NORTHERN IRELAND PALLIATIVE CARE IN PARTNERSHIP PROGRAMME MANDATE

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Owner:	**Dr Miriam McCarthy & Director of Nursing (PHA)**
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Introduction

1. The purpose of this document is to describe:

i. The role of the regional Palliative Care in Partnership Programme Board (the Programme Board) and it's working groups in supporting the delivery of quality palliative and end of life care across care settings in Northern Ireland.

ii. The regional palliative care priorities and work plan for 2019 and beyond.

The structure and purpose of the Programme Board have been adopted from the work previously completed by the Living Matters Dying Matters Implementation Board (2010-16) and the Transforming Your Palliative & End of Life Care Regional Steering Group (2013-16).

Background and Context

2. Good palliative and end of life care is an important part of health and social care. Living Matters Dying Matters (LMDM) defined palliative and end of life care as *"the active, holistic care of patients with advanced progressive illness".*

3. LMDM identified 25 recommendations to improve palliative and end of life care through developing, commissioning and delivering a model for quality palliative and end of life care.

4. Transforming Your Care (2011) further supported the work of LMDM and identified 7 key principles to inform future palliative care service design and implementation.

5. From 2013 -2016 the Transforming Your Palliative and End of Life Care (TYPEOLC) programme, a partnership between Marie Curie, Health and Social Care Board (HSCB) and the Public Health Agency (PHA) worked towards the enhancement of palliative and end of life care through engagement with key stakeholders including health and social care, Department of Health, independent providers and voluntary and community sector representatives.

6. Phase 1 & 2 of the TYPEOLC programme made significant progress in building the evidence base and setting the direction for transformational change to improve the co-ordination and delivery of palliative care services across Northern Ireland.

7. In January 2016, the Regulation and Quality Improvement Authority (RQIA) Review of the Implementation of the Palliative and End of Life Care Strategy was published and made eight recommendations for future implementation.

8. In September 2016, the previous LMDM and TYPEOLC structures were brought together to form the Palliative Care in Partnership (PCIP) programme.

9. The PCIP programme management support has been sponsored by Macmillan from June 2018.

Principles of the Palliative Care in Partnership Programme

10. The Palliative Care in Partnership (PCIP) Programme is based on the following principles:

- One structure, one work plan and one direction for palliative care in Northern Ireland;
- Good palliative care is everyone's business;
- Palliative care is not just for cancer;
- Palliative care is not just about the last weeks or days of life;

- Palliative care supports the person with palliative care needs and improves the experience of those important to them; and
- Good palliative care is about supporting quality of life until the end.

REGIONAL PALLIATIVE CARE IN PARTNERSHIP STRUCTURE

11. The regional Palliative Care in Partnership structure consists of the regional PCIP Programme Board, Clinical Engagement Group, Voices4Care Service User and Carers Group and Palliative Care Locality Boards in five locality areas across Northern Ireland. A structure diagram is included in Appendix A.

12. The Programme Board consists of members from across the five localities coterminous with HSC Trust boundaries in NI. Membership also includes representatives from Department of Health, HSCB/PHA, Northern Ireland Ambulance Service, Hospice and independent palliative care providers, community and voluntary sector, Integrated Care, Integrated Care Partnerships, Primary Care, Bereavement Network, Community Planning and service users and carers. The Programme Board is co-chaired by the Executive Director of Nursing and AHPs, PHA and Dr Miriam McCarthy, Director of Commissioning, HSCB [see Appendix B]

13. The role of this Programme Board will be to:

- Ensure the delivery of key palliative care priorities regionally and locally;
- Support the local implementation of regionally agreed policies, processes and activities;
- Ensure the programme activities are person centred;
- Assist in accessing and providing information and data relevant to the programme activities;
- Advise on and share best practice already in place to support people with palliative care needs;
- Provide support and advice for any escalated issues; and
- Act as a communication channel between member organisations and the programme sharing information as required.

14. The Programme Board will ultimately be responsible for the work delivered by the programme and any working groups established under its structure including the Clinical Engagement Group and the Voices4Care Service Users and Carers Group.

Co-opted Members

15. There may be occasions when the Programme Board requires attendance by other individuals or organisations not on the core membership. Attendance by any others will be agreed in advance by the Co- Chairs of the Programme Board.

Meetings

16. The Programme Board will meet at key milestones in the Programme and no less than twice a year. The Programme Board is supported by the Macmillan sponsored programme management support. Notes and action points of all meetings will be kept by the programme team and distributed to all members following the meetings. Meeting attendance will be monitored by the programme team. In addition, the Co-Chairs may call an extraordinary meeting of the Board should any critical issues arise.

Programme Scope

17. The scope of the programme will include:

- Include all people resident within Northern Ireland with palliative and end of life care needs aged over 18 years of age;
- People with non-malignant and malignant conditions;
- Make no differentiation in care on the basis of gender, ethnicity, religious belief, disability, sexual orientation or socioeconomic status;
- Include those important to the person and their needs in respect to palliative and end of life care; and
- Address holistic palliative care support (physical, psychological, social and spiritual) from identification to bereavement.

Clinical Engagement Group

18. The purpose of the Clinical Engagement Group (CEG) is to provide a forum for clinicians to share good practice and guidance, input to the development of and contribute to the progression of the regional palliative care programme and work plan.

19. Members of the CEG will be invited from all settings across localities coterminous with Health and Social Care Trust boundaries in Northern Ireland.

20. Two members of the Clinical Engagement Group will be nominated to the regional PCIP Programme Board to represent the professionals working in palliative care.

21. Clinical working groups for other pieces of work will be set up and facilitated when needed or as new priorities emerge.

22. Appendix C outlines the membership of the Clinical Engagement Group.

Service User and Carer Engagement

23. The purpose of this engagement is to involve service users and carers in all aspects of service developments and key work areas in the regional palliative care work plan.

24. The Northern Ireland based members of All Ireland Institute for Hospice and Palliative Care (AIIHPC) Voices4Care group (Palliative Care in Partnership Voices4Care) will form the key service user and carer engagement forum for the programme.

25. The PCIP Voices4Care membership and meetings will be facilitated by the AIIHPC.

26. In addition for particular pieces of work the programme may also seek the views of service users and carers involved in the Health and Social Care Trust PPI Groups, regional PPI groups, other voluntary service user and carer groups e.g. Marie Curie and Macmillan.

Palliative Care Locality Boards

27. The purpose of the Palliative Care Locality Boards is to promote collaborative working between key stakeholders at locality level and as a mechanism for communicating and implementing agreed palliative care priorities and activities locally.

28. The Palliative Care Locality Board structures build upon structures which have been in place, and are co-terminus with HSC Trust boundaries and Local Commissioning Groups.

29. The Palliative Care Locality Boards are responsible for communicating and facilitating the implementation of the regional palliative care work plan at locality level through their diverse stakeholder membership which should be in line with the suggested Locality Board membership listed in Appendix D.

30. Activities, polices and processes endorsed by the regional programme should be tabled at Palliative Care Locality Boards and plans agreed for local implementation/operationalisation of same.

31. Palliative and end of life care is one of the priorities for Integrated Care Partnerships. It is envisaged that Palliative Care Locality Boards will be the structure by which the Integrated Care Partnerships deliver on the palliative and end of life care priority areas of the ICP work plan.

32. The Locality Boards will be co-chaired by the HSC Trust Director with responsibility for palliative care and a nominated member of the local Integrated Care Partnership Committee or Local Commissioning Group. The Co-chairs of the Locality Boards are responsible for ensuring their membership is representative of local service provision and partnerships.

PROGRAMME PRIORITIES

33. The 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).

34. The 4 key priorities of the Palliative Care in Partnership programme are:

IDENTIFICATION: To improve the early identification of people who could benefit from a palliative care approach (regardless of their condition) ensuring their information is captured, recorded and shared to co-ordinate supportive care for the person.

KEYWORKER: To ensure everyone identified as being in their possible last year of life has an allocated keyworker who is appropriately trained and that operational processes and communication is in place 24/7 across care settings.

ADVANCE CARE PLANNING: To ensure everyone identified as likely to benefit from a palliative care approach has the opportunity to discuss and document an Advance Care Planning Summary which will facilitate the sharing of their preferences for care across settings (via a Key Information Summary).

GENERALIST & SPECIALIST PALLIATIVE CARE SERVICES: To continue to improve the provision of generalist and specialist palliative care services in all care settings across Northern Ireland.

The programme's key priorities will be underpinned by:

- Regional good practice tools and guidance;
- Communication skills; and
- Public health approach to palliative care.

Regional Palliative Care Workplan

35. The programme will develop and facilitate the activities of the regional palliative care workplan which will be reviewed and endorsed at the regional programme board meetings.

36. The regional work plan will be reviewed at least quarterly to take account of new priorities, changes in service delivery and emerging policy direction.

37. The work areas commenced under the 'Transforming Your Palliative and End of Life Care' initiative, and some outstanding work from LMDM will progressed via the regional work plan, as will the eight recommendations of the RQIA Review of the Implementation of the Palliative and End of Life Care Strategy (LMDM).

Communication & Stakeholder Engagement

38. Engagement is an integral part of developing understanding of the current palliative and end of life care systems and services in place across Northern Ireland and the benefits and barriers to delivering real choices for people with palliative and end of life care needs. Proactive and appropriate engagement with all stakeholders and interested parties will help develop realistic and achievable solutions, as well as high quality, safe and efficient services, systems and processes moving forward. The aim is to ensure that all stakeholders have an opportunity to express their views.

39. Through planned stakeholder engagement the programme aims:

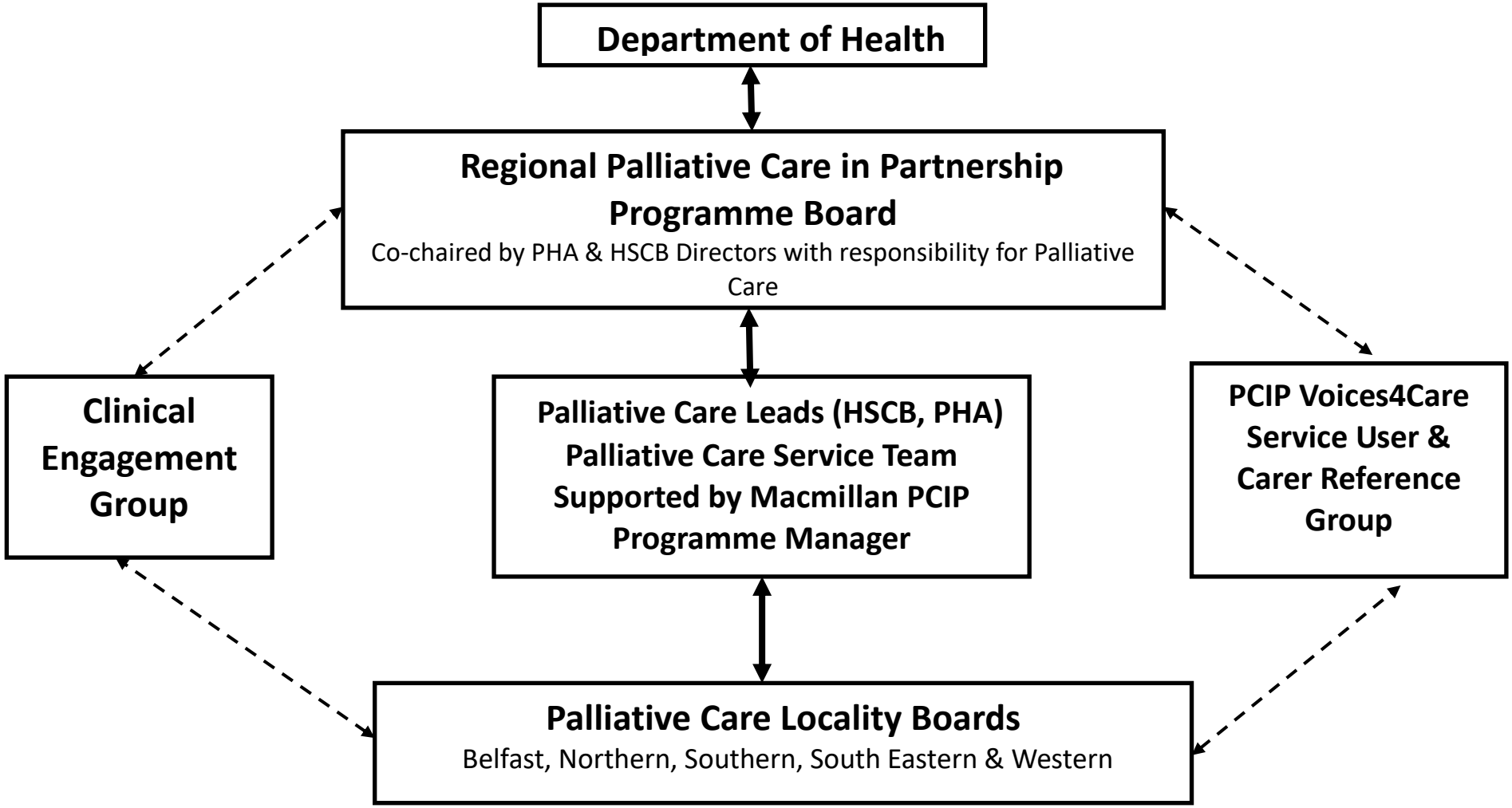
- To engage proactively and appropriately with all stakeholders taking account of different perspectives whilst continually working to fulfil the overarching aim of the programme;
- To keep all of the key stakeholders informed of the programme progress and to communicate the rationale behind the direction and decisions taken;
- To encourage and work with the other stakeholder groups to increase their interest and/or influence in palliative and end of life care; and
- To promote and champion the need for and benefits of appropriate and proactive palliative and end of life care in the community.

40. A range of activities will be employed to ensure clear communication to stakeholders including face to face meetings, electronic media, website and social media, highlight reports and newsletters/updates.

Spokespeople

41. Director of Nursing and Allied Health Professionals, PHA and Dr Miriam McCarthy, Director of Commissioning, HSCB will be responsible for responding to, or designating a PHA/HSCB leads to respond to enquiries regarding palliative and end of life care on a regional level and will be the key speakers at regional events.

Appendix A: **Regional Palliative Care Structure**



<u>Please note:</u> This structure may be subject to change given the review of Health and Social Care.

Appendix B:

Regional Palliative Care in Partnership Programme Board Membership

	Organisation/Role	Members
1	Public Health Agency (Co-chair)	TBC
2	Health & Social Care Board (Co-chair)	Miriam McCarthy
3	Macmillan (Sponsorship)	Heather Monteverde
4	Palliative Care Lead (HSCB)/ Local Commissioning	Paul Turley
5	Palliative Care Lead (PHA)	Corrina Grimes
6	Department of Health	Chris Matthews
7	Belfast HSC Trust	Marie Heaney
8	Northern HSC Trust	Phil Hughes
9	South Eastern HSC Trust	Nicki Patterson
10	Southern HSC Trust	Melanie McClements
11	Western HSC Trust	Bob Brown
12	NI Ambulance Service	Brian McNeill
13 14	Clinical Engagement Group	Bernie Corcoran TBC
15	Service User and Carer Group	As nominated
16 17 18	Integrated Care Partnerships	Martin Hayes Dr Grainne Bonnar Roberta Tasker
19	Macmillan	Paula Kealey
20	Marie Curie	Eamon O'Kane/ Joan Regan
21	Northern Ireland Hospice	Heather Weir
22	Foyle Hospice	Paul McIvor
23	Southern Area Hospice	Liz Cuddy
24	Independent Health Care Providers	Pauline Shepherd
25	Royal College of General Practitioners	Shauna Fannin
26	NIGPC	Brian Patterson
27	Integrated Care (HSCB)	Sloan Harper
28	All Ireland Institute for Hospice and Palliative Care	Karen Charnley
29	Patient & Client Council	TBC
30	RCN Independent Sector Nurse Manager Network	Connie Mitchell

31	Community Planning (HSCB)	Louise McMahon
32	Bereavement Network	Paul McCloskey
33	Macmillan GP Facilitators	Dr Graeme Crawford
	Palliative Care in Partnership Programme Manager	Diane Walker

<u>Please note:</u> This structure may be subject to change given the review of Health and Social Care.

APPENDIX C:

PALLIATIVE CARE CLINICAL ENGAGEMENT GROUP MEMBERSHIP	
Corrina Grimes	Palliative Care Lead & AHP Consultant, PHA (Chair)
Catherine Coyle	Public Health Consultant, PHA
Loretta Gribben	Nurse Consultant, PHA
Donal Diffin	Social Care Commissioning Lead, HSCB
Joe Brogan	Medicines Management, HSCB
Diane Walker	Palliative Care in Partnership Programme Manager, PHA
Professional Representatives	
Bernie Corcoran	Consultant representative (RPMG)
Jennifer Doherty	Consultant representative (RPMG)
TBA	SPC Nursing representative
Miriam McKeown*	SPC Nursing representative
TBA	SPC Physio representative (SPC AHP Forum)
Fiona Patterson	SPC SLT representative (SPC AHP Forum)
TBA	SPC OT representative (SPC AHP Forum)
Lorraine Graham	Social Work representative (NI Assoc. of Palliative Care Social Workers)
Denise Kelly	Social Work representative (NI Assoc. of Palliative Care Social Workers)
Jaquie Hanley	Palliative Care Pharmacy representative
TBA	General Practice representative
TBA	District Nursing representative
Co-opted Members	
Gillian Traub	Belfast HSC Trust representative
Roisin Toner	Southern HSC Trust representative
Ray Elder	South Eastern HSC Trust representative
Sally Convery	Northern HSC Trust representative
Conn Haughey	Western HSC Trust representative
Miriam McKeown	Marie Curie Hospice representative
Gemma Aspinall	NI Hospice representative
Fiona Robinson	Southern Area Hospice representative
Yvonne Martin	Foyle Hospice representative
Paula Kealey	Macmillan
Joan Fyvie	NIMDTA
Joan Regan	Association of Palliative Medicine representative
Heather Finlay	Department of Health representative
Brendan McGrath	Nursing Workforce representative
Jill Bradley/ Margaret Moorehead	AHP Leads representative
Jacqueline McGarry	Social Work Training Forum representative
Laura O'Loan	NI Centre for Pharmacy Learning & Development

*Member also acting as a co-opted member for their organisation

APPENDIX D: Proposed Palliative Care Locality Board Membership

1	Trust Director with responsibility for Palliative Care (Co-chair)
2	ICP Committee Representative (potential Co-chair)
3	Local Commissioning Group (potential Co-Chair)
4	Palliative Care Service/Strategic Improvement Lead
5	Consultant representation (Palliative and other related specialties)
6	GP representation
7	Community Nursing
8	Acute representation
9	Local Hospice Provider/s
10	Local generalist and specialist palliative care providers
11	Case Management/ Social Work
12	Community & Voluntary Sector representatives
13	Nursing & Residential Home representation
14	Domiciliary Care representation
15	Pharmacy
16	Service User & Carer
17	Condition specific services
18	Bereavement Services
19	Faith Groups
20	Information/ Performance Management
21	Community Planning/ Local Council representative