Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-11-11 15:56:48

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:
Dr David Graham

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 a Consultant Paediatrician, and I work within general paediatrics, neonatology, and part of my role within the Southern Health and Social Care Trust is paediatric palliative care. I am also the cochair of the Northern Ireland paediatric palliative care network, which has been running since 2019. I am working at a regional level within the palliative care network in paediatrics to promote good practice and also to try and achieve service development according to the Department of Health Strategy on paediatric palliative care.
In my week to week role in the Southern Trust, I have an interest in caring for children and young people with paediatric palliative care needs and aiming to try and develop palliative care services within the Southern Health and Social Care Trust.

5 What is your organisation?

Organisation:
SHSCT

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

Yes

1500 characters:

Part of my job as a Consultant Paediatrician in the Southern Trust involves working with children and young people who have palliative care needs. I am involved in meeting with these families and trying to achieve the optimal level of care in relation to their life limiting condition. I work closely with colleagues in Children's Hospice in Belfast as well as colleagues in the tertiary services in Children's Hospital in Belfast. Locally, within the Southern Health and Social Care Trust, I also work alongside community children's nurses and allied health professionals as well as my medical colleagues.

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:

The overall understanding of palliative care by the general public is quite poor, I feel. The difference between paediatric palliative care and adult palliative care has some distinct challenges also. I think that there is often a perception that paediatric palliative care is all about death and end of life care, whereas

it is more about the longer term care of children with life limiting conditions to help achieve a good quality of life. These differences between adult and paediatric palliative care often mean that it is very challenging to introduce the concept of palliative care to families as it often evokes negative emotions and feelings. It can be challenging not only with members of the public but quite often with other health professionals to introduce this concept as I feel the misconception is right throughout our society. I cannot really comment on the understanding of adult palliative care fully within public as it generally has a different meaning than paediatric 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:

I feel that the paediatric palliative care services are much less well resourced than the adult palliative care services. This is evident in the number of medical professionals who work as a consultant in adult palliative care compared to paediatric palliative care. I can also say with confidence that the palliative care and the end of life care that is given to certain groups of children in Northern Ireland are better than other groups of children. For example, children with oncology needs are often better supported than children who don't have an oncological condition such as a neurodisability or another condition that has significant life limiting potential.

There is also a difference between the teams in each trust in relation to psychology cover and support from other allied health professionals. In paediatric palliative care, there is no funded end of life care team for children with palliative care needs. This is often provided by community children's nurses who do this work on a goodwill basis, and it is not properly funded. The Together for Short Lives survey that is being done at the present time will reveal the differences right across the United Kingdom in relation to end of life and 24/7 palliative care services for children throughout the UK.

There is a big group of children in the transitioning age >14yrs with life limiting conditions as there needs are being poorly met - often falling between 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:

Barriers include - no clear model for providing 24/7 EOL care for children and young people. Poor transition services. No clearly funded EOL care teams for children. No legislation for Paediatric Palliative care rights in Northern Ireland.

BIG problem when trying to develop services is the lack of DATA in NI - we need urgent review of the data and the number of children in NI with life limiting conditions and EOL needs - similar work has been done many years ago in othe rparts of UK (e.g. Scotland CHISP study)

12 What additional services could/should be provided?

1500 Characters:

Proper EOL care teams and structure in NI for all children and young people.
Proper consideration to transition needs.
Develop proper training schemes to train the future workforce including specialist consultants and specialist nurses
Fully funded EOL care teams as per NICE guidance for children.

Integration of Services

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

1500 characters:

Within paediatrics, I feel that palliative care services are not very well integrated between primary, secondary, and specialist care. We do not have a proper specialist palliative care team within paediatrics in Northern Ireland. This is something that we need to develop. Children who have palliative care needs are often cared for by their paediatrician or community paediatrician and are well known to the community children's nurses teams. They often have medical specialists within the children's hospital also. There is varying degrees of involvement from primary care with these children. Quite often, there is minimal contact from primary care when a child has significant complex needs. I think that there could be much more done to develop paediatric palliative care services and also to improve the integration.

As well as the integration between primary and secondary care, I feel that there also needs to be improvement in the integration between paediatrics and the adult acute services and more integration between paediatric palliative care services and adult palliative care services. Because at the present time, they are working as two distinct entities.

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

Yes

1500 characters:

I think that the concept of palliative care as a regional service is probably a good idea. I could see that there would be benefit in having a pool of specially trained palliative care clinicians who can not only deal with adults but also who can look after children. There is a similar model that works in the Republic of Ireland where children will be looked after by adult palliative care teams with specialist input from the paediatric palliative care consultants centrally. I think this would allow for a better funded model that could develop this service right throughout the life of a patient. At the present time, I think that the services are too disjointed, particularly the integration between paediatric and adult palliative care.

15 What can be done to improve integration?

1500 characters:

Build stronger teams that work across trusts, directorates and between primary and secondary care.
I think the funding and distribution needs to be simplified.

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:

Antenatal Palliative care pathway in NI
PALLS nurse project in RBHSC
Other paediatric palliative care teams across UK that we could model on e.g. Welsh team in Cardiff, Scottish team, ROI teams

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

No

1500 Characters:

I think that we could do better.
We often don't meet the full holistic needs of families and children when caring for them in PC.
Could have better psychosocial and spiritual care

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 is no much need for change and improvement in Paediatric palliative care and we have many ideas for improvement.

We are told every time the limiting factor is funding and money.

It is clear the current provision is not providing an excellent service.

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:

A big problem is the difference between paediatric and adult hospices with no good transition service. There are groups of young people who really need a bespoke tailored service.
The Children's hospice is struggling to financially do the things it wishes to do and then to expand their services to include more symptom management and EOL 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

Yes

1500 characters:

YES - the paediatric palliative care strategy is due to run our in 2026 and there are many ongoing aspects within it that need updated. We have been working towards many of the previous objectives but it is evident it needs refreshed to give some clear direction to our future goals. Big areas include training and workforce as well as service development.

Any other comments

21 Any other comments

1500 characters:

No thanks but I would be happy to do a face to face focus group in relation to this as it is such an important area that we need to get right in NI.