

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-11-11 12:41:49

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?

No

1500 Characters:

This has traditionally been known as a service which inputs when the patient is at the point of end of life. Education is needed to explain that PCT can input at different points of the disease pathway. There needs to be a greater explanation that palliative care can support the patient and their families earlier in the pathway to provide good quality of life while on treatment which is to prolong life. They can support side effects of treatment as well as the psychological impact of their diagnosis.

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:

Adolescent and Young Adults. There are fab services for paediatrics and adults but AYA patients have a distinct set of needs which need acknowledged across all health services including palliative care.

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:

As above

12 What additional services could/should be provided?

1500 Characters:

The addition of AYA specific courses, modules etc in palliative care to support the PCT in supporting this patient group with confidence. I have recently worked closely with the palliative care team in relation to side effects with a young patient and it was a very positive experience because the understanding applied from PCT to AYA specific needs were so supported.

Integration of Services

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

1500 characters:

I refer to community teams but don't necessarily have any feedback as to how well it works. Patients describe their perspective and feel well supported but I'm not sure how the professional teams feel.

I know that any interactions I have had have been hit and miss. There isn't any case conferences as to how support can be given in a holistic way.

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

Not sure

1500 characters:

Not sure that a regional service will always support local teams effectively as resources can vary. I think there is something to be said for having a regional support network for staff.

15 What can be done to improve integration?

1500 characters:

There can be a feeling that when a patient is being managed by PCT that there is no need for input from hospital teams. An MDM which has true multi disciplinary input would support integration.

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:

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

Not sure

1500 Characters:

Sometimes families might have to work hard to access services rather than be offered services and opt out.

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'm not aware of the system for funding. We have a good sized team within the hospital I work in but they are stretched.

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:

It's very difficult to get a hospice bed unless the patient is clearly identified as very close to the end of life. There are no AYA specific beds in hospices. The community support is good but again very stretched.

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:

It needs to incorporate the entire trajectory of a disease to include side effect of treatment management, early conversations about when disease can't be cured and the support needed for patients on active treatment, AYA palliative care and what that looks like and palliative care MDMs that have attendance from the whole team.

Any other comments

21 Any other comments

1500 characters:

Thinking specifically about cancer, this is becoming a chronic disease with multiple treatment plans which prolong life but increase side effects. We need more consideration for this part of cancer care which is in the palliative setting. This will help people to have a more rounded quality of life as it will look at the totality of their illness, side effects of treatment and disease and also help with preparation for end of life so it isn't done at the very end. This will allow more open conversations between the patient and their family as well as their treatment team.