

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-15 15:35:13

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:

SHSCT do not have a Palliative Care team specifically for U18.
My staff provide palliative care to children and families who are at end of life

current state of palliative care services

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

Neither

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:

Public would think Palliative Care covers end of life associated with cancer diagnosis, helping patients in pain and about to die.

Palliative Care within Cancer services, for both adults and children have received significant support through fund raising activities which has raised the profile of cancer services, but not for other life limiting diagnoses especially in CYP services.

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:

Under 18's in particular, no designated palliative care team regionally nor locally for our children and young people
No Regional Consultant lead in Palliative care in Children and young people services
Extremely limited funding for local Consultant lead in Palliative care for example local Consultant is funded for max 3 hours/week approx. to work in Palliative care
2 regional Macmillan palliative care nurses to support children and families throughout NI (not 2 WTE staffing)
NO paediatric professional training for AHP's

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:

No protected funding or staff to manage referrals for children who are palliative, this work is absorbed by core/existing services
Inequitable access to services within our own trust for CYP when compared to adult services, as there is an adult Palliative Care team.

12 What additional services could/should be provided?

1500 Characters:

A designated Palliative Care team for U18's - not sure how this would work best, could be regional team to support local teams, with emphasis on key worker role particularly with children and young people

More professional specific training for physio in Palliative care for U18's
Building resilience, advanced communication strategies -having difficult conversations
Knowledge and availability of complementary therapies
Support for staff who are working in Palliative care, around health and wellbeing

Integration of Services

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

1500 characters:

Dis-jointed between regional and local care, no outreach support for end of life.

Management of child in community should be by the team who know them best and have specialist skills in Palliative care, if services are well integrated there should be early identification of palliative care children, well before end of life.
Timing of referral to local services is vital in the best management of the child and support family

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

Yes

1500 characters:

Yes, to make it sustainable-
Right care right time right place.
Equitable service
Worth further discussion for Paediatric Palliative care team across the age spectrum
Local Community Nursing Teams cannot sustain current activity within Palliative care for support the child to die at home and often the child is in hospice/hospital

15 What can be done to improve integration?

1500 characters:

More regional work to review current palliative care pathways for CYP

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:

PEARL -C is in development within SHSCT as an educational resource for staff [REDACTED]

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

No

1500 Characters:

In CYP
No key worker
No designated palliative care consultant
No Designated MDT
Lack of psychology support
Lack of education and training for NHS and voluntary sector staff

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:

Only Palliative care funding in SHSCT is approx. 3 hours/week for a Consultant

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:

These families require significant support and there is limited funding for hospice at home or respite for these families.

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:

Please include under 18 in this new strategy

Any other comments

21 Any other comments

1500 characters: