palliative Care MDT run by NHS.
- 7 day hospital palliative clinical nurse specialist service
- 7 day community palliative clinical nurse specialist telephone service
- 7 day community assess to core palliative drugs

Integration of Services

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

1500 characters:

In Southern Trust
- Community Specialist Palliative Tem well integrated with GP/DN as NHS run. (Only Trust in NI).
- Hospital based Palliative Care Team well integrated.
- Current charitable organisations in area not well integrated. (4 operational in our area)

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

Not sure

1500 characters:

Specialist Palliative Care should be properly commissioned.
Palliative Care should be a legal right.

I am not sure a regional specialist service would be any better if the resources (funding and staffing) are still kept in Belfast or SE Trust.

15 What can be done to improve integration?

1500 characters:

A science based Public Health approach to the needs of palliative patients - to refocus both general and specialist palliative care priorities through NHS structures (which charitable organisations can fund if they choose to). But NHS run.
Strong leadership.
Commissioning.

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:

I am not sure we need pilots and services. We need the common sense simple basics done well. I'm not sure chasing after the next new shiny programme is helpful.

We need to remember that 95% of care provided to patients and relative during dying, bereavement and death is provided by the community. Healthcare provided 5% so ensuring we are providing good safe professional advice is crucial.

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

No

1500 Characters:

There is no such thing as 'sufficient support'. There is always more needed and more which could be done.
Also, we need to remember that 95% of care provided to patients and relative during dying, bereavement and death is provided by the community. Healthcare provided 5% so again, ensuring we are providing common sense, practical advice is crucial.

Funding and Strategy

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

Not sure

1500 characters:

It would be very difficult to work this out.
If we think of specialist services only; how much goes from NHS to hospices? Then how much from fundraising? When a hospice runs inpatient beds - how much does this cost per pt per night? How does this compare to an NHS inpatient unit? Is running a hospice as a private hospital the best value for money?
How much is spent on the doubling up of services in a particular area?
How much is spent by all the various charities for community support?
How much does the NHS spend on its various specialist services?

It is a lot more complicated than saying 'we can't run a service on coffee morning donations' - because you can't ask the NHS to write a blank check. An element of quality has to been value and I don't believe anyone knows how much (donations and from taxing) we as the people of Northern Ireland, are spending on specialist palliative services or where the money is going to. Or if it is being spent in the best way possible.

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:

Of course it is not enough to fund the current 6-plus major charities or the work they do.

But the answer is not more simply money. Where is that money coming from and where is it going to? What are the key priorities and what are the 'nice luxuries'?

We will NEVER be able to offer weekly reflexology to all patients and their carers in their last year of life. So what are the big priorities? What do we want to pay for?

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

No

1500 characters:

We have the information and the specialist expertise to decided what needs done. (And no, it wouldn't be perfect but we could go back and get the basics right.)

I am not sure wasting energy, time and money to listen to everyone's opinion for a few years before coming out with a lengthy/unreadable document with vague principles and flowery-statement will help anyone in their last year of life. Will it?

Any other comments

21 Any other comments

1500 characters:

Please consider listening to your NHS Palliative Medicine Specialists. Please consider taking a pragmatic view.
Something you can do today, that will cost very little money:
- call for a REGIONAL LAST DAYS INDIVIDUALISED CARE PLAN to support the care of people dying in hospital.
- Ask the 3 Regional Specialist Palliative Care Groups to write it (Medics, nurses and pharmacist) and have it approved regionally.
- A training video for doctors and one for nurses can be made (with a short multiple choice quiz at the end like we have to do for other mandatory learning modules) can be made an on HSC learn within 6 months.