

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-17 14:42:13

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?

Yes
1500 characters:
Research Nurse

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?

No
1500 Characters:

Public considers pall care as end-of life care to be accessed by those who are actively dying.

Barrier to the public understanding palliative care include: lack of public campaigns, insufficient knowledge among healthcare professionals, taboo surrounding everything related to death & dying.

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:

There are huge inequalities between rural and urban areas (even the waiting times to access a pain relief could be 15min in Belfast compared to 2h in rural areas), differences between HSC trusts who commission different services in various areas.

Most of care and support is available in-hours (IH) with very limited resources out-of-hours (OOH). There is also an issue during the time between the services - when OOH is finished but IH are not yet operational.

Also, e.g. some DN are aware of pall care services and would actively promote these to service users, while others don't.

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:

Inconsistency among service provision between trusts. There should be one commissioning for whole NI to ensure consistent and equal approach.

12 What additional services could/should be provided?

1500 Characters:

More respite care by healthcare assistants overnight and during a day to allow carers time to recover from care duties. Rapid response services should be provided 24/7 across all areas by nurses with palliative care training and experience.

Integration of Services

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

1500 characters:

Big part of palliative care is delivered by charities. However, during some recent events I attended I noted that charity impact is ignored by those working in NHS and they only focus on NHS services. There is a lack of true partnership and equality among partners and all providers which are non-NHS are treated by NHS colleagues as 'poor cousins'.

NHS wouldn't even give access to Encompass to charity providers? So where is the integration here?

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

Yes

1500 characters:

Absolutely yes! I have already highlighted the issue of commissioning of different services across different locations in previous answers.

15 What can be done to improve integration?

1500 characters:

Improve the culture within NHS to ensure charity partners are treated truly as equal partners.

Ensure all service providers have access to Encompass.

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:

Rapid Response services by Marie Curie are an excellent example of service meeting people's needs during OOH period. This is not happening widely across Northern Ireland.

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

No

1500 Characters:

Families I visited often have no idea about the services they could access. District Nurses at times act as gatekeepers in some areas and don't share the information families need due to multiple factors (lack of knowledge about such services, staffing and workload issues, workplace culture, etc).

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:

The need is much greater than what is provided.

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:

I really don't understand why end-of-life care which is a core service, something that most of people will need is often depending on people fundraising through running marathons.

Are we fundraising to provide prescriptions for B12 injections, or for a hospital bed for a child in paediatric ward or for a salary for a surgeon? We are not, so why are we fundraising to care for the dying in their homes and hospices? We already pay taxes and they should be used to provide well-integrated services.

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:

Funding, service models, commissioning, promoting innovation within service delivery.

Any other comments

21 Any other comments

1500 characters:

Access to medication and to change prescriptions OOH is a big issue. Very few nurses can prescribe (those who can are not allowed to due to beaurocratic barriers), lack of GP OOH and extremely limited access to OOH pharmacies. Also, why 2 practitioners are needed to check CD drugs where there is no clear evidence that the practice increases safety? Yet, it uses unnecessary resources and prolongs patients suffering and causes families' and practitioners' distress.

Why not look out to other countries where e.g. family caregivers are trained to administer wide range of medication including subcut morphine injections. There is a growing evidence that the practice is safe and beneficial. Yes, trusts want to control all the care, refusing any innovations where there is even low risk involved.

People don't just need care 9-5, they don't die 9-5 only.

It's about time that services responded to the unmet needs and people's daily suffering.