

NORTHERN IRELAND PALLIATIVE CARE IN PARTNERSHIP PROGRAMME MANDATE

Date:	May 2025
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Version:	4.1



Palliative Care
in partnership

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 its 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 2023 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, Strategic Planning and Performance Group (SPPG formerly known as the Health and Social Care Board), Department of Health 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, recognising the collaborative progress which had been made despite and lack of investment. The report made eight recommendations for future implementation including Recommendation 1 to develop a 3 year Action Plan (2016-19) building on the work which had been completed since the LMDM Strategy.
8. In response to this recommendation, in September 2016, the previous LMDM and TYPEOLC structures were brought together to form the Palliative Care in Partnership (PCIP) programme to champion palliative and end of life care and to oversee the delivery of the Regional Palliative Care Work Plan for Northern Ireland.
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, Palliative and End of Life Care Education and Training Steering Group. In addition, five Palliative Care Locality Boards oversee the local delivery of care and services at in 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 stakeholders responsible for the delivery of palliative and end of life care across care settings. This includes, but is not limited to, from Department of Health, SSPG/PHA, Health and Social Care Trusts, Hospice and independent palliative care providers (including Care Homes), community and voluntary sector, Primary Care, NI Bereavement Network, Community Planning and service users and carers. The Programme Board is co-chaired by Heather Reid, Interim Director of Nursing, Midwifery and AHPs, PHA and Ciara McKillop, Interim Director of Hospital & Community Care, SSPG [see Appendix B Regional Programme Board membership]

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

- Ensure the delivery of key palliative care priorities regionally and locally through oversight of the Regional Palliative Care Workplan;
- 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, the Voices4Care Service Users and Carers Group and the Palliative and End of Life Care Education and Training Steering 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 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 (AIHPC) 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 AIHPC.
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 and are responsible for ensuring co-ordination of practice and process to support their local palliative care population.
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, policies 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. 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/Local Commissioning Group or Primary Care. The Co-chairs of the Locality Boards are responsible for ensuring their membership is representative of local service provision and partnerships.

Palliative and End of Life Care Education and Steering Group

32. The purpose of the Regional Palliative and End of Life Care Education and Training Steering Group (established 2024) is to take forward the PCiP Priority 3 – to develop a regional palliative and end of life care (PEOLC) framework. Appendix E outlines the diverse membership of this group
33. Consider the skills and knowledge required by all tiers of staff to care for adults in all care settings across the palliative and end of life care journey
34. Scope existing training and education pathways and develop plans to standardise content, spread and scale and consider options for new 'solutions' where significant gaps are identified
35. Advocate for PEOLC within pre-registration and postgraduate education pathways across professions
36. Provide opportunity for those working in specialist palliative care to advance their skills through education
37. Maximise opportunities for interdisciplinary training where possible and make recommendations regarding mandatory/priority HSC training
38. Identify and explore opportunities to standardise the provision of information/training for patients and/or those important to them across the PEOLC pathway.

PROGRAMME PRIORITIES

39. 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).

40. The 4 key priorities of the Palliative Care in Partnership programme for 2023 -2026 are listed below. These priorities were regionally agreed following an extensive stakeholder engagement exercise and Programme Board workshop in June 2023:

EARLY IDENTIFICATION & TIMELY INTERVENTION: 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.

CO-ORDINATION & QI IN PALLIATIVE CARE SERVICES: programme focus on quality improvement and supporting localities/providers to co-ordinate services. Including PC Keyworker QI Project 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.

PALLIATIVE CARE EDUCATION & TRAINING: Including communication skills

PUBLIC HEALTH APPROACH TO PALLIATIVE CARE: upgraded to be a key PCiP programme priority. Activity will include promoting advance care planning as per the public messaging pillar of the regional Advance Care Planning Policy for adults.

The programme's key priorities will be underpinned by regional good practice tools and guidance.

Regional Palliative Care Workplan

41. 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.
42. The regional work plan will be reviewed at least quarterly to take account of new priorities, changes in service delivery and any emerging policy direction.
43. 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).

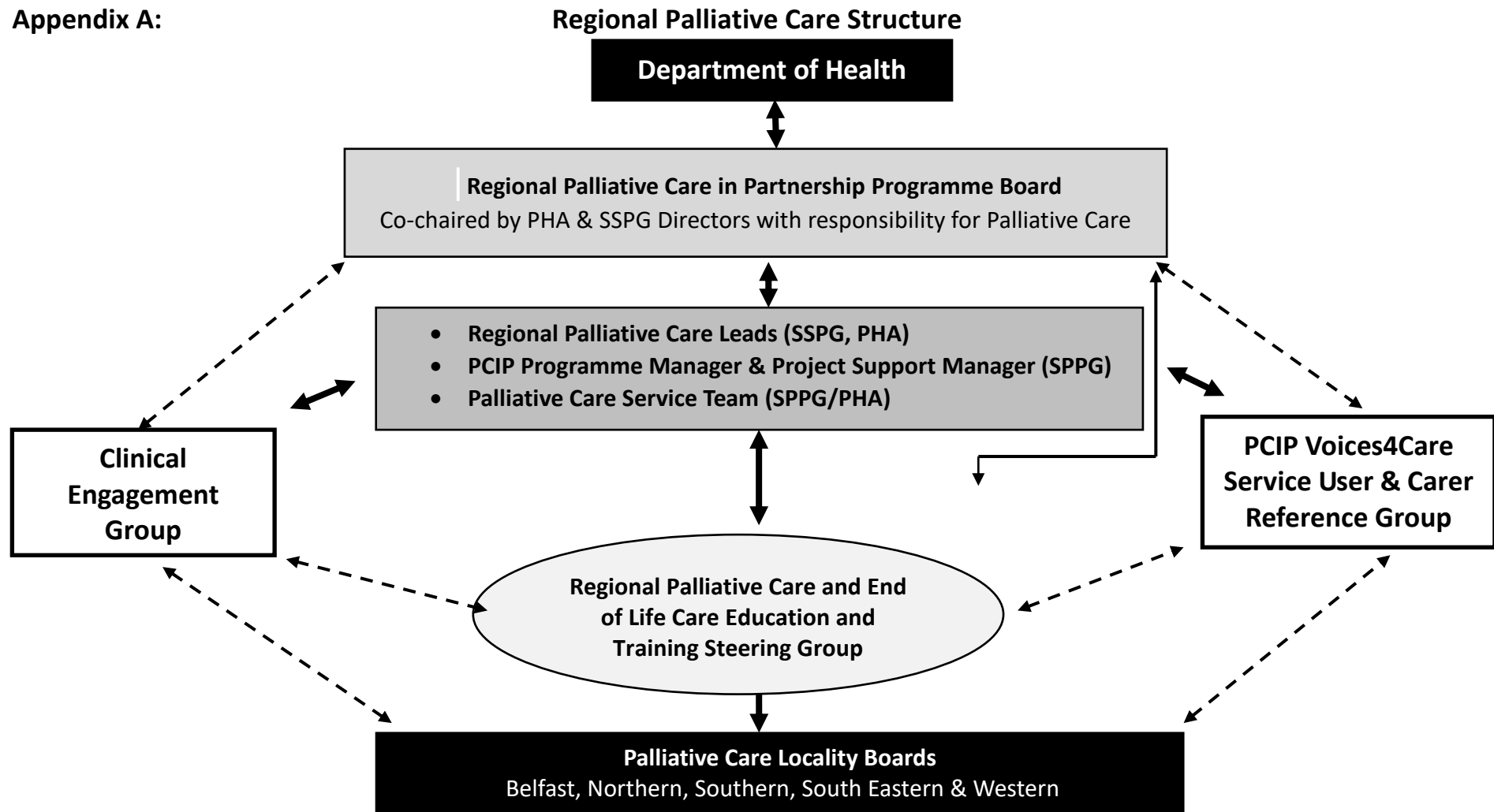
Communication & Stakeholder Engagement

44. 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.
45. 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.
46. 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

- 47.** Interim Director of Community Care, SSPG DoH Ciara McKillop and Interim Director of Nursing, Midwifery and AHPs, PHA Heather Reid will be responsible for responding to, or designating a PHA/SSPG 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:



Appendix B:

Regional Palliative Care in Partnership Programme Board Membership

Organisation/Role		Members
1	Public Health Agency (Co-chair)	Heather Reid
2	Strategic Planning and Performance Group, Department of Health (Co-chair)	Ciara McKillop
3	Palliative Care Lead (SSPG, DoH)/ Local Commissioning	Roger Kennedy
4	Palliative Care Lead (PHA)	TBC
5	Department of Health	Gearoid Cassidy
6	Belfast HSC Trust	Colin McMullan
7	Northern HSC Trust	Diane Spence
8	South Eastern HSC Trust	David Robinson
9	Southern HSC Trust	Brian Beattie
10	Western HSC Trust	Maura O'Neill
11	NI Ambulance Service	TBC
12	Clinical Engagement Group	Sally Convery
13		Bernie McGreevy Alan McPherson
14	Service User and Carer Group	As nominated
15	Belfast Locality Board	Grainne Bonnar
16	Regional Quality Improvement Group	Heather Sleator
17	Macmillan	TBC
18	Marie Curie	Paula Heneghan
19	Northern Ireland Hospice	Trevor McCartney
20	Foyle Hospice	Paul McIvor
21	Southern Area Hospice	Liz Cuddy
22	Independent Health Care Providers	Pauline Shepherd
23	Royal College of General Practitioners	Ursula Mason
24	Royal College of Nursing	Karen Bowes
25	NIGPC	TBC
26	Integrated Care (SSPG)	Louise McMahon
27	All Ireland Institute for Hospice and Palliative Care	Karen Charnley
28	Patient & Client Council	TBC

29	RCN Independent Sector Nurse Manager Network	Connie Mitchell / Linda Graham
30	Community Planning (SSPG)	TBC
31	Bereavement Network	Donna Louise Laird
32	Macmillan GP Facilitators	Yvonne McGivern
33	Hospice UK	Aileen Morton
34	Palliative Care in Partnership Macmillan Programme Manager	Diane Walker

APPENDIX C:

Clinical Engagement Group

PALLIATIVE CARE CLINICAL ENGAGEMENT GROUP MEMBERSHIP	
Sally Convery	Palliative Care and end of life Nurse Consultant, PHA
Catherine Coyle	Public Health Consultant, PHA
Lorna Nevin	Nurse Consultant- Cancer, PHA
Jane McMillan	Social Care Commissioning Lead, SSPG
Andrea Linton / Fiona McConnell	Medicines Management, SSPG
Ceara Gallagher	AHP Consultant, PHA
Diane Walker	Palliative Care in Partnership Macmillan Programme Manager, PHA
Professional Representatives	
Alan McPherson	Consultant representative (RPMG)
Jennifer Doherty	Consultant representative (RPMG)
Lesley Rutherford	SPC Nursing representative
Bernie Torley	SPC Nursing representative
Bernie McGreevy	SPC Physio representative (SPC AHP Forum)
Joanne Mullan	SPC SLT representative (SPC AHP Forum)
TBA	SPC OT representative (SPC AHP Forum)
Emily Murray	Representing Social Work (Southern Area Hospice))
Niall Gallagher	Social Work representative (NI Assoc. of Palliative Care Social Workers)
Peter Armstrong	Palliative Care Pharmacy representative
	General Practice representative
Deirdre Cunningham	District Nursing representative
Co-opted Members	
Debbie Wightman/ Roisin McSwiggan	Belfast HSC Trust representative
Gerard Leddy	Southern HSC Trust representative
Denise Cranston	South Eastern HSC Trust representative
Joanne Currie	Northern HSC Trust representative
Damien McMullan	Western HSC Trust representative
Thomas Hughes	Marie Curie Hospice representative
Gemma Aspinall	NI Hospice representative
Bridget Lynch	Southern Area Hospice representative
Anne Marie Casey	Foyle Hospice representative
TBC	Macmillan
Sinead Hutcheson	NIMDTA
Joan Regan	Association of Palliative Medicine representative
TBC	Department of Health representative

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

APPENDIX E

Palliative and End of Life Care Education and Training Steering Group

	REGIONAL PEOLC EDUCATION & TRAINING STEERING GROUP MEMBERSHIP	
	Member	Representing
1	Loretta Gribben	Chair All Ireland Institute of Palliative Care (AIHPC)
2	Diane Walker	Palliative Care in Partnership/SPPG
3	Louise Hagan/Rocio Munia Lopez	Belfast HSC Trust representative
4	Anne O'Hagan/Fiona Gilmour	Northern HSC Trust representative
5	Denise Cranston	South Eastern HSC Trust representative
6	Gerard Leddy	Southern HSC Trust representative
7	Emma King	Western HSC Trust representative
8	Chris Clarke	Northern Ireland Ambulance Service representative
9	Kathleen Gallagher	Foyle Hospice representative
10	Thomas Hughes	Marie Curie Hospice representative
11	Fiona Flynn	Northern Ireland Hospice representative
12	Bernie Torley	Southern Area Hospice representative
14	Yvonne McGivern	General Practice (2 representatives)
15	Deirdre Cunningham	District Nursing representative
17	Zainab Alabi Linda Graham	Care Homes (2 representatives)
18	Ronnie Cartwright	Home Care
19	Mervyn Bothwell	Northern Ireland Social Care Council
20	Peter Armstrong	Pharmacy (including Community Pharmacy) representative
21	John Wonnacott	Chaplaincy representative
23	Sharon Williams	Compassionate Communities NI representative
24	Monica Burns	Voices4Care representative (2 representatives)
26	Donna Louise Laird	Northern Ireland Bereavement Network
27	Sally Convery Lesley Rutherford	PCiP Clinical Engagement Group (2 representatives)
28	TBC	Regional Palliative Care Facilitators Group representative
29	Tom Mulligan	Clinical Education Centre
30	Esther Beck	University of Ulster

31	Joanne Reid	Queens University
32	Emma Woods	Open University
33	Karen Bowes	Royal College of Nursing NI
34	Sinead Hutcheson	Northern Ireland Medical and Dental Training Agency
35	Gary Cousins	Northern Ireland Practice and Education Council
36	Suzanne Nimmo	Macmillan
37	Melanie Nugent	All Ireland Institute of Palliative Care
38	TBC	Regional Quality Improvement Authority