Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-06 16:43:24

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:

Palliative Care Service Improvement Facilitator - as above. Working alongside teams in the trust to support provision of palliative care services and development of services. Also working in the community to develop a public health approach to palliative care - helping communities develop a culture of being able to feel empowered to support people they know living with palliative conditions and through grief and bereavement

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:

People still associate palliative care with end of life and dying - that's not just the public, it's also within healthcare professionals. There is a general taboo in our culture around talking about death and dying. Palliative care has been medicalised - seen as the work of hospices and specialist teams. People forget that so many conditions are palliative and that people live with them for years and years ago, communities cared for each other. That palliative care is provided by all health care professionals and many voluntary/statutory organisations have a huge role to play in this. There needs to be more

interaction with local communities - a compassionate community approach - starting with schools and young people, empowering people to be able to have these conversations, know what is available, what is normal in living and dying and be able to support each other. We try to go out to/create public events - people will not come to events about palliative care - we use the arts, chatty libraries, community group events, farmer's lunches, schools arts projects, offer community volunteers/organisations training etc - there is limited time and funding for this and it needs to be invested in more.

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:

Within Cancer services the emphasis is definitely on acute cancer, not advanced cancer.
The Hospice tends to see a majority of those with cancer - what about other conditions?

Physical symptoms tend to be catered for - lack of psychosocial services eg counselling, psychology and spiritual support.

Rural communities are disadvantaged eg Out of Hours services - one o- call nurse at night - how do they get to Carrick, then Causeway when people waiting for pain medication.
Centralised services eg Antrim Hospital - transport links poor. There aren't the staff to take services out to the communities - we don't have one full palliative care team for the Trust, despite being the largest geographical trust in NI.
Digital - online services - many people do not use this.
Learning Disability - conditions still diagnosed at late stages. New resources available but there needs training for staff, organisations and families in this area. Regional working group needs someone to lead.
Different communities/cultures - appears unfair representation of these groups within services - why not?
Homelessness - we supported our homelessness nurse with info re palliative care. She requested training for regional colleagues.
Severe mental illness - very different life expectancy in this group. PhD ongoing with Marianne Tinkler but outcomes from her work should be applied regionally.

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:

Working in silos - eg cancer services and palliative care in different directorates in trust. Lots of teams eg dementia, LD, mental health - how do we join this up more

Competing for funding - a lot of palliative services are provided by charities and they need to receive funding - this often can depend on outcomes and recognition of this - I think it can understandably lead to competitiveness and a need to protect work yet the work needs to be done with a wide range of partnerships.

Lack of staff knowledge/training and exposure to some differences - eg Mental Health, Learning Disability, different cultures etc

Geographical including transport networks, internet access

Lack of staff - covering the essentials. Can be a postcode lottery as to what service you receive.

12 What additional services could/should be provided?

1500 Characters:

Public Health Approach - fund roles to go into schools/communities to upskill communities and groups on how to support each other and have knowledge about palliative care, grief and bereavement. Use these people to create networks and work with groups, especially those with little voice, to find out what they really need and work alongside them to produce creative solutions.

psychological and spiritual support services - if people were supported earlier and learned some coping strategies they would have the skills to help throughout the condition and for those in future around them. Create roles so that staff have time to input into local community groups to build skills in the community so people can support each other.

One stop shop services - cancer has macmillan information and support services - for other conditions who do they go to?

For our [redacted] specialist community palliative care MDTs - they can see complex needs but also work to advise and upskill generalist, improve services and connect with the public to identify gaps and empower local communities. Despite being the largest geographical trust we have no full SPC community team to cover even one area - we have one SW and one dietitian.

Integration of Services

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

1500 characters:

Varies - some excellent egs of team working but from what I see often tends to depend on the interest and passion of the individuals to maintain this.

The DN in our trust is the key worker in community for palliative care. We provide a range of training opportunities and action learning sets to support them, plus resources. It is difficult to maintain this as the teams are constantly changing - there are continually people leaving the profession. This job is demanding and under resourced given their key role in the health care in community. It should be invested in. They are the one service who cannot refuse to take a referral and so should be key to resources.

In our trust specialist palliative care in the community is almost non existent outside the NI Hospice nursing service. It makes it difficult to form wider networks/teams. Staff have little time to attend team meetings to discuss patients.

GPs appear under a lot of pressure - it is difficult to know how to update re the different developments and ensure awareness and referrals to new or established services.

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

Not sure

1500 characters:

There are a lot of areas that should be developed regionally eg LD is a small specialty - it needs a regional approach and although we as local professionals are trying to develop this, we are finding it difficult to get who can lead on this.

In our trust we've developed a toolkit for advanced cancer - it should be further developed as a regional resource but it needs a central person to take the lead and have the time and resources for this.

There are definitely limited funds and organisations competing for this - doesn't encourage good close partnerships.

Different areas have differing needs - how would these be addressed equally?

15 What can be done to improve integration?

1500 characters:

Awareness of the palliative term - all health care professionals aware they have a role in this and the training to feel skilled and aware of supports and resources
Investment in DN role as key workers to have skills and time to link with others and fulfill the role adequately
Fully established SPC teams in each area to work alongside the teams in partnership
Review how funding is created for various groups to reduce need to compete. Could there be a way of a regional view of the services and each take on roles within the services and do them well, so there isn't need to compete and it's more a collaboration
Identify leads with time and resources to support regional working groups eg homelessness, LD, mental health, advanced cancer etc.

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:

The need for our advanced cancer toolkit was identified by service users (SU) and co-designed by SUs. It has been recognised regionally and by Macmillan at UK awards and is to be developed regionally - however it needs continually developed and reviewed with wider SU input, regional professionals input, different media etc and this takes resources and time including a project lead regionally.

Our public health approach - developing a compassionate community to empower and equip people to support their own communities. As an eg... One project our team did was into schools alongside Cruse with a grief ally and art workshop to help pupils understand palliative care, grief and how to support each other. This is building resilience in young people for skills needed later - several pupils were currently experiencing bereavement. Teachers requested further training and wanted this provided to other schools. There are examples of compassionate schools initiatives in UK with project leads funded for this.

Rural communities - we are working with Ulster Farmer's Union, HWB team to bring info and resources to the farming communities through events, the arts and key speakers. There is a format that could be rolled out regionally.

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

No

1500 Characters:

especially regarding respite and out of hours services - including advice and sitting services etc.

also psychological and spiritual support.

It is also hard at times for families to know who to turn to.... there are many people often involved in care and conditions are complex

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:

I don't know enough about the funding regionally for palliative care so my answers are local.

We have been wanting a full community SPC team for years but there is no funding. We're the only trust who do not have this. It is difficult for the team to function - well it really isn't a team, but to function as a holistic resource if it doesn't have the key players.

I also think the palliative care public health approach including advance care planning is one of the key priorities but is not considered when it comes to funding

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:

NO - also the way hospices is proving difficult already. they've had to cut services and it also causes difficulties in team working and collaboration across the trust. How can they plan for the future if they don't have a dedicated sustained funding.

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:

Key priorities

how to engage underserved groups - involve them in the development of the strategy

Assign leads for different areas and form groups to work together

how to ensure everyone in health sees a role in pallaitive care

reinforce holistic approach
public health approach/compassionate communities - give it proper credibility

Any other comments

21 Any other comments

1500 characters:

there is a lot of good work going on. j

we should not reinvent the wheel

find a way that we can share what is happening across different areas and create people/leads who will help groups develop work in a regional way

if we don't get it right and feel we are doing our best, there's no second chance. Staff need to feel able to do their best to be able to continue in their roles and maintain the compassion for what they do.

there also needs to be some way of supporting staff psychologically - this should be appreciated to be time within their jobs.