Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-11-29 11:26:29

## 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:

No

1500 Characters:

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?

Very 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?

Yes

1500 Characters:

The public's awareness of palliative care reflects what they observe, that specialist beds are for those with cancer (not those with non-cancer illness) and accessible at the end of life. The limited specialist beds then leads to the public viewing those who are dying that are in need, on trolleys in A&E, waiting for GP out of hours or waiting for specialist community and generalist staff (who are already stretched) to come into the home. Many of the public also see their loved one moving into a care home as there is not sufficient resources to ensure their wishes to remain and to die in their home became a reality. So do the public understand - they understand that the premise of palliative care is a theory not a reality.

## 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:

On a personal and professional level the gaps in provision are huge. The gaps are as follow

- in the lack of identification/ assessment and recognition that the person has a life limiting condition among professionals is huge.
- in getting a person with a life limiting condition recorded on the palliative care register
- in getting services (joined up thinking) in the access of equipment, families having to push for equipment and then being told they cannot use it without training - causing delays
- in the number of specialist community staff
- in the number of hospice beds (hospices should not be charity funded)
- in the number of hospital hospice beds
- in out of hour care when families and patients are most vulnerable
- in the education and training of support workers - who pick up with majority of the personal care - they are not adequately trained in providing palliative and end of life 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:

- The barriers are due to multiple factors
a) lack of funding - which overrides it all
b) lack of joined up thinking and usage of existing resources
c) lack of planning to ensure the workforce has sufficient numbers and skills to cater to the need
d) lack of education for ALL professionals on palliative and end of life care

12 What additional services could/should be provided?

1500 Characters:

a) Out of hour services needs to think about a hospice linkage and/or palliative care consultants in hospitals
b) More single point of access that is 24 hr for those families who are caring for palliative/ end of life patients in the home
c) funding for hospices so that needed beds and community services do not need to be cut.
d) teams that are truly multidisciplinary and know the patient.

## Integration of Services

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

1500 characters:

They are not. The lack of sharing of data is key and may not change if the new data system does not collect palliative care details. As a carer I have experience of having to go through hurdles just to get to some services. Primary care is not working yet to get to specialist or secondary you need your GP. Its a farce and a lack of respect for those who are at the end of life.

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

Yes

1500 characters:

Yes a regional public and hospice service that are all funded.

Given the country's size we do not need several hospices under differing management - we should have a NI hospice with several sites - with specialist teams in the community, in hospice and in the hospital all working as one.

15 What can be done to improve integration?

1500 characters:

A overhaul of the service structure
attention to understanding the palliative care needs of the future and the levels of staff that are needed to respond to this change

## 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:

Good practice is ad-hoc and very dependent on staff who are not as yet burnt out delivering the best care.

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

No

1500 Characters:

Please, what a question!

No they do not receive sufficient support.

They do not know the system so have to learn it whilst taking on the role of a carer, which impacts on their health and quality of life.

When they do get access its at best piece meal which is very dependent on where you live and what you then can access.

No one teaches a carer about the system or how to care. Its just expected.

## 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:

Please!

We have had hospice beds closed, hospital wards closed, newly qualified nurses who can't get jobs in Northern Ireland.

Patients dying on trolleys or back of ambulance, families calling and waiting for appointments for months for loved ones, no care in the community with patients left on their own..... and people dying on their own at home, care homes, hospitals and hospices.

Funding is not and never has been sufficient.

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:

The aging population alone will tell you that demand will outstrip supply now and in the future. Combined with increasing complex conditions and lack of trained staff all means that we are not prepared.

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 Answered

1500 characters:

Yes there is a need for a new palliative care strategy with an overhaul on estimates for palliative care need to working solutions that reduce wastage and increase access to those patients who have palliative care

1 leading hospice
several hospice sites
speciality community teams that link to hospital and hospice
sharing of hospice staff with hospital's and vie versa
OOH services that are connected to hospices
have hospital areas for hospice
more emphasis on education for all for those who are dying

## Any other comments

21 Any other comments

1500 characters:

none