

Response ID ANON-PEFR-6RBK-2

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-17 14:08:55

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:
Dr Patrick Loughran

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:

Retired NHS Consultant Anaesthetist/Medical Director
I am currently the voluntary chairman of the Southern Area Hospice Services - the charity which controls the Palliative Care services which are headquartered in Newry

5 What is your organisation?

Organisation:
Southern Area Hospice Services

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

Yes

1500 characters:

see answer to Q 4

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:

1. Specialist Palliative care is usually provided outside the NHS.
2. Palliative care not usually recognised by the public as a speciality in the way that, for example, cardiology is seen.
3. Palliative care is frequently associated with imminent death and/or a painful or accelerated end of life.
4. Many health care professional refer patients to palliative care services as a last resort and confirm the myth that palliative care is for comfort only and a good life can not coexist within palliation.
5. Many families fear that receipt of palliative care will frighten their loved one as it heralds an early end of life.
6. Palliative care is rarely recognised for the benefit it brings to life.

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. In patient beds are unevenly distributed within the geography of N Ireland and tend to only be found in the charity sector.
2. There are underdeveloped home care palliative services both in the NHS and the charity sector.
3. There are very few specialist doctors and very few medical training places- not enough to cover future needs.
4. Emergency access to palliative care is patchy and uncertain, or absent.
5. Late diagnosis of cancers and late referral for palliative care are denying many patients good symptom control and comfort.
6. The pace of development of the palliative care sector has not matched the demands of an ageing population and increased incidence of cancers which end in the need for palliative care services.

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:

1. The current provision is too heavily dependant on an underfunded charity sector.
2. There is no NHS plan for palliative care, nothing is measured to assess the adequacy or otherwise of palliative care.
3. Services are unevenly spread as in answer above [10.1].
4. Many palliative care crises end in Emergency Departments [10.4 and 10.5]

12 What additional services could/should be provided?

1500 Characters:

1. The answer to this lies in the correction of all the shortcomings set out within this consultation response.
2. In an incremental way the Department of Health should endorse a policy to provide NHS support for the charity sector both financially and target an endpoint in the quality and the distribution of care both geographically and by day and night.
3. The charity sector wants to and can provide some extra marginal support if the NHS build the core services.
4. The public have shown great generosity to palliative care services and will continue to support patients and families.

Integration of Services

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

1500 characters:

1. There appears to be little or no formal integration - relationships are informal and highly dependant on senior staff. There is no planned development between NHS and charity services.
2. IT arrangements do not reach across the NHS/charity gap.
3. There is no uniform referral system between the sectors.
4. There is no evidence that the SPSS are promoting integration.

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

Yes

1500 characters:

1. This would address the many shortcomings set out within these answers. - palliative care should be a core NHS service, financed and delivered by the NHS
2. Standard service model.
3. Fair geographical distribution of beds and homecare.
4. Training medical and nursing and other professional staff towards the needs of the region.
5. Recruitment and retention and terms and conditions would be standardised.
6. Palliative care would gain the same funding and development opportunities and status as the other main specialities - cardiology, nephrology, neurology etc.

15 What can be done to improve integration?

1500 characters:

1. Set out a regional standard for integrated care and fund Trusts and Charities who cooperate with each other and achieve measurable end points.
2. Audit and measure best integrated practice and fund success.

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:

1. There are many examples of good care within the Southern Area Hospice Services.
2. I am not familiar with the details of other providers.
3. In SAHS we run a continuous audit of several outcomes eg infection control, audit of pressure lesions, daily progression of symptom control, family "satisfaction" audits, audits of medication accuracy and others. We have a clinical governance committee, made up of clinicians and Board members, which reports directly to the Board.
4. Our home care pilot has been measured as successful, but the future funding is uncertain.
5. We have RQIA inspections as do all hospices and currently SAHS are measured as compliant with all requirements.
6. A more fulsome file of our good practices is available if members of the Assembly Committee would accept an invitation to visit our site in Newry!

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

Yes

1500 Characters:

1. I can only answer for SAHS.
2. Answer is "Yes" when they access our services.
3. We have a catalogue of uninvited positive comments from our patients and families. There are received both before and after the patients/family have been in receipt of palliative care.
4. We also actively seek out complaints and comments on our performance and on balance these are mostly very positive.
5. Also the answer can be "No", because as set out widely in this consultation response there are many patients/families who do not reach our 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:

1. We [SAHS] are very heavily dependant on charitable donations, and we do not reasonably forecast this will be sufficient for the future.
2. We will never be able to redevelop our patient accommodation within our current financial model [donation dependant] and current inadequate government support.
3. Our greatest costs are our staff and we struggle to fundraise to cover our current T&Cs. If we do not keep up with the NHS terms then recruitment and retention will be impossible. The Department of Health should immediately agree a formula towards incrementally increasing the annual financial support to cover staff costs.

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:

1. The Government funding covers about one third of our costs. It is self evident the answer to this question must be "no"
2. There is no model at present.

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:

1. The last N Ireland strategy is 15 years old, outdated and unfunded.
2. A new strategy should be coproduced by frontline clinicians [primary care, secondary care and existing palliative care teams] and public health specialists.
3. An agreed method of needs analysis should be set out.
4. National and international best practice must be followed.
5. Funding must follow the development of new services.

6. An incremental approach to funding and service development would be acceptable provided an end point date is agreed.

7. The charity sector should be invited to remain as part of the arrangements.

Any other comments

21 Any other comments

1500 characters:

Thank you