

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-11-13 09:24:58

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?

No

1500 characters:
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?

Not sure

1500 Characters:
The term Palliative Care is used frequently by health care professionals but I am unsure if patients would be clear re what it means to & for them. Everyone's prognosis and disease trajectory will be different and this makes the term very broad.

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:

District Nurses are the Palliative Care Key Workers for all patients requiring care at home, they provide holistic person-centered care, co-ordinate services and aim to manage the patients' symptoms alongside supporting families, friends etc

However not all areas in NI have the same capacity and demand due to vacancies and sickness and therefore palliative care varies.

The DN Service led by myself have formatted a DN Palliative Care Nursing Quality Indicator and are able to measure several aspects of care in this area, with continual improvement noted since Jan 2023. We continue to aim for the best care regardless of where people live and we have received much feedback via Care Opinion re Palliative Care provision in DN to date.

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

Not sure

1500 characters:

Some barriers exist if there is a later than expected referral to Specialist Palliative Care or District Nursing resulting in later assessment of need or if there are not the right staff with the right skills available when needed.

Rural v Urban challenges may also exist as result of challenges with time needed for staff travel/ equipment provision etc

12 What additional services could/should be provided?

1500 Characters:

Clearer public messaging re Palliative Care-what it is and what it isn't

Regional education re Palliative Care for all HSC staff (currently being scoped)

More compassionate community focus

Integration of Services

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

1500 characters:

Palliative Care delivery varies across Trusts and across Primary Care depending sometimes on people to lead rather than processes in place.

District Nurses sometimes get later than required referrals from Secondary Care with inadequate information and at that stage the patients are very ill and possibly nearing the end of life

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

Not sure

1500 characters:

It is provided regionally but every Trust seems to be working at different speeds and focusing on a variety of areas which could be both time consuming and could be financially inefficient.

15 What can be done to improve integration?

1500 characters:

A greater focus not just on what the patient needs now but also on the next step of their journey ie advance care planning

Encompass may improve communication in this area

Looking at holistic Palliative Care needs in relation to what can be offered instead of working in silos for example Pharmacies/GPs/District Nurses/Specialist Pall Care Nurses/Secondary Care with the patient at the center of their work

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:

District Nurses in NI are the Palliative Care Keyworkers for patients, there is a regional quality indicator ensuring they provide excellence regionally and this is monitored quantitatively monthly and qualitatively via Care Opinion and Complaints/SAIs which all Trusts access and I have regional sight of.

We work regionally and aim to learn together & share good practice.

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

Yes

1500 Characters:

I can only speak for District Nursing and I am confident that the patients on DN caseloads are cared for holistically and families are also supported well on this journey.

I am happy to be contacted if required

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:

I do believe that Hospices are a vital part of the delivery of this care and they depend too heavily on charity!!!

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:

With increasing deaths moving forward Hospices definitely need more sustainable funding and other areas need consideration too.

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:

Need to look at new HSE Pall Care Strategy first to see what it adds to our current work.

Any other comments

21 Any other comments

1500 characters:

Everyone is entitled to the best possible palliative care and as professionals we only get one chance to do this right.

We need the best equipped workforce, processes and systems that support our work & integration with other areas in addition to a culture that is motivated, compassionate and person-centered.

Our patients need improved health literacy to know what this stage means for them and their families and communities need to be engaged & compassionate.