1. Consent

2. What is your name?

Name – South Eastern Health and Social Care Trust Locality Board (SEHSCT)

3. What is your email address?

Email – denise.cranston@setrust.hscni.net

(OBO The co-chairs of the South Eastern Trust Palliative Care Locality board
Dr David Robinson and Dr Yvonne McGivern)

4. Are you a healthcare professional? If yes, what is your role: If no, what is your interest in palliative care services:

Yes

This submission is on behalf of the SEHSCT Palliative Care Locality Board. The SCHSCT Palliative Care Locality Board is responsible for guiding collaborative working, communicating and facilitating the implementation of the regional palliative care work plan at locality level through their diverse stakeholder membership.

5. What is your organisation?

Organisation SEHSCT

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

Yes

The locality is made up of representative from Special Palliative care, Acute Hospital Services, Unscheduled Care, Bereavement Co-ordinators, Nursing Home and Residential Care, Domiciliary Care, Primary Care and the Voluntary sector.

The SEHSCT Palliative Care Locality Board is responsible for and implementing the outworkings of the regional palliative care priorities from the Palliative Care in Partnership board.

CURRENT STATE OF PALLIATIVE CARE SERVICES

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

Good

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 – There seems to be a misunderstanding whereby some think that palliative care is ‘end of life care’. There seems to be a lack of understanding of who delivers palliative care. Some think that when they are referred to palliative care a specific team of nurses / AHPs are going to come and deliver 24 hour care. Also there seems to be a misconception that palliative care is only for cancer patients, rather than everyone. People can fear death and dying. There can be a lack of understanding of the different roles and the different health care professionals or agencies.

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?

Some Trusts do not have a full complement of specialist multidisciplinary teams.

There is no palliative care strategy. Lack of out of hours access to specialist palliative care face to face consultations. Lack of 24/7 specialist palliative care allied health care support.

Rural versus urban provision. Difficulty with social care support in rural areas to support patient staying at home.

Lack of advance care planning documents eg ReSPECT,

Challenges with IT systems with information sharing, between trusts, primary care and external organisations.

Anticipatory prescribing and emergency medication boxes for EOL care not available in all regions or settings.

11. Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes

Barriers of lack of knowledge of services available.

Services need to be more inclusive of homeless, LGBTQ, prison etc

Difficulty transitioning from children to adult services.

Workforce barriers – concerns over current specialist palliative care workforce numbers and projected numbers over the next five years. No 24/7 specialist palliative care service. Vacant post within Palliative care Consultant grade and GP.

Variation in services available between trusts which can causes challenges at trust boards.

12. What additional services could/should be provided?

More hospital at home models to support care in the community

More domiciliary care workers to support care in the person own home

More 24/7 access to specialist palliative care

Implementation of the ACP policy

Implementation of the ReSPECT and DNACPR policy

Regional strategy with funding aligned to it

More joint up MDT working more rapid access hubs with MDT support.

Better linkage for IT systems

Regional education to promote good practice

INTEGRATION OF SERVICES

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

Services not well integrated continues to be some silo working.

Commissioning of services needs to be aligned with the aging population.

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

Yes

Northern Ireland is a small region which may lend itself to a regional service as opposed to individual trusts.

15. What can be done to improve integration?

Shared working practices.

No more silo working

Specialist palliative care hubs

Joint disciplinary partnerships eg heart failure and palliative medicine, frailty and palliative care, COPD respiratory teams and palliative care.

Better integration of trust and external agencies

Role out of intermediate communication skills training

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?

Care home facilitators linking with care homes to prevent hospital admission and support earlier discharge

Multidisciplinary Rapid access hubs to support earlier discharge and prevent hospital admission

Joint disciplinary working eg heart failure and palliative health care professionals

Educational programmes to support best practice – TEAMS lunch and learn, F2F sessions

Communication skills training including Sage and Thyme Foundation and Advance communication skills

Bereavement / comfort calls post hospital community bereavement

Marie Curie rapid access and overnight sits

Marie Curie and Cruse project bereavement awareness in schools

NIAS OOH Palliative and End of Life Care Referral Guidance - NI wide with direct referral to District/ Community Nurse or Marie Curie Nurse varies in line with local service delivery.

OOH SPC Advice Lines (medic to medic advice arrangements available in all Trusts)

Just in Case Boxes / Anticipatory Medication in the patients' home

Belfast Palliative Care Community Hub (launched w/c 28 April 2025) – single point of access and triage for patients with complex PEOLC needs.

NHSCT Palliative Care at the Front Door Project in Antrim Area Hospital

SHSCT Qlik Sense Project in ED which identifies patients known to the Community SPC MDT Team or who have a Palliative Care Keyworker (DN) if they attend ED.

Foyle Hospice 7 day Community SPC Nursing Pilot Project available in the Northern Sector of the WHSCT

Foyle Pathfinder Project working to develop a process to support hospice non-medical prescribers to be able to prescribe in the community – early indications show a substantive reduction in the time from a decision to change patient prescriptions to the when the patient receives the medication.

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

No

Difficult for families to know what to ask for

Once in the system there is better support but it can be difficult knowing when to ask for support as well as being able to access 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

Charity partners have to fund raise to run their service

More domiciliary / primary care support required to keep the person at home

More training positions to facilitate succession planning

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

The aim to care for people in their preferred place of care requires the support of hospice at home, community care, rapid response and other multi agencies some of these service rely on charitable donations which can pose a challenge

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

Strategy needs to sit along sit policy but needs a funding commitment. Needs to be comprehensive with tangible outcomes

21. Any other comments

1500 characters

There is a limit of 1500 characters