Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-05 19:26:48

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 response.

Who are you?

2 What is your name?

Name:
Corrina Grimes

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:

Previously worked as a:
Clinician in a Specialist Palliative Care Team in Northern Ireland
Palliative Care Commissioner and Policy (development and implementation) in Northern Ireland
Palliative Care in Partnership Clinical Lead for Northern Ireland
National Deputy Director Community Health Policy NHS England

Currently :
Atlantic Fellow at The Global Brain Health Institute (Brain Health & dementia) & Research Fellow (Palliative Care) - Trinity College Dublin
Associate Consultant at HSC Leadership Centre

5 What is your organisation?

Organisation:
Response as a individual

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?

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:

I think in recent years there has been improved understanding of palliative care by the public, through the work of the Palliative Care in Partnership programme and respective members, and the work of the All Ireland Institute's (AIIHPC) yearly palliative care week campaign, however there is scope to improve understanding of palliative care. Not just for the public but also those who work within the health and social care system.
The main barriers are :

Historic background to palliative care - funded for cancer and those at end stages of life.
An emotional response to the subject of progressive illness, and the association with dying and death.
The commissioning and operational arrangements for generalist and specialist 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:

1. Workforce capacity - the first interdisciplinary workforce review for medical, nursing, AHP , Pharmacy and Social Work was completed remains unpublished. This outlines the workforce requirements.

2. Implementation of "For Now and For the Future - An Advance Care Planning Policy for All Adults in Northern Ireland".

3. Funding for the delivery of the Palliative Care in Partnership workplan and the commitments in New Decade New Approach including 7 days specialist palliative care advice service, day hospice community model, palliative care pharmacist and 'Just in case boxes', full role out of Palliative Care keyworker.

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:

Barriers include -
Absence of palliative care in strategy documents such as the draft Programme for Government, Public Health Agency draft Corporate Plan.
The funding model for generalist and specialist palliative Care services.
Developments in specialism in medicine, can lead to less holistic approach to an individuals needs.
Reduced capacity in primary care
Access issues for certain groups - Deaf community, Prison population, certain conditions - eg renal , heart failure , MND

12 What additional services could/should be provided?

1500 Characters:

1. Workforce capacity - the first interdisciplinary workforce review for medical, nursing, AHP , Pharmacy and Social Work was completed remains unpublished. This outlines the workforce requirements which should be provided.

2. Implementation of "For Now and For the Future - An Advance Care Planning Policy for All Adults in Northern Ireland" to enable all adults including those with palliative care need to have the care , support and treatment in line with their wishes.

3. Funding for the delivery of the Palliative Care in Partnership workplan and the commitments in New Decade New Approach including 7 days specialist palliative care service, day hospice community model, palliative care pharmacist and 'Just in case boxes', full role out of Palliative Care keyworker.
4. Regional provision of generalist palliative care services such as acute care at home which is not available in all areas in NI.

5. Palliative Care interventions such as blood transfusions, paracentesis to provided 'out of hospital.
6. Omagh Hospital have palliative care beds - which provides step up community care for those with palliative care needs. This model could be explored in other localities

Integration of Services

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

1500 characters:

There has been significant improvements from 2016 but there is scope for further integration, including with HSCNI and charity sector and also integration within public health.

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

Not sure

1500 characters:

I'm unsure what the question is asking.

There should be regional principles - such as services specifications, commissioning and policy developments.
The Palliative Care in Partnership (PCiP) programme was officially formed in Northern Ireland in September 2016, bringing together previous structures and workstreams from Living Matters, Dying Matters (2010) and the Transforming Your Palliative and End of Life Care programme (2013 – 2016) and taking cognisance of recommendations from the RQIA Review of Living Matters, Dying Matters (2016) and the key findings of the Let's Talk About Palliative Care Survey (2016).

The Palliative Care in Partnership programme is based on the following principles:

One structure, one regional work plan and one direction for palliative care in Northern Ireland;
Good palliative care is everyone's business – no one service, professional, organisation or person can provide everything required to support a person at the end of their life.

A regional specialist palliative care service could be explored as a potential model , particularly given the challenges in recruiting SPC medical consultants.

For those with palliative an end of life care needs , continuity ad strong links with their GP practice, primary and community teams is imperative.

A very response, needs led service is required.

15 What can be done to improve integration?

1500 characters:

Continued effective clinical and system leadership and accountability ,through the Palliative Care in Partnership (PCiP) Programme. (see question 14)

Revised and published PCiP programme mandate and workplan

Funding for the delivery of the agreed PCiP workplan

Corporate prioritisation of palliative care from Pfg, DOH, SPPG, PHA , Trust and other providers, RQIA and other arms length bodies such as PCC.

Focus on realistic medicine and advance care planning

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:

There are numerous examples of good practice - mostly detailed with the Palliative Care in Partnership Programme.

1. Early identification of those who could benefit from a palliative care approach - AnticiPal , which increased identification up to 70% of participating GP practices - pilot ended.

2. Palliative Care Keyworker - typically the District Nurse - rolled out across NI
3. Palliative Care Rehabilitation - lead by AHPs - no community provision in some localities.
4. Pharmacy - Just in case box - pilot but not fully rolled out.
5. Specialist Palliative Care advice - 7 day per week - not commissioned.
6. Advance Care Planning - DoH policy published by not implemented.
7. Community Palliative Care beds - ie as per Omagh Hospital model
The Life and Time Service is an exemplar for care in the last days of life www.lifeandtimecare.orgHome - Life & Time which has potential to be rolled out across NI.

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

No

1500 Characters:

Identify those who could benefit from palliative care can be difficult, therefore the first challenge of accessing services.

Services can be disjointed, with layers of referral and access criteria to navigate, eg Needing a District nursing referral to access Marie Curie service in some localities.

Families can find it hard to articulate their need and know of the support available.

Consideration also need to be given to the impact of caring, balancing with other commitment including employment.

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 funding envelop and model for generalist and specialist palliative care needs to be reviewed, including charity sector and public health approach to palliative care.

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 an increase in workforce requirements as demonstrated in the Specialist Palliative Care Workforce review which was completed but not published, coupled with increasing palliative care needs in the population, both components must be funded appropriately.

Community support such as acute care at home, GP access and MDT interventions are vital in all areas to ensure appropriate generalist palliative care.

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

No

1500 characters:

I strongly believe that a new strategy would require resources capacity, and time, without providing any additional or new recommendations beyond those that inform the Palliative Care in Partnership Programme.

Palliative Care in Partnership : The key aim of the Palliative Care in Partnership programme is to provide regional direction so that everyone identified as likely to benefit from a palliative care approach (regardless of their condition):

Is allocated a palliative care keyworker
Has the opportunity to discuss and record their advance care planning decisions; and
Is supported with appropriate generalist and specialist palliative care services to be cared for in their preferred place (whenever it is safe and appropriate to do so).
The programme aim is underpinned by:

Regional good practice tools and guidance
Communication
A public health approach to palliative care

A revised, endorsed and funded mandate and workplan would be the preferred option.

Any other comments

21 Any other comments

1500 characters:

Recommendation to improve palliative and end of life care

1. Ensure it is a strategy priority from PfG through to each organisations corporate and delivery plans.
2. Refresh, fund and published Palliative Care in Partnership Programme mandate and workplan as opposed to a new strategy.
3. Explore the impact on people with palliative and end of life care needs and those important to them from a employment, financial and legal perspective.
4. Implement the For Now and for the Future - An Advance Care Planning Policy For Adults in Northern Ireland.
5. Focus public and health and social care system on 'realistic medicine' approach to care
6. Review palliative care content in undergrad and post grad education programmes for Health and Social Care Professionals
7. Utilise the research and academic capacity locally and globally
8 . Explore a creative approach to increase public and staff understand of palliative and end of life care.