

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-17 10:52:05

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:

I am an Advanced Nurse Practitioner in District Nursing. I have also previously worked as a district nurse where my role included that of a Palliative Care Keyworker (PCKW). I have an interest in palliative care services through my experience of caring for patients and their families throughout their palliative care and end of life care journey. I believe that people should be given the choice of where they wish to die and that their wishes are respected. The PCKW is the linchpin of this service delivery in people's own homes through coordination of care, support to caregivers and providing timely access to services.

5 What is your organisation?

Organisation:
[REDACTED]

6 Do you currently work in palliative care services? If Yes, in what capacity?

Yes

1500 characters:

I am an Advanced Nurse Practitioner in District Nursing. I have also previously worked as a district nurse where my role included that of a Palliative Care Keyworker (PCKW). I currently visit people in their own homes and assess their needs. I prescribe relevant medications specific to the patient's symptoms and provide a management plan to help avoid a crisis. I ensure the patient and their family have up to date contact information for healthcare professional and out of hours services. I provide support and education to district nursing teams when required. I have completed two pieces of research regarding the Palliative Care Keyworker (PCKW) role and how it impacts patients and their caregivers. I aim to further my studies with regards to how the role can be best supported by organisations through appropriate education and support.

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:

Most people will have been affected by someone close to them having a terminal illness, though their experiences may differ depending on their knowledge, where they live and the support they have received. I believe that public understanding of the term palliative care varies depending on experience and health literacy. Some areas of Northern Ireland have better access to Community Palliative Care Teams and will therefore experience a different palliative care journey. Through my work as a PCKW, I have educated patients and families on what palliative care means to them. Some of the barriers to public understanding are that it is a 'taboo' subject with some people not wanting to talk about it as there is a preconception that it is when a person can no longer take care of themselves. Families believe that palliative care means that death is imminent when that may not be the case. Also, the public are not fully aware that cancer is not the only disease that can cause a person to require palliative care, it can include diseases such as dementia, COPD, neurological conditions. From my experience, people who have an understanding of what palliative care means, are less fearful of death and are also prepared for end of life care. It provides time to listen to what is most important to the person receiving palliative care.

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:

Some areas of Northern Ireland have better access to Community Palliative Care Teams and will therefore experience a different palliative care journey. The Palliative Care Keyworker (PCKW) role in community settings is generally the district nurse. There is documented evidence that highlights the need for regional robust education and support of the role to ensure that every person in Northern Ireland receives the same coordinated care when they need it. I believe that we also need to expand our homecare services such as healthcare assistants. We could use our workforce effectively by training healthcare assistants and families to help provide aspects of palliative and end of life care to patients. Equipping them with the tools they need to know what signs and symptoms to look out for and have contact numbers for services readily available to them.

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:

I believe some of the barriers to accessing palliative care services are that not all services are available in all areas. Some the public are not aware of the services available to them, therefore do not know to ask for them.

12 What additional services could/should be provided?

1500 Characters:

I feel that every trust in NI should be allocated a Community Palliative Care Team, lead by a palliative care consultant with a team of multiple professional including nurses, physios, occupational therapist and social workers. every district nurse should have access to regional PCKW training to equip them with the knowledge and competencies to provide high quality palliative care. Patients should have access to transport to hospital appointments, particularly in rural areas and those living in areas of deprivation. we should be non-judgmental in our approach to caring for the public as we may not always be aware of someone's personal circumstances.

Integration of Services

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

1500 characters:

I feel that communication in the past has been variable between primary, secondary and specialist care making caring for someone requiring palliative care difficult. I hope that Encompass will help to remedy this when all 5 trusts are live and when GPs are able to join.

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

Yes

1500 characters:

Most definitely. A regional service will result in equitable care for all no matter where a person lives. A regional service would be beneficial to the patient and their family as they would be assured that they would receive high quality palliative care. It would also benefit healthcare professionals to be able to work as a network of people providing palliative care to our population.

15 What can be done to improve integration?

1500 characters:

Encompass is one step forward but this will not prove fully effective until all elements of the healthcare service are embedded in the system. setting up regional group meetings would be beneficial for professionals with some including PPI involvement.

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 district nurse carries the title of 'Palliative Care Key Worker' (PCKW) in Northern Ireland. This is in addition to their other duties undertaken as a District Nurse. This role is instrumental in coordinating care for the patient and their families to aid a seamless palliative and end of life care journey. This role is bespoke to the patient and individualised care is delivered to meet the needs of the patient and family. Research has shown that family care givers and patients value this role as it supports them through a difficult time in their lives. The district nurse provides physical and emotional support when it is required. They also are a single point of contact for families which helps to lessen the burden that is already present when caring for someone who has palliative care needs. Though families recognise the pressures that district nurses face in their day to day work and carry heavy caseloads which can impact on whether families contact the PCKW/DN in a timely manner.

This role is embedded in the district nursing framework, though its implementation is not standardised with all five trusts doing different things such as the training requirements needed to carry out the role. Some trusts have eight days mandatory training and some have two.

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

No

1500 Characters:

I believe that there are too many occasions where families are referred to services when it is too late and their loved one has already entered the end of life phase of their illness. If these patients were referred to appropriate services such as the PCKW when a palliative diagnosis has been given, patients wish's could be discussed and action plans put in place.

The knowledge and education that people have regarding palliative care and what is available to them plays a major role in how and when families access services. If they don't know they exist, then they don't know to ask for them. They rely on healthcare professionals to guide and direct them for equitable access to appropriate services.

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:

There will never be enough funding for this area but if the money we have was utilised and directed towards the areas that are failing, then this would help to improve patient experiences. I feel that funding should be spread out among cancers services but to also include areas where palliative care is often excluded such as dementia, respiratory illnesses, neurological disease and other chronic conditions which are incurable.

I believe there could be more funding made available for staff training and awareness throughout the hospital, community and voluntary sectors.

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:

There is more scope for further education staff in these areas and to increase the hospice workforce. There is a need to increase the bed capacity as palliative care is increasing year on year.

community palliative care teams are not in place at a regional level with some trusts relying on district nursing services (which are not always 24hr).

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:

New ways of thinking to inspire those already in roles where they could make a difference. Listening to the views of healthcare professionals who deliver palliative and end of life care. I feel emphasis is required to deliver this care in the community setting but upskilling our health care assistants and developing the role of the palliative care key worker.

Any other comments

21 Any other comments

1500 characters:

No.