Response ID ANON-PEFR-6RSE-D

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-11-14 10:48:37

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:
Paul Prasad Kodiyan

3 What is your email address?

Email:

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:

Macmillan Specialist Advanced Practitioner Physiotherapist in Community Specialist Palliative Care Team , BHSCT

5 What is your organisation?

Organisation:
Belfast Health and Social care Trust

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

Yes

1500 characters:

Community Specialist palliative care team as a Macmillan Specialist Advanced Physio Practitioner :
Palliative Rehabilitation
Emotional Support
Complex Symptom management
Palliative Oxygen management in community
Chest Physio/ Respiratory needs in Palliative Patients
Complex Functional Mobility Ax and Advise
Palliative Education to Families , patients and Professionals
Visiting Lecturer to Ulster University AHP students to teach Palliative Module
Visiting Lecturer to QUB to Teach AHP role in Palliative care to Palliative Specialist Nursing students

current state of palliative care services

7 In your view what is the current state of palliative care services in Northern Ireland?

Poor

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 public are afraid of the terminology Palliative .
Palliative has been termed as End of Life care for most of my patients .
Community palliative care is poor due to poor resources .

Unfortunately most of my patients wants to die at home , however we do not have sufficient resources to provide this care and which leads to Hospice or Hospital admission against their wishes .
We do not have a 24 Hrs support team in palliative care other than DNS for symptom management .

Main Barriers :
Lack of education
Poor communication between professionals
Experience in their life by words , action
Lack of funding to team to provide necessary resources
History from their own experiences of beloved ones

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:

There is definite gaps between different areas in the trust .
AT present there is Palliative MDM for one area of people and other area doesn't have it because of lack of resource person .
We do not have adequate beds in Hospices to take patients for symptom management
WE do not have social services commissioning(In palliative teams) to provide care for EOL Patients
I feel there is sometimes a post code lottery for carers availability
There is poor communications between Hospices and Trust due to separate e - documentation.

There is no Inpatient palliative are service by AHP's in Belfast trust compared to southern and Northern Trust .

There needs to be some palliative symptom management bed in our BHSCT hospitals which would take the pressure off Hospices .

All hospices have to work together with trust in sharing the fund to ensure the care of palliative population rather than focusing own funding and developments .

The research work in palliative needs to be more extensive .

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:

Shared Palliative services throughout all areas of the trust .
Need Common communication strategy .
Need clarity regarding Roles .
There is much potential for Experienced Specialised AHP's to rise to the standard of advancing practice .

There should be a commonness feeling with BHSCT palliative services , at present all stand as their own services providers .

12 What additional services could/should be provided?

1500 Characters:

1: Speedy psychology and counselling services for palliative patients and family
2: Research council for palliative care
3: Specialised education for palliative specialists
4: Doctorate programmes in palliative care for all working in palliative care
4: Work force assessment to help all teams
5: Advanced roles for AHP's to appreciate their experience and knowledge
6: Common platform to communicate
7: All palliative patients should have dedicated palliative support worker --that role should be spread even to AHP's and not just nurses .
8: Focus on possibility of giving palliative rehabilitation to maintain QOL of palliative patient .
9: More focus of ACP and ADRT
10: Timely referrals and all professional outside palliative needs education regarding breaking bad news to patients
11. Hospital At home facility should be open for specific palliative patients (Who have decided not for hospital escalation in their ACP) rather than saying

they are only for patients above 75

Integration of Services

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

1500 characters:

I am sad to say that Primary and secondary palliative care services within AHP services is not doing well .
This is because there is no dedicated palliative AHP workforce within BHSCT Inpatient service.
The aim of In reach and Out reach of Current community palliative care team AHP's was a great idea , however never materialised due to low staffing .
The current system is running so divided that our communications with Specialist care from Hospices and and other teams are poorly .

I am sorry to even say that Macmillan services in acute sector are not even aware of our team in community --Community Specialist Palliative care team which also carries Macmillan AHP's.
The referral system in hospital is confusing at times , as any referrals to community palliative team by Nurses from Hospitals goes directly to Hospice Spec nurses and not to AHP .
Hopefully there is a palliative Hub formation which may direct referrals to our team .
Acute has no full awareness of this team , which needs lot of education within inpatient settings , which i have tried in the past but never happened because of lack of time in acute teams .

I would be keen for Macmillan Palliative team in acute to be ware of this team in community , as we very rarely receive referrals form them , this could be because there is no inpatient palliative AHP's to follow up palliative patients in acute.

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

Yes

1500 characters:

Palliative care should have a regional standard throughout to maintain equality within all areas of NI.
There should be a regional framework for palliative care and there should be an NI Palliative forum to discuss and improve all services delivered all over NI region .

The re should be more In services and training facilities for AHP's within Palliative sector .

Unfortunately due to distance and need of urgency , each trust may need to have their pathway of service , however this should be regionalised for NI .

There should be dedicated palliative care emergency team available in the community to support family and patients .

There should be In reach and Out reach palliative care AHP's in all regions.
There should Community palliative care Consultant or speciality doctor for community teams to approach .

AHP's should be raised to a role of Advanced Practitioners level 2 with prescribing responsibilities

15 What can be done to improve integration?

1500 characters:

1: Communications should be common
2:: Improve work force
3: Formation work for all palliative care professionals within trust
4: Avoid the feeling of split services in the trust
5: Escalate AHPs to advance to Advanced Practitioner roles
6: Educate various teams in palliative team regarding the palliative care provision of various teams in BHSCT
7: Organise Palliative care forum and event to welcome speakers and presentations of all team in NI
8: Organise Palliative care event in NI to recognise and award palliative care workers

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: Palliative Oxygen therapy installation by Myself ----AS an AHP I don't think its happening in other areas , as other areas are depending on Community Respiratory team to provide this

2: HSN --Hospice Spec Nurses role in Community , I value their role and this model would be vary useful , however there is bit of confusion regarding CSN from marie curie and HSN from NI Hospice .

This needs to be clarified , as Marie curie CSN would manage only S&E area of BHSCT and HSN would manage N&W .

3: DNS role is so vital and their 24 Hrs availability for palliative patients

4: Unfortunately there is no SW commissioning services in palliative teams in BHSCT , which is making lives harder for patients during their EOL care .

5: We also need dedicated Psychology/Counselling services for our patients and families

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

Not sure

1500 Characters:

1: I have had various situation where family is confused regrading whom to contact for urgency . They get confused with Hospice nurse s, DNS and our team
2: Need Leaflets to be issued to families regarding various teams and their roles
3: Family should be able to make self referrals for palliative needs of their beloved ones .
4: there should be an audit with families who had recent bereavement or who are going through Palliative care of their dear ones reg various aspects of care received and their concerns
5: There should be more feedback methods for families to come back about the care they received for their dear ones .

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: Lack of resources in primary sector
2: Teams are working hard , our team is having waiting list for urgent and routine
3: need thorough assessment of Workforce available and workforce needed .
4: capacity demand ration need to be completed for all teams in 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.

Not sure

1500 characters:

1: HSN are doing excellent outreach work , however i feel trust should be working hard to have their own Specialist nurses and let Hospices run their services as an inpatients sector with increased bed availability
2: I feel Hospice bed should be increased and these out reach Nurses should be utilised for more bedded Hospice service..
3: There should be more Specialist palliative teams with DNS and trust wide Medics and trust wide AHp's with adequate workforce to run the community palliative services .
4: the current sharing models is not really sustainable long term in view of increase in palliative patients in coming years .

5: there should be more hospice branches with beds to support patients for symptom management and EOL.

6: We should develop trust workforce to provide specialist services for our patients and let hospices accept them for inpatients settings only .

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:

There is a need for palliative care strategy in NI .

1: Current divisions within palliative care offered in each areas (Inequality)
2: Quality of work need to be analysed within each specialities
3: Work force assessment need to be completed and appropriate action should be taken
4: Staff need to be recognised and more areas of professional development should be available
5: Palliative research works need to established with support from QUB and UU
6: Staff recognition events and palliative events should be conducted in NI
7: Palliative doctoral programmes should be offered for professionals who wants to pursue their academic career
8: Advanced practitioner roles should be implemented for AHPs with NMP roles.

Any other comments

21 Any other comments

1500 characters:

I love my work .
I have worked for 20 + years and this is the role that has given me immense satisfactions , however it also breaks my heart when i am unable to assist and support my palliative patients due to lack of staffing and waiting list due to work force issues .
I have always felt that Trust has never recognised Palliative Workers , however the families and patients have appreciated a lot .

Its true that we don't get feedback from our great patients and its hard for some families to think about feedback questionnaire during their grieving times . However we are satisfied more than anywhere with their words of thanks .

I would request trust to hear our requests and needs in our teams as we are struggling with less workforce and more patients . Just assessment of situation doesn't give resolution , need to take hard and positive steps to make that change .