

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals

Submitted on 2024-11-13 10:43:40

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:

Physiotherapist

Community Palliative Care Lead [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:

Community Palliative Care Lead

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:

Terminology- believe palliative care to mean end of life care

Unaware that it encompasses so much more than oncology

Unaware of the specialist services that palliative care professionals can provide e.g. pain services, breathlessness management, fatigue, palliative rehabilitation

Confusing to access for public - multiple providers and pathways

Access to services

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

Yes

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

1500 characters:

Demand greatly outstrips supply of specialist practitioners
Some trusts have minimal to no community service
Acute hospitals have no palliative care AHPs who are the backbone of the community palliative care services alongside the hospice nurses (hospice nurses are not trust staff)
Issues with information sharing as different organisations and systems

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

Not Answered

1500 characters:

Not barriers as such to access but more public knowledge of what exists and how to access

12 What additional services could/should be provided?

1500 Characters:

Full community MDTs providing rapid access to address complex issues these service users present with - this would stop those palliative conditions spending hours in A&E and avoiding unnecessary hospital admissions at a time in their lives when every minute is precious.
Better interagency communication and collaboration in provision of services.
Hospice linked with each trust area for use by those residing in that area
Hospice services to be fully funded
Update and implementation of the workforce plan
Palliative care hubs in each trust to allow for rapid MDT assessment and facilitate earlier hospital discharge

Integration of Services

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

1500 characters:

Not well enough, better integration would benefit the public greatly
Barriers lie in governance arrangements and different recording and communication systems and structural differences in roles/grades

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

Yes

1500 characters:

Remove regional variation in services
Easier access and referral
Adequately staffed to fulfill demand
Already all island group - AllHPC and ROI has a comprehensive strategy and funding that goes along with it - it mentions all island collaborations too

15 What can be done to improve integration?

1500 characters:

Full Encompass access for hospices, NIAS and GPS - to allow everyone the same patient information system, overview of teams involved and safer practices.
Each trust being linked with a hospice - allows better integration as focuses resources.
NI Palliative Care strategy that aligns with ROI

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:

In reach [redacted] dietetics and speech and language therapists to patients in Marie Curie hospice (they only employ physiotherapists and occupational therapists as AHPs in hospice)
Joint working [redacted] community palliative care education and Marie Curie into healthcare in prison and NIAS

Communities of practice in palliative care started across whole of island for professionals e.g. physio, OT, SLT, dietetics to share best practice etc.

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

Not sure

1500 Characters:

Social workers who are specialist in palliative care need to be core members in community teams. They provide not only signposting to other services but support in navigating complex emotional, grief and social issues. They help with advanced care planning, supporting families and memory making to name a few things.

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:

Not even close!

Hospices rely on fundraising

Community AHP posts are mainly charitably funded and unable to keep up with numbers referred so need to prioritise patients (who would benefit from their services) out.

Need a workforce review and funding for full implementation

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:

See previous response

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:

Pinch with pride the ROI strategy!

Any other comments

21 Any other comments

1500 characters:

I would welcome any members of the health committee who would want to come out and meet with the community palliative care teams in trusts