FROM THE MINISTER OF HEALTH

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Dear Keith,

BRIEFING ON PALLIATIVE CARE – 16 JANUARY 2025

Thank you for your invitation for officials to provide oral briefing on Palliative Care to the Health Committee.
The briefing session, which will be held on Thursday 16 January 2025, will be attended by the following officials:

Adult Palliative Care

Gearóid Cassidy	Director of Primary Care
Roger Kennedy	Programme Director Community Care Directorate (DOH Strategic Planning and Performance Group).

Children's Palliative Care

Ryan Wilson	Director of Secondary Care

In advance of the briefing session, please find attached an overview paper on palliative care for both adults and children for the Health Committee's consideration.

I hope you find this information helpful.

Yours sincerely,

Mike Nesbitt MLA
Minister of Health

OVERVIEW OF PALLIATIVE AND END OF LIFE CARE SERVICES AND FUNDING ARRANGEMENTS FOR ADULTS AND CHILDREN

1. Palliative and end of life care is the active, holistic care of patients with advanced progressive illness. This is an integral part of the care delivered by all health and social care professionals, and by families and carers, to those living with, and dying from any life limiting and progressive condition. Palliative and end of life care focuses on the person rather than the disease and aims to ensure quality of life for those living with an advanced non-curative condition.

2. A palliative care approach includes managing physical symptoms and providing emotional, spiritual, social and psychological support to the person and support for families and carers.

3. Palliative care is a continuum of care that can evolve over time as a person's condition progresses. Palliative care may be appropriate for a number of years, when a person may have extended periods of being well and may move in and out of palliative care services as their needs change.

ADULT PALLIATIVE CARE

Strategic and Policy Context

4. *'Living Matters:Dying Matters'* (LMDM), the Department's palliative and end of life care strategy for adults, was published in March 2010 with a vision that any person with an advanced, non-curative condition is supported to live well and die well, irrespective of their condition or care setting. The Strategy can be accessed at Living matter dying matters

5. The overall aim of the Strategy is to improve the quality of palliative and end of life care for adults by providing a policy framework which enables public, independent, community and voluntary care providers to deliver high quality palliative and end of life that is focused on the person rather than the disease.

6. The LMDM Strategy included a 5-year Action Plan with 25 recommendations covering a range of areas including:
   - raising awareness of palliative care for both professionals and public;
   - education and training for professionals;
   - promoting research and development;
   - improving the identification of people with palliative and end of life care needs and the assessment of their needs to inform personalised care planning;
   - the establishment of a key worker role to help co-ordinate care;
   - improving access to information for people living with terminal illness and their families and carers;
   - communication and involvement of people with palliative and end of life care needs in designing services;
   - access to specialist care advice and support across all care settings.

7. A LMDM Regional Implementation Board, comprising key stakeholders and chaired by the Director of Nursing, Midwifery and Allied Health Professionals at the Public Health Agency, was established to take forward the implementation of the Strategy's recommendations.

Transforming Your Palliative and End of Life Care Report (2011)

8. The Transforming Your Care report (2011) endorsed the model for palliative and end of life care set out in the LMDM Strategy. A number of the LMDM Strategy's recommendations were subsequently taken forward through the Transforming Your Palliative and End of Life Care (TYPELC) programme. This was a 2-year programme that commenced in August 2013, based on the Delivering Choice methodology developed by Marie Curie that involved a whole systems approach to improving palliative and end of life care.

9. As part of TYPELC, Marie Curie worked in partnership with the then Health and Social Care Board (HSCB), the Public Health Agency (PHA) and other statutory, voluntary and independent sector providers to focus on specific areas for improving palliative and end of life care. These included identification and planning for people with palliative care needs; palliative pharmacy; supporting planned discharge; and training for healthcare providers.

Regulation and Improvement Authority (RQIA) Review and Report (2015/16)

10. In 2015, the RQIA undertook a commissioned review of progress on the implementation of the '*Living Matters:Dying Matters* Strategy and the 25 recommendations included in the strategy's action plan. The RQIA's subsequent report, published in January 2016, noted that despite a period of financial constraints, very significant progress had been made towards implementing the Strategy's recommendations.

11. It also concluded that although many initiatives had been developed to raise awareness of palliative and end of life care, there was a continuing need to raise public understanding of palliative care. The report also pointed to a need to standardise the availability of core services across the region. In addition, the report found that the increasing demand for palliative and end of life care was likely to continue with many patients having more complex needs.

12. The RQIA report made 8 recommendations.
    i. DHSSPS (the Department), in partnership with stakeholders should develop a new Living Matters Dying Matters Action Plan for a three- year period for 2016 to 2019 building on the work which has been completed since the strategy was developed in 2010. The action plan should include defined timescales, organisational responsibilities and monitoring arrangements.
    ii. Raising public and professional awareness of palliative and end of life care should be a core component of the new action plan.
    iii. The Public Health Agency should lead on the development of a new needs assessment exercise to assess the impact of projected demographic, epidemiological and service changes on the delivery of palliative and end of life care and to inform the future specification of services.
    iv. DHSSPS and HSC organisations should evaluate the roles of key workers for palliative and end of life care to determine if regional guidelines for this function should be modified in the light of experience.
    v. The HSCB, in partnership with stakeholders, should review the regional coordination arrangements for developing palliative and end of life care to ensure clarity about the roles of different partnerships and groups. This review should inform a decision whether to establish a managed clinical

network for palliative and end of life care, or determine if this approach is no longer appropriate.

vi. HSCB should develop a service specification for out of hour's provision for palliative and end of life care in both hospital and community settings to increase standardisation of the availability of services across Northern Ireland

vii. HSCB in conjunction with HSC trusts should review the arrangements for holding multi-professional palliative care meetings at practice level to identify and address any constraints to establishing these as routine practice in all areas.

viii. Raising public and professional awareness of the Breaking Bad News guidance, once revised, should be a core component of the new action plan.

13. The RQIA did not identify the need for a new palliative and end of life care strategy, however as noted above it recommended that a new action plan should be developed, building on the work that had been completed to date.

Palliative Care in Partnership

14. A recommendation of the RQIA review was that the regional coordination arrangements for developing palliative and end of life care should be reviewed to ensure clarity about the roles of different partnerships and groups.

15. The regional Palliative Care in Partnership (PCiP) Programme was established in 2016 as a single programme to support the further development of palliative and end of life care in Northern Ireland. The PCiP brings together stakeholders from across the HSC Trusts, the NI Ambulance Service, hospice and independent palliative care providers, community and voluntary sector, primary care, pharmacy, and service users and carers.

16. The Palliative Care in Partnership Programme's remit includes:
    - providing regional direction for palliative and end of life care in Northern Ireland;
    - ensuring the delivery of key priorities in palliative and end of life care both regionally and locally;
    - supporting standardisation and improving quality of care for patients approaching the end of their lives in all care settings across NI;
    - ensuring what is designed and developed is person-centred; and
    - advising on and sharing best practice already in place to support people with palliative care needs.

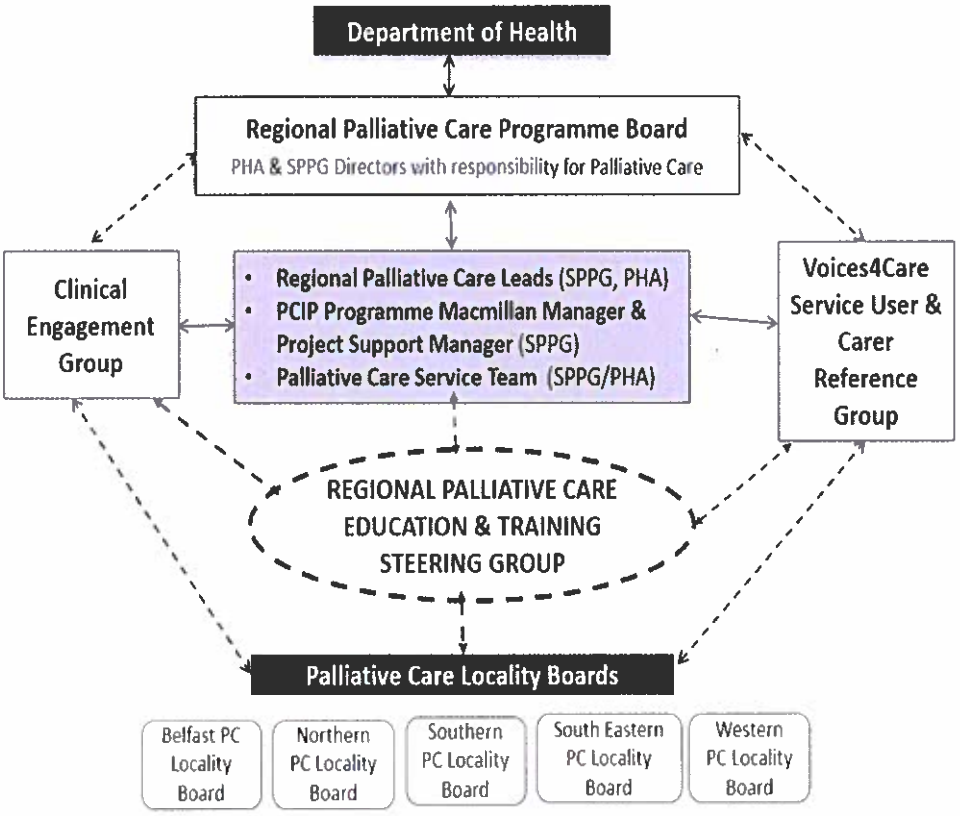
17. The scope of the Programme includes all people resident within Northern Ireland aged over 18 years of age with palliative and end of life care needs with both non-malignant and malignant conditions.

18. The Programme covers holistic palliative care support for physical, psychological, social and spiritual needs, from identification of palliative care needs for people living with life limiting conditions, to bereavement and support for those important to the person and their needs in respect to palliative and end of life care.

19. The Regional PCiP Programme Board is responsible for overseeing the delivery of the key priorities of the Palliative Care in Partnership Programme both regionally and locally. It is co-chaired by the Department's Strategic Planning and Performance Group, SPPG (formerly the Health and Social Care Board) and the Public Health Agency.

20. The current structure of Palliative Care in Partnership is set out in the diagram below.

Palliative Care in Partnership Programme – Structure



Clinical Engagement Group

21. The PCiP Clinical Engagement Group (CEG) provides a forum for clinicians to share good practice and guidance and to provide input to the development of the regional PCiP palliative care programme and work plan and its progression and implementation.

22. Membership of the CEG is invited from all settings across localities that are coterminous with Health and Social Care Trust boundaries. Two members of the Clinical Engagement Group are nominated to the regional PCIP Programme Board to represent the professionals working in palliative care at Programme Board level.

23. Clinical working groups for specified areas of work are set up and facilitated when needed or as new priorities emerge.

Service User and Carer Engagement - Palliative Care in Partnership Voices4Care

24. The service user and carer voice has been integral to the Palliative Care in Partnership Programme since its conception, with service users and carers involved in all aspects of service developments and key work areas in the regional PCiP palliative care work plan.

25. The PCiP's service user and carer engagement group is made up of Northern Ireland based members of the All Ireland Institute for Hospice and Palliative Care (AIIHPC) Voices4Care group and meetings are facilitated by the AIIHPC. 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 Personal and Public Involvement (PPI) Groups, regional PPI groups, other voluntary service user and carer groups, for example, Marie Curie and Macmillan.

Palliative Care Locality Boards

26. Palliative Care Locality Boards promote collaborative working between key stakeholders at a locality level and provide a mechanism for communicating and implementing agreed palliative care priorities and activities locally.

27. The Palliative Care Locality Board structures are coterminous with HSC Trust boundaries and Local Commissioning Groups. They are responsible for communicating and facilitating the implementation of the regional PCiP palliative care work plan at a local level.

28. The Locality Boards are co-chaired by the HSC Trust Director with responsibility for palliative care and a local clinical representative (usually a GP) The Co-chairs of the Locality Boards are responsible for ensuring their membership is representative of local service provision and partnerships.

Palliative Care in Partnership Work Programme and Priorities 2023-26

29. In June 2023, following engagement with stakeholders, the PCIP Programme agreed its most recent work programme with priorities and actions for 2023-26.

30. The 4 key priorities of the Palliative Care in Partnership programme for 2023-26 are:
    - **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 & Quality Improvement In Palliative Care Services**: a programme focus on quality improvement and supporting localities/providers to co-ordinate services. This includes a Palliative Care Keyworker Quality Improvement 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 are in place 24/7 across care settings.

- **Palliative Care Education & Training:** including communication skills. To develop a regional palliative and end of life care education and training framework to promote competence and confidence in staff caring for people approaching the end of their life across all care settings.
- **Public Health Approach To Palliative Care:** Activity will include encouraging open discussion about death and dying and promoting advance care planning in line with the regional Advance Care Planning Policy for adults, when implemented.

31. The programme's key priorities continue to be underpinned by the development of regional good practice tools and guidance.

32. The PCiP 2023-26 Work Programme, with progress on workstreams and key actions at October 2024, is provided separately as an attachment.

Public Health Approach to Palliative Care

33. During 2017-18, at the request and on behalf of the Department of Health, the Department of Finance (DoF) Innovation Lab undertook research to explore what constitutes a public health approach to palliative care and how this might be taken forward in Northern Ireland.

34. A workshop, led by DOF Innovation Lab, was held in May 2019 and brought together 30 key stakeholders from the Health and Social Care and palliative care fields to consider a definition for a public health approach to palliative care in NI. An agreed definition was subsequently endorsed by the PCiP Programme Board. The definition is:

35. *A public health approach to palliative care recognises the role of society and community in enabling and supporting people living with life-limiting conditions, and those important to them, to live well with flexible, holistic and person-centred care based on positive and collaborative partnership.*

A public health approach to palliative care will involve working collaboratively to:

- *Increase awareness, understanding and discussion around palliative care through education and information;*
- *Create and enhance networks across communities and sectors to support people living with a life limiting illness and those important to them;*
- *Encourage people to think about and plan for their future physical, emotional, social, financial and spiritual needs.*

36. Follow up Insight labs, again facilitated by DOF Innovation Lab, were held in November 2019. These brought together a wider range of stakeholders, including representatives from other NI Civil Service Departments, the voluntary and community sector, funeral directors, faith groups and the education sector.

37. Within the context of the agreed definition of a public health approach to palliative care, attendees considered how such an approach could be implemented. A

number of opportunities were identified and prioritised across the three key elements of the public health approach definition.

38. A number of next steps were identified, namely:

- **Develop a Resource of support services** - the information gathered about existing services would be collated and themed to provide the basis for the development of a toolkit of services and resources to support a public health approach. It would also inform shared learning and future scope for potentially scaling up.
- **Engagement and Awareness Raising** - engage with organisations regarding any current or planned initiatives that support a public health approach to palliative care.
- **Framework of Action** - develop a framework of actions to take forward the implementation of a public health approach to palliative care in NI.

39. Three key areas were considered essential to progressing a public health approach to palliative care:

- **Education** – progressed at a community level by using planned initiatives as opportunities to inform and educate both HSC professionals and the public about palliative care.
- **Communication** – through a messaging campaign which will aim to address some of the taboos and terminology around palliative care; and
- **Engaging across the community** – identifying what successful initiatives are already in place in communities and finding ways they might be replicated or adapted across other communities.

40. The emergence of the Covid-19 pandemic led to a pause in this work. In the context of resourcing pressures, it has not been possible to re-start this. Notwithstanding this, some elements of a public health approach have been taken forward. For example, the Department continues to support raising awareness and understanding of palliative care, for example through its support for the annual all-island Palliative Care Week campaign, led by the All Ireland Institute for Hospice and Palliative Care.

41. In October 2022, the Department also published its Advance Care Planning policy for adults *"For Now and For the Future"*.

42. The policy aims to increase public awareness and understanding of what Advance Care Planning is, encouraging adults at any age or stage of life to consider and plan ahead for their future, including their wishes, feelings, beliefs and values about future treatment and care.

43. Establishing momentum with implementation of the policy has been extremely challenging within the context of other priority projects and current financial and resourcing pressures across the Department and Public Health Agency.

44. The Department and Public Health Agency are currently considering next steps.

DELIVERY OF PALLIATIVE CARE SERVICES FOR ADULTS

Generalist Palliative Care Services

45. Palliative care includes both Generalist and Specialist palliative care services.

46. *Generalist palliative care* is delivered by multi-disciplinary teams in primary and community care settings, hospital units and wards. This is the level of palliative care required by most people and is provided by core healthcare teams.

47. Generalist palliative and end of life care is also provided by health and social care professionals who have expertise in particular health and social care fields, such as respiratory disease, heart failure, renal disease, neurological conditions and dementia. Experts within these conditions are pivotal in recognising when a palliative care approach is needed as the person's disease trajectory changes.

48. A high proportion of people with palliative care needs will be living in their own home and may have been living with one or more long-term conditions for a number of years. Many of these individuals will already be known to social services and may have home care support in place to assist with activities of daily living based on their assessed need. On average, around 18% of deaths each year are people who live in care homes who again, as part of the core provision, will have their day to day care needs met by the care home staff.

49. The majority of palliative and end of life care and support is delivered in the community by GPs, District and Community nursing teams, Allied Health Professionals (AHPs), social workers, community pharmacy, care home staff and home care workers.

50. This core level of generalist palliative care is not specifically commissioned but is an inherent part of the delivery of good quality holistic health and social care.

Palliative Care Key Worker

51. *Living Matters; Dying Matters* included a recommendation that "*Each patient identified as having palliative and end of life care needs should have a key worker*". When a person is identified as 'likely to be in their last year of life' they will be allocated a Palliative Care Keyworker. The operational role of the palliative care keyworker is to:

    - Support the identification of people likely to be in their last year of life
    - Act as a key contact in co-ordinating care across services
    - Provide care in the last weeks/days of life
    - Bereavement follow up with those important to the person.

52. In 2017, after extensive consultation, all HSC Trusts agreed the District Nurse would typically be the palliative care keyworker. The District Nurse was chosen as the most suitable HSC professional to fulfil the role of the palliative care keyworker for a number of reasons including:

- The majority of people want to be cared for and die in their own home.
- To maximise cover for out of hours periods – District Nursing services in all HSC Trusts operate wider than the traditional Monday to Friday, 9am – 5pm. All Trusts have a 7-day District Nursing service, with two Trusts currently operating on a 24/7 basis.
- To maximise existing well-established referral pathways and communication with GPs, specialist nurses, social work/ social care and for ordering equipment.
- The majority of people identified as likely to be in their last year of life are already known to the District Nursing service.

53. Work was undertaken to develop a role description, competences and functions of the Palliative Care Key Worker. The role and function of the Palliative Care Key Worker is provided as a separate attachment.

Other Generalist Palliative Care Support Services

54. In some circumstances, people with palliative care needs may require a greater level of generalist care than existing core healthcare teams are able to offer.

55. Marie Curie offer a range of Community Nursing Services which work alongside District Nursing. In addition, they also offer an out of hours Rapid Response Service to provide support for palliative and end of life care patients who find themselves in crisis during out of hours periods.

56. All HSC Trusts have arrangements in place with the Marie Curie Nursing Service (sometimes called Hospice at Home) to provide some element of in-hours planned or variable services to palliative care patients. The hours, operational arrangements and monetary value of these contracts vary across HSC Trusts depending on what other services are available within the particular locality. Referral to the Marie Curie Nursing Service is usually through District Nursing within a Trust.

57. All HSC Trusts also have contracts in place with Marie Curie to provide out of hours Rapid Response Services which include weekend and bank holiday cover. Through this service, Marie Curie nurses aim to provide prompt and timely response to calls for care and assistance, telephone advice to families and patients who may not need a home visit, and urgent at home care to patients. Again, these contracts with the Rapid Response Service vary with regards to hours, operational arrangements and the monetary value dependent on the existing core services available in the locality.

58. In three of the HSC Trusts, the Marie Curie Rapid Response Service nurses are situated with the GP Outs of Hours service and in the other two Trusts the service is co-located with the 24/7 District Nursing service.

59. Some of the other independent hospices also have similar 'generalist'/ Hospice at Home nursing services which operate in the community locally. It is the understanding of the Department that none of these are formally commissioned by

Trusts and are being operated separately by hospices out-with commissioned arrangements.

60. Within the Department's contract with the Northern Ireland hospice, there is a historical small amount of funding to provide a similar hospice at home service. In recent times the NI Hospice have highlighted issues with delivering this service as previously specified. This element of the NI Hospice contract is currently under consideration as part of the ongoing regional review of Day Hospice services (see below).

Specialist Palliative Care Services

61. Specialist Palliative Care (SPC) is the management of unresolved complex symptoms and more demanding care needs which require additional expertise and cannot be managed by the core healthcare team.

62. SPC is provided by specialist personnel with expert knowledge, skills and competences. It is delivered by specialist multi-disciplinary teams dedicated to palliative and end of life care. The responsibilities of specialist palliative care professionals will include the physical management of pain and other symptoms and the provision of psychological, social and spiritual support to individuals and their families.

63. Specialist palliative care is provided in four main ways:

Inpatient Hospice and Specialist Palliative Care Units

64. The Department of Health's Strategic Planning and Performance Group (SPPG) currently commissions SPC inpatient beds within the 4 independent hospices across Northern Ireland - Northern Ireland Hospice (18 beds), Marie Curie Hospice (18 beds), Foyle Hospice (9 commissioned beds, 10 beds in total) and Southern Area Hospice Services (12 beds). These beds are commissioned based on a 50/50 funding model introduced by the Department of Health in 2004/5 (further information below).

65. In addition, there are two HSC Trust-led SPC inpatient units, the purpose built 12 bed Macmillan Unit on the Antrim Area Hospital within the Northern HSC Trust and a 10 bed Consultant-led specialist palliative care ward based in the Omagh Hospital and Primary Care Complex within the Western HSC Trust.

Hospital – based Specialist Palliative Care Services

66. All acute hospitals and most community hospitals in Northern Ireland have access to a SPC multi-disciplinary team which might include Palliative Medicine Consultants, Speciality Doctors, SPC Nurses, SPC Allied Health Professionals (Physiotherapist, Occupational Therapist, Dietician, Speech and Language Therapist), Palliative Care Social Workers and Palliative Care Pharmacists. The make-up and staff numbers of these hospital-based teams varies across Trusts and hospital sites.

Specialist Palliative Care Community Teams

67. Specialist Palliative Care Community Teams provide advice and care to patients with complex and unresolved palliative care needs living in the community (in their own home or in a care home). All Trusts have SPC multidisciplinary teams which usually include community SPC nurses, SPC Allied Health Professionals and palliative care social work. The composition and staff numbers of these teams differ across individual Trusts.

68. All Trusts have provision of community specialist palliative nurses to provide advice and support in the person's home:

- the Northern Ireland Hospice has a contract with the Department to provide community SPC nursing in the Belfast and South Eastern Trusts
- Foyle Hospice delivers the service in the northern sector of the Western Trust with the contract for this held by the Department.
- Northern Ireland Hospice have a separate contract with the Northern HSC Trust to deliver community SPC nursing in that area.
- Foyle Hospice have a separate contract with the Western HSC Trust to deliver community SPC nursing in the southern sector of the Trust.

69. Similarly to the commissioning of inpatient beds, contracts with hospices to provide community SPC services are funded on a 50/50 model introduced by the Department in 2005/06.

70. The Southern HSC Trust have their own cohort of community SPC nurses who work within the wider community SPC multi-disciplinary team delivering care to patients in that area.

71. In addition to SPC nursing services, some (but not all) HSC Trusts have moved to a model of community Palliative Care Consultant cover where Palliative Medicine Consultants will undertake domiciliary visits and/or provide clinical support to the community SPC nurses, GPs and the wider SPC Multi-disciplinary team.

72. There was no dedicated recurrent funding accompanying the *Living Matter, Dying Matters Strategy.* Despite this, the SPC workforce in both acute and community has grown substantially. The growth to date in SPC roles has been facilitated mostly by demography funding/ reprofiling of funding within Trusts to meet patient demand and complexity or through significant investment from Macmillan Cancer Care. Macmillan has pump prime funded a significant proportion of the SPC posts with Trusts over the last 10 years. Such arrangements have been progressed by Trusts. Accordingly, the Department does not have oversight of those developments and associated funding arrangements which are in place.

Day Hospice Services

73. The traditional Day Hospice model was often a combination of both clinical and social provision which enabled patients to continue living at home while having access to day facilities provided by a multi-disciplinary team within the hospice. This hybrid approach required patients to attend in person and often provided carers with a period of respite.

74. Existing Department of Health contracts with all four of the independent hospices have an element of Day Hospice funding included. The value and service expectations of the Day Hospice element vary between hospices.

75. Through performance management of the contracts, it has been evident for some time that there are challenges with the existing Day Hospice model, in particular, patients' ability to attend this type of the traditional delivery model and professionals' uncertainty that it supports those patients most in need.

76. A regional review of Day Hospice Services commenced in early 2020, however this was unable to be progressed due to the Covid-19 pandemic. Infection control restrictions in place during the pandemic meant that Day Hospice services were unable to operate as they had previously.

77. Post pandemic, providers reported that patient feedback, alongside a review of patient need, has demonstrated that generally patients were presenting to all services at a later stage and with more complexity. This resulted in services transitioning in an effort to meet patient needs and ensure more timely responses.

78. Currently, all hospices offer some element of 'Day Hospice' service. These differ across providers and from the original intention and expectation of their contracted service. In some instances, the Day Hospice services have been supplemented by funding from other sources, such as the Cancer Charities Fund, St. James Place or the Big Lottery, without the knowledge or engagement of the Department.

79. In October 2023, a review group was convened from the Palliative Care Service Team within the PCiP structures, to revisit the review work that had commenced prior to the pandemic. The aim was to find a new way forward for Day Hospice services given the changes to need and complexity which had been identified. This work is progressing in collaboration with the hospice providers and it is expected that this will conclude in April 2025. The review aims to agree a way forward for Day Hospice services in Northern Ireland, ensuring an element of standardised approach, tailored to meet the needs of the local population, whilst ensuring value for money and reducing duplication of effort within the system.

National Audit for Care at the End of Life

80. The National Audit for Care at the End of Life (NACEL), co-ordinated by NHS Benchmarking, is an annual national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them. The overarching aim of NACEL is to improve the quality of care delivered to people at the end of life in acute and community hospitals.

81. The National Audit of Care at the End of Life in Northern Ireland is commissioned by the Northern Ireland Public Health Agency on behalf of the Regional Palliative Care in Partnership Programme.

82. Northern Ireland has participated in NACEL for four rounds. The most recent round took place in 2022 with a report published in April 2023. All five HSC Trusts participated in the audit In Round 4, covering 20 hospital sites (12 acute and 8 community).

83. The audit comprised:
    - an Organisational Level Audit covering hospital/submission level questions for 2021/22;
    - a Case Note Review which reviewed consecutive deaths in the first two weeks of April 2022 and two weeks of May 2022 (acute providers) or deaths in April and May 2022 (community providers) and
    - a Staff Reported Measure, completed online.

84. The Round 4 NACEL report and Good Practice Compendium for Northern Ireland are available at the links below.

    PowerPoint Presentation
    PowerPoint Presentation

85. The NACEL report includes recommendations from the fourth round of NACEL for Northern Ireland. These relate specifically to the findings of NACEL.

86. Recommendations from NACEL are reviewed by the Palliative Care in Partnership Programme in line with the regional palliative care work plan and where applicable, a regional approach may be taken to consider the NACEL recommendations.

87. There was no NACEL audit in 2023 as NHS Benchmarking undertook a review of the audit processes and metrics. In 2024, NHS Benchmarking launched a new redesigned version of NACEL with a goal of providing more frequent and timely data aimed at driving organisational quality improvement. All 5 five HSC Trusts are participating in this latest NACEL audit round.

Cancer Strategy – Palliative Care

88. The 10-year Northern Ireland Cancer Strategy was launched in March 2022. The Cancer Strategy Implementation Plan includes three actions on palliative care. These are:
    - Action 47 - Deliver integrated, co-ordinated and personalised palliative and end of life care to people with non-curative cancer when and where they need it.
    - Action 48 - All people with non-curative cancer will have access to a palliative care key worker.
    - Action 49 - Extend palliative and end-of-life support and continuity of care to seven-day working for all people with non-curative cancer.

89. A small amount of Cancer Strategy funding has been made available to support the implementation of the three palliative care actions. This is being taken forward through the PCiP workplan including;

    - The development of Regional Syringe Pump Guidance, education and documentation to standardise processes, education and documentation relating to syringe pump usage across all care settings;
    - Regional subscription to the Palliative Care Formulary to provide instant access on a 24/7 basis to medication support for 250 clinicians caring for end of life and palliative care patients;
    - The Quality Improvement project with District Nursing to support the continued development of the Palliative Care Keyworker role;

- Improving access to Out of Hours specialist palliative care advice available to support generalist HSC professionals caring for palliative care patients in the out of hours period; and
- Scoping and costing options for moving to a 7-day Specialist Palliative Care Nursing service in Northern Ireland.

HOSPICE FUNDING – ADULT

90. There are four main providers of adult hospice services within Northern Ireland – the Northern Ireland Hospice, Marie Curie, Southern Area Hospice Services and Foyle Hospice. All hospice organisations provide a combination of inpatient services in addition to specialist community palliative care services.

91. The Department of Health's Strategic Planning and Performance Group is responsible for the commissioning of specialist palliative care services and has Service Level Agreements in place with hospice providers. SPPG has ongoing engagement with the hospice sector as part of the arrangements in place with hospices for the delivery of contracted specialist palliative care services.

92. Current funding for adult hospice services is based on a 50:50 funding arrangement for inpatient services (in place since 2004/05) and also for community-based care (in place since 2005/06). This has been the basis of the funding arrangements between commissioners (both SPPG, formerly HSCB, and HSC Trusts) and the four local hospices. The funding arrangements are for agreed commissioned services costs and not actual hospice running costs.

93. Annual funding provided by the Department to hospices for contracted adult services over the past 6 years is set out below:

Year	Funding *
2019/20	£7.502m** (includes £867k recurrent funding allocated in response to the review of funding)
2020/21	£7.916m**
2021/22	£9.300m**
2022/23	£9.142m** (this includes £0.324million non-recurrent funding in recognition of financial pressures facing hospices)
2023/24	£9.334m** (this includes £74,081 non-recurrent funding in recognition of non-pay inflationary pressures)
2024/25	£9,388m** following non pay uplift for 2024/25

*These figures do not include funding provided by HSC Trusts for any contract arrangements they have with hospices.
**The above figures do not include:

- non-recurrent funding of £16million which was provided to hospices in NI in 2020/21 for COVID-19 in recognition of the impact on fundraising and the additional costs and impact on services due to the pandemic (largely in 2020/21).
- funding provided to hospices for the special Staff Recognition Payment for hospice staff (2021/22 and 2022/23).
- funding provided regarding Advanced Communication Skills training in respect of the Cancer Strategy Action 53 (2023/24).
- Core grant funding provided to the NI Hospice as part of the Department's Core Grant funding scheme (annually).

94. SPPG meets with all four hospices at least once annually as part of formal contract monitoring and has ongoing engagement with the hospice sector as part of the arrangements in place with them for the delivery of contracted services. These arrangements provide the opportunity, where possible to do so, to respond to pressures highlighted by hospices where there may be a threat to service sustainability.

95. In 2022/23 for example, in addition to funding of £8.818million provided for agreed contracted services for adult services, non-recurrent funding of £0.324million was made available in recognition of financial pressures facing hospices.

96. Similarly, in 2023/24, in addition to the gross contract uplift of 4.9%, additional non-recurrent funding, equating to 0.8% of contract value, was provided to hospices in recognition of non-pay inflationary pressures (c£74k).

97. In July 2024, SPPG wrote to all hospice providers to confirm a non-pay interim uplift for 2024/25 of 1.38% (inclusive of 0.78% uplift in funding to support statutory increase in NLW from April 2024) in respect of contracts from 1 April 2024.

98. The majority of the Department's funding for adult hospices is directed towards hospice inpatient beds. For example, in 2022/23, £6.9m of funding went to hospice inpatient beds. In the same year there were 866 admissions to the hospices of which 473 people died in hospice, circa.3% of the total annual deaths.

Previous Reviews of Adult Hospice Funding

99. There have been two exercises to review adult hospice funding arrangements.

100. In **2014**, the then HSCB undertook a regional exercise to gauge the equivalency of funding to hospice providers and to make a broad assessment as to whether the level of funding provided to hospices for adult services was appropriate.

101. To inform this assessment a "benchmark" of 50% of the average cost of a General Medical bed in NI was applied as an appropriate proxy for reasonable cost when assessing the application of a 50% funding contribution for hospice inpatient beds.

102. The analysis undertaken at that time showed that funding for hospices was appropriate, except in the case of one hospice, as a result of which additional funding was added recurrently to the funding provided to that hospice to address the shortfall identified.

103. Since then, as part of the annual review of voluntary and community contracts, the funding envelope to hospices has been uplifted through annual increases to the contract value.

104. In **2019/20**, the then HSCB undertook a further comparative review of adult hospice funding which was completed in 2020. As part of this review, the costs of hospice services were benchmarked against equivalent services provided in Health and Social Care via Trusts.

105. In order to ensure broad comparability with services in the NI HSC system for benchmarking purposes, professional medical and nursing advice was sought from the Public Health Agency in respect of the professional inputs to the various elements of the services commissioned from hospices.

106. In respect of in-patient hospice services, the benchmark used was the average cost of a Trust General Medical bed. The benchmarking exercise also included consideration of Day Hospice costs and those of the specialist community palliative care nursing services.

107. The HSCB also undertook a desktop exercise to understand the funding of similar services in GB.

108. The 2019/20 review process identified a total funding shortfall of £867k between the 2019/20 funding provided to hospices, compared against the costs assessed based on the benchmarking review. The identified funding shortfalls were made to hospices backdated to 1 April 2019.

Proposed Review of Adult Specialist Palliative Care

109. The Department has acknowledged that the current funding arrangements for adult hospice services have been in place nearly 20 years and it is appropriate that these arrangements are reviewed.

110. In 2021, it was therefore proposed that a comprehensive review of adult specialist palliative care services, based on a co-production approach, would be helpful to inform future planning and delivery of services and funding arrangements, as well as providing greater clarity about what specialist adult palliative care services are needed and how these can best be commissioned, delivered and funded to meet the future needs of our population.

111. Given the ongoing and challenging financial and resource pressures facing the Department, it has not been possible to undertake a proposed review of specialist palliative care for adults.

112. The Department recognises that as the population increases, with more people living longer and with more complex conditions, the demand and need for palliative care will continue to grow. It is important that the Department ensures that palliative care services are planned and designed to meet demand and need.

113. On 19 December, Minister Nesbitt met with representatives from Hospice UK and the Hospice Alliance NI (made up of the 4 local hospices). At that meeting, the

Minister advised that the Department will undertake a scoping exercise in 2025 to consider the current provision of adult palliative care services and undertake an assessment of projected needs.

114. The outcome of this exercise will inform the future planning and commissioning of adult palliative care services across the region, including specialist palliative care services provided by hospices.

115. The Department has commenced work on the remit of this exercise and will engage with stakeholders as part of this.

PAEDIATRIC PALLIATIVE CARE

Strategic and Policy Context

116. In 2016, the Department of Health published two paediatric strategies: *A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community 2016-2026* and *A Strategy for Children's Palliative and End of Life Care 2016-2026*.

117. The strategies were built upon the principles of "Health and Wellbeing 2026: Delivering Together", with the clear aim of delivering better health and wellbeing outcomes for children in Northern Ireland.

118. The *Strategy for Children's Palliative and End-of-Life Care*, published in November 2016 (accessible via the link below), sets out 23 objectives across the spectrum of paediatric palliative care from diagnosis through to bereavement care.

https://www.health-ni.gov.uk/sites/default/files/publications/health/paediatric-strategy-palliative-end-of-life-care.PDF

119. A concerted effort to deliver against the 23 objectives as set out within the Strategy was not practicable until funding was made available to assist with a number of priorities. Funding became available as part of the Confidence and Supply agreement.

120. In 2019 a Regional Paediatric Palliative Care Network (RPPCN) was created, chaired by a Paediatric Palliative Clinical Care Lead. The network is made up of key clinical and nursing leads from each Health and Social Care Trust as well as the Northern Ireland Children's Hospice. The network works on two main areas. Firstly, the network identifies the key priorities for delivery in line with the Strategy and puts in place measures to deliver same, and secondly the network acts a vehicle for the region to identify areas of best practice and share clinical opinion on specific cases.

121. To date, the network has developed ante-natal care pathways, rapid discharge plans, advanced care plans and has agreed pathways regarding pain relief, amongst others. Currently the network is also working on other key issues, including the provision of 24/7 end of life care as well as examining how to best develop closer ties with colleagues in the Republic of Ireland.

122. Much work has been done on the development of improved paediatric palliative care provision in Northern Ireland and more will be done by the RPPCN to ensure Northern Ireland can continue to improve. The network works closely together to ensure that irrespective of where a child lives in Northern Ireland, they can access high quality paediatric palliative care.

123. There are paediatric palliative care clinical leads in each of the Health and Social Care Trusts to lead paediatric palliative care in their Trusts and ensure that best practice is shared with colleagues in other Trusts and regionally and a regional paediatric palliative care consultant was appointed to clinical leadership to the service across Northern Ireland. However, currently the regional paediatric palliative care consultant post is vacant and the RPPCN and Belfast Trust are working together to find a short-term solution to the needs of the service until a longer solution is available.

124. In addition, there is a Paediatric Palliative and Life Limited Nurse employed by the Northern Ireland Children's Hospice at the Royal Belfast Hospital for Sick Children.

125. The RPPCN has identified three key priorities and is working on delivering those now. These are:
    - the amendment and improvement to ante-natal care pathways
    - advanced care plans; and
    - assessment of the current provision on 24/7 end of life care.

126. The RPPCN will continue to review and deliver improvements to paediatric palliative care to ensure children and young people in Northern Ireland receive optimal care.

Children's Hospice Services- Funding

127. The Northern Ireland Children's Hospice provides specialist respite, palliative and end-of-life care to children and young people living with life limiting and life-threatening illnesses. It is the only children's hospice in Northern Ireland and provides care and support to children from across the region and their families.

128. The needs of life limited children are often complex and will involve a range of professionals collaborating to meet their palliative care needs. Children's palliative care services are largely provided by the Health and Social Care Trusts in hospital and community settings, however alongside this, there are services that are provided by the Northern Ireland Children's Hospice.

129. Funding for the NI Children's Hospice is different to that for adult hospice services. The Department of Health has Service Level Agreements in place with the Northern Ireland Children's Hospice for the delivery of agreed commissioned services for bed nights and community support services. Relative to the total cost of commissioned services, funding has been in the range of 30% for bed nights and up to 50% for community support services.

130. In 2023/24, the Department provided funding of £1.857m to the Northern Ireland Children's Hospice. This funding included £0.015m for support in respect of inflationary pressures and £0.17m to support a bed in Northern Ireland Children's Hospice following on from the closure of the Horizon West facility.

131. In May 2018, following the closure in 2017 of the four-bedded Horizon West hospice unit based in Fermanagh[1], the Department of Health provided funding for 50% of a bed in the NICH - £0.17million. This bed, the 'Horizon West/ One-hour bed' provided families who had to travel more than one hour to the NICH, the opportunity to avail of an additional night in the NICH facility. This funding was agreed for three years from 2018/19 to 2020/21. Due to COVID, the funding was extended for a further two years until end of March 2023. Following representations by the Northern Ireland Children's Hospice, this funding was further extended until the end of March 2024.

132. In 2024/25, the Department provided funding to the Northern Ireland Children's Hospice of £1.685 million to commission NICH to deliver:
    - Bed nights in Horizon House, an inpatient unit offering supported short breaks.
    - A specialist community team including a 24-hour on call service.
    - A family support service, including bereavement support.
    - The Palliative and Life Limited Service - the PALLS nurse facilitates the transfer of children from hospital to non-hospital settings, which could be back to home or to the Northern Ireland Children's Hospice, for step down or step up care, or where appropriate end of life care.
    - The Hospice at Home Service providing practical nursing care, support and short breaks to children in their own home or community.

133. The 2024/25 funding for the Northern Ireland Children's Hospice includes inflationary uplifts for non-pay and National Living Wage.

Annual NICH Funding

Year	Funding *
2021/22	£1.326m** (this includes £68,897 non-recurrent funding in relation to staffing)
2022/23	£1.830m** (this includes £64,756 non-recurrent funding in recognition of non-pay inflationary pressures)
2023/24	£1.857m** (this includes £14,738 non-recurrent funding in recognition of non-pay inflationary pressures)
2024/25	£1.685m**

*These figures do not include funding provided by HSC Trusts for any contract arrangements they have

**The above figures do not include:

- The NI Hospice, including the NI Children's Hospice, received £8.23m of additional non-recurrent COVID-19 funding which was made available to local hospices in 2020/21 to recognise the impact of the COVID-19 pandemic on both fundraising ability and the provision of services;
- funding provided for the special Staff Recognition Payment for hospice staff (2021/22 and 2022/23).

[1] Horizon West was a NI Children's Hospice service previously provided in Fermanagh but which was not commissioned by the then HSCB.

Core grant funding provided to the NI Hospice as part of the Department's Core Grant funding scheme (annually).

REGIONAL PALLIATIVE CARE WORK PLAN 2023-26

Oct 2024

This document is an overview of the Regional Palliative Care Work Plan 2023 -26 for Northern Ireland. The information contained is correct at a point in time for presentation following the Regional Palliative Care in Partnership Programme Board meeting on Monday 14th October 2024 (Meeting 19).

Palliative Care
in partnership

TABLE OF CONTENTS

Work Plan Key:

Complete
In progress/on track
Not on track (requires escalation)
Not yet started
New Workstream/Activity added since last Regional Programme Board Meeting

REGIONAL WORK PLAN STATUS: October 2024

	Workstreams
Complete	11
In progress (within timeline)*	34
Not on track (for escalation)	0
Not yet started	6
Total Workstreams	**51**
No. of which added since last Programme Board	**(4)**

*10 of the workstreams currently in progress have been classified as Business As Usual (BAU) and therefore are not expected to complete during the lifetime of this regional work plan. These workstreams are indicted by BAU on the following dashboard.

Palliative Care in Partnership Programme Team	Roger Kennedy (Programme Director, SPPG), Diane Walker (PCiP Macmillan Programme Manager, SPPG), Saika Akram (PCiP Macmillan Project Support Manager, SPPG), Sally Convery (Nurse Consultant Palliative Care, PHA)

Palliative Care in partnership

WORKSTREAM DASHBOARD

Priority	Work stream #	WORKSTREAM	Progress	Due to complete	Lead	Notes
Early identification	1	**Regional roll out of AnticiPal in GPiP**		Jun-25	PCiP	Continuing to explore potential opportunities/mechanisms for roll out to General Practice
Co-ordination & QI	2	**Updating Regional Symptom Management and Opioid Equivalence Guidance**		Jun-23	CEG	8000 copies of Symptom Management & 4000 copies of Opoid Equivalence printed and distributed. QR codes developed for both.
Public health approach	3	**Palliative Care Week 2024 (8 - 15 Sep 2024)**		Sep-24	All members	All activites for PC Week 2024 Completed
Early identification	4	**Working with HSC professionals to encourage proactive identification of PEOLC patients**		2026	PCiP	Further discussions required with primary care, care home and unscheduled care colleagues to agree PCiP actions
Co-ordination & QI	5	**Hospice Quality Indicators Project**	BAU	Mar-25	PCiP/ Hospices	Hospice inpatient online reporting piloted May - Sep 24 - final amendments being made ahead of go-live. Community SPC Nursing online reporting pilot due to commence Nov 2024.
Co-ordination & QI	6	**Palliative Care Pharmacy Posts**		Jun-23	PCiP/SPPG/Trusts	Business cases completed and approved - all Trusts have now recruited to the available posts.
Co-ordination & QI	7	**National Audit for Care at End of Life**		Oct-25	PCiP/Trusts	Data collection began July 2024. All 5 Trusts participating (17 submissions, 21 hospital sites).NI Data Improvement Tool live and available for participating Trusts to view.
Co-ordination & QI	8	**SPC Workforce Planning Report Update in light of Covid**		Oct-23	CEG	Update agreed - submission to DOH through PHA Directorate of Public Health Feb 2024. Accepted and waiting noting by Minister.
Public health approach	9	**PCiP Website**	BAU	Ongoing	PCiP	Full refersh of PCiP webiste and updates to meet 'Accessibility' requirements underway. Site to be updated with current Winter Prepaeredness information by end of Nov 2024.
Co-ordination & QI	10	**Scoping and costing a 7 day model for SPC nursing**		Apr-25	CEG	Nursing census developed,to be completed and returned by 20 Sept 2024 to allow QA process to commence.
Co-ordination & QI	11	**Regional Palliative Care 'Status of Services Report'**		TBA	PCiP	Initial scoping underway to support Assembly researchers request ahead of the Health Committee Inquiry into palliative care.
Public health approach	12	**Interim Reprint of Your Life Your Choices Booklet**		Nov-23	PCiP	Content signed off - pdf available on PCiP website and hard copies available through Be Macmillan website

Priority	Work stream #	WORKSTREAM	Progress	Due to complete	Lead	Notes
Co-ordination & QI	13	**Palliative Care Keyworker Quality Indicator Project**	BAU	Ongoing	PHA	Monthly returns (2 month lag) - Full presentation at PCiP Board Meeting 17, continuing updates on Trust compliance to be included in PCIP Programme updates. SET and BHSCT currently unable to participate due to encompass and need to validate the data extractions.
Co-ordination & QI	14	**Regional Syringe Pump Guidance & Education**		Sep-24	CEG	Final amendments being made ahead of design process
Co-ordination & QI	15	**Regional Syringe Pump Documentation**		Sep-24	CEG	Final amendments being made by Medical Illustrations
Education & training	16	**Advanced Communication Skills Project**		Mar-25	PHA/PCiP	Workstream reopeded Jan 2024 - PCiP working ollaboratively with Interim Regional ACST Project Lead to support the project until permanent postholder recruited.
Co-ordination & QI	17	**Regional approach to Individualised EOL Care Plans**		N/a	TBA	DOH statement shared at Sep 23 Regional Board meeting - not to be progressed at present.
Co-ordination & QI	18	**Progressing Cancer Strategy Palliative Care Actions 47 -49**	BAU	Ongoing	PCiP	Also see Workstreams 13 & 23. Quarterly updates provided to Actions SRO and Regional Cancer Programme Board.
Co-ordination & QI	19	**Encompass Palliative Care Workflow**		Ongoing	Epic	SET & BHSCT now live on encompass - range of palliative care concerns rasied by clinicians & hospice- PCiP working with partners and encompass/ epic and Digital Health Care NI to try to resolve.
Co-ordination & QI	20	**Regional SPC Referral Form Update**		TBA	CEG	Unable to progress until current functionality of encompass (epic care link) is clarified - see workstream #19
Co-ordination & QI	21	**Integrated Care System and PEOLC**	BAU	Ongoing	ICSNI	Awaiting further direction from ICSNI
Public health approach	22	**PCiP collaboration with NI Bereavement Network**	BAU	Ongoing	NIBN	Bereavedni.com website testing in Dec 2023- Website launched by Minister March 24. PCiP continue to support content upload and functionality and sit on editorial board.
Co-ordination & QI	23	**OOH Access to Specialist Palliative Care Advice**	BAU	2026	PCiP	SCUK OOH service operating in 3 Trust areas. Allocations extended through 24/25. Participating Trusts to return PPEs and provide quarterly service activity to SPPG.
Early identification	24	**Developing new regional 'Identification & Pathways in ED project'**		On Hold	PCiP/ Marie Curie	Options assessment complete - Information Governance arrangements would be complex and may requie ethics approval - Trusts cautious about proceeding in 24/25 due to encompass implementation.
Co-ordination & QI	25	**Improving Palliative Care in Care Homes**	BAU	2026	PCiP/ PHA/RCN	Additional Care Home representation at Regional Board and CEG - ongoing discussion re. actions to be taken
Co-ordination & QI	26	**Palliative Care Formulary**		Mar-25	PCiP/CEG	PCF subscription renewed to Mar 2025. Audit undertaken of users and usage and unable to justify renewal of subscription beyond Mar 2025. CEG members informed and partners to prepare staff withdrawl of subscription
Co-ordination & QI	27	**Review of End of Life Care Operational System (ELCOS)**		TBA	CEG	Due to programme and CEG capacity- unable to progress at present.

Priority	Work stream #	WORKSTREAM	Progress	Due to complete	Lead	Notes
Co-ordination & QI	28	**Transitions to Adult Palliative Care Services**		Ongoing	PCiP & Paeds PCN	Scoping meetings undertaken with Paediatric Palliative Care Network. Data requested from NISRA to quantify potential need. Agreement to develop joint Briefing paper to bring to regional Boards Q1 2025.
Co-ordination & QI	29	**Regionally agreed patient level outcome mesaures for SPC services**		2025	CEG	Timeline to progress to be agreed.
Public health approach	30	**Inequalities in Palliative Care (hard to reach populations)**	BAU	2026	PCiP	Scoping re. LBGTQi, Prisions and Disabilities commenced. Arrangements in place for AIIHPC/ Rainbow Project to facilitate 3 x Pride in Death events in NI during Q1 2025.
Co-ordination & QI	31	**Palliative Care Health Needs Assessment (Phase 2)**		TBA	TBA	Ongoing discussions with partners to explore feasibility of collaborative approach to HNA PHASE 2
Co-ordination & QI	32	**Belfast Locality Single Point of Access Project**		Jan-25	Belfast PC Locality Board	PCiP membership of Project Steering Group and Service Workstream Model continues.
Education & training	33	**Establish Regional Palliative Care Education & Training Steering Group**		Mar-24	PCiP	Regional Steering Group established. Chair confirmed. Members recruited and first meeting held May 2024. See workstreams 44 - 47 for next steps.
Education & training	34	**Post-graduate Education Pathways for Social Work, SPC AHPs & Pharmacists**		Ongoing	CEG	SPC AHP & NIPCPG considering options for pathways
Public health approach	35	**Use of Marie Cuire Talk About Resources within PCiP work**		TBA	PCiP/ Marie Curie	PCiP to pick up previous work undertaken pre-pandemic.
Co-ordination & QI	36	**Improving Palliative Care Approach in NIAS**		2026	PCiP/NIAS	PCiP link to NIAS reestablished June 24. Exploring next steps in line with NIAS needs and programme/ NIAS capacity to progress.
Co-ordination & QI	37	**Palliative Care Pharmacy Improvements**		2026	PCiP/NIPCPG	Pal Care Pharmacy work plan 2024/25 being led by Regional Palliative Care Consultant Pharamacist
Co-ordination & QI	38	**Pandemic Preparedness - Palliative Care**		Mar-24	Service Team	Emergency Preparedness for Health and Social Care Organisations. Pandemic Preparedness Plan for Hospices agreed with providers
Education & training	39	**Non-medical prescribing SPC Nursing Project (Foyle Pathfinder)**		Jun-25	PHA/CEG	Initial census complete, pilot project proposal accepted by the Prescribing Oversight Board and will run to Mar 2025
Co-ordination & QI	40	**Hospice Monitoring Meetings**	BAU	Ongoing	Service Team	Qtrly meetings with hospice providers
Education & training	41	**Developing proposal for Regional Career Framework for SPC Nursing**		TBA	PHA	Hot Topic Paper prepared for CNO - more scoping required and next steps to be informed by palliative care nursing census completed under workstream # 10
Public health approach	42	**Winter Preparedness for terminally ill patients**		Ongoing	Marie Curie	Roundtable discussion and follow up online seminar delivered. PCiP updating website with current signposting information ahead of 24/25 winter pressures.

Priority	Work stream #	WORKSTREAM	Progress	Due to complete	Lead	Notes
Public health approach	43	**Dignity in Care Conference**		Jun-24	Collaborative	Workshop completed May 2024. Awaiting event report from AIIHPC.
Education & training	44	**Develop Regional PEOLC training framework to support all tiers of staff currently caring for adults with PEOLC needs across all care settings**		2026	Regional PEOLC Education & Training Steering Group	Draft Framework for Tier 1 & Tier 2 staff provisionally agreed by the Steering Group in Oct 24. Work undertaken over the summer identified >100K staff across care settings who could benefit from some level of PEOLC training in their role (estimated >50% of those are outside HSCNI). Next steps- Steering Group members to map existing training provision.
Education & training	45	**Identify opportunities to provide/ standardise training/ information for patients and carers**		2026	Regional PEOLC Education & Training Steering Group	Work being progressed through engagement with new Voices4Care members and Compassionate Communities NI Community of Practice
Education & training	46	**Explore existing provision and advocate for pre-registration and postgraduate PEOLC education across professions**		2026	Regional PEOLC Education & Training Steering Group	Workstream project plan and timeline drafted - to be agreed
Education & training	47	**Explore and make recommendations for SPC professionals to advance their skills through education**		2026	Regional PEOLC Education & Training Steering Group	Workstream project plan and timeline drafted - to be agreed
Co-ordination & QI	48	SPPG review of Day Hospice Services		Apr-25	SPPG/ Hospices	Established as a substantice workstream. Provider scoping undertaken and cost templates for new models completed and submitted by hospices. Awaiting confirmation from SPPG finance of Day Hospice contract allocations 24/25 before progressing next steps.
	49	Respond to Covid Inquiry Module 3 Healthcare provision and treatment (5B)		Aug-24	SPPG	Request from Covid Inquiry team to SPPG to inform this response. Drafted, agreed and submitted in line with inquiry deadlines.
Co-ordination & QI	50	Regional and locality assessment of palliative care provision against the National Ambitions Framework		Apr-25	PciP/ Locality Boards	Initail regional level review complete. Preparation to request consideration at Palliative Care Locality Board underway.
	51	Support development of evidence and briefings for Assembly Health Committee into Palliative Care		TBC	PCiP/SPPG	Awaiting full scope of the inquiry from Assembly Health Committee. SPPG initial response to Assembly researcher requests being progressed with DOH policy colleagues.

Notes:

- Further details of the actions associated with each workstream are available under each priority area in the following pages of this work plan.

PRIORITY 1: Early identification & Timely Intervention

WS #	Workstream	Action Ref	Action	Timeline	Progress	Lead
1	**Regional roll out of AnticiPal in GPiP**	1.1	Testing of AnticiPal in GPIP & dashboard functionality	Jun-23		PCiP
		1.2	Explore with eHealth cost for full regional roll out to all practices and seek in year funding to progress	Apr-25		PCiP/ E-Health
		1.3	Seek permission from GPIP Editorial Board for full roll out and confirm timeline	TBA		PCiP
		1.4	Explore opportunities within Primary Care MDTs for roll out of AnticiPal	Jan-25		PCiP
4	**Working with HSC professionals to encourage proactive identification of PEOLC patients**	4.1	Bring together GP advisers and PCiP GP colleagues to mechanisms to support GPs to improve early identification of palliative care patients	Apr-23		PCiP
		4.2	Explore Social Finance model to support Palliative Care Facilitators for GP Federations	Jun-23		PCiP
		4.3	Facilitate inclusion of e-SPICT tool within Encompass In-patient to support identification at discharge	Oct-23		PC eFDCG
		4.4	Discussions with DOH policy re. QOF and pallaitive care	May-24		DOH
		4.5	Work with SHCSCT Servive Improvement Lead to consider currently identification work in ED, learning and potential for scale and spread	Feb-25		PCiP/SHCST
		4.6	Invite SHCST to present ED work at futire Regional PCiP Programme Board meeting	TBA		PCiP/SHCST
24	**Developing new regional 'Identification & Pathways in ED project'**	24.1	Develop options for delivery within funding and timeline & have exploratory dicussions with Trusts & Marie Curie re. feasibility	Sep-23		PCiP
		24.2	Agree reprofiling of funding with CFNI	Oct-23		Marie Curie
		24.3	Explore possible challenges re. recruitment and data sharing arrangements with BSO.	Oct-23		PCiP
		24.4	Meet with SPPG Unscheduled Care colleagues to guage level of support for next phase of scoping	Oct-23		PCiP
		24.5	Agree Preferred Option for delivery	Dec-23		PCiP/Marie Curie
		24.6	Explore feasibility of third party delivery with SPPG information governance	Jun-24		PCiP

		24.6	Explore feasibility of third party delivery with SPPG information governance	Jun-24		PCiP
		24.7	Discuss preferred option with Trusts and determine locality participation	On Hold		PCiP
		24.8	Establish Project Working Group - members and Terms of Reference	On Hold		PCiP/Marie Curie
			Follow on actions to be added Project Working Group is established	On Hold		

PRIORITY 2: Co-ordination & quality improvement of palliative and end of life care services

WS #	Workstream	Action Ref	Action	Timeline	Progress	Lead
2	**Updating Regional Symptom Management & Opioid Equivalence Guidance**	2.1	Circulate updated drafts to GEG for comments	Feb-23		PCiP
		2.2	Source funding for printing	Feb-23		PCiP
		2.3	Gather quotes for printing and complete procurement process	Feb-23		PCiP
		2.4	Oversee editorial process printers and sign off for print	Mar-23		PCiP
		2.5	Arrange delivery to Trusts to Hospices	Apr-23		PCiP
		2.6	Upload update Guidance to PCiP website	Apr-23		PCiP
		2.7	Circulate updated Guidance to CEG members to use across network	Apr-23		PCiP
		2.8	Ensure updated guidance uploaded to GP Primary Care Intranet	Apr-23		PCiP/ SPPG
		2.9	Share updated version with RQIA for circulation to Care Homes	Apr-23		PCiP/ RQIA
		2.10	Develop QR codes for both regional documents and circulate to network	Aug-23		PCiP
5	**Hospice Quality Indicators Project**	5.1	Develop and agree data definition and data metrics for the quality indicators	Apr-23		PCiP & Hospices
		5.2	Complete application for PMSID time to develop data collection tool and dashboards	May-23		PCiP/PHA
		5.3	Submit Data Definitions to HSC Information Standards Group for review	Oct-23		PCiP/PHA

		5.4	Submit requested information to PSSID to gauge PSSID time required for work	Oct-23		PCiP/PSSID
		5.5	Develop inpatient and community nursing data collection tools	Mar-24		PSSID
		5.6	Internal testing of inpatient data collection tool and dashboard	Apr-24		PCiP/ PSSID
		5.7	Inpatient pilot preparation sessions with Hospices	Apr-24		PCiP/ Hospices
		5.7.1	Invite Macmillan Inpatient Unit @AAH to join the online inpatient reporting	Apr-24		PCiP
		5.8	3 month inpatient data pilot with Hospice providers	Jul-24		Hospices
		5.9	Review and amend inpatient data collection tool and dashboard following pilot phase	Nov-24		PCiP/ PSSID
		5.10	Go - live for inpatient online reporting and regaionl dashboard	Dec-24		Hospices
		5.11	Community nursing pilot preparation sessions with hospices	Jul-24		PCiP/Hospices
		5.12	Internal testing of community nursing data collection tool and dashboard	Oct-24		PCiP/Hospices
		5.13	3 month community SPC nursing data monitoring pilot (Nov 24 - Jan 25)	Jan-25		PCiP / Hospices
		5.14	Review and amend community nursing data collection tool and dashboard following pilot phase	Feb-25		PCiP/PSSID
		5.15	Go live for community nursing online reporting and regional dashboard	Feb-25		Hospices
		5.16	Invite other Trusts who hold additional community nursing contracts to participate in online reporting to provide full regional overview of Community SPC Nursing activity	Feb-25		PCiP/NHSCT/ SHSCT/ WHSCT
		5.17	Explore ways of capturing requirements for Hospice reporting staff education & training and patient experience through online reporting	Mar-25		PCiP/ Hospices/ PSSID
6	**Palliative Care Pharmacy Posts**	6.1	Identify funding available and assess options for Palliative Pharmacy provision to address existing gaps in service	Feb-23		Service Team
		6.2	Draft 3 x Business Cases	Apr-23		Service Team
		6.3	Review and return of signed business cases	Jun-23		Trusts
		6.4	Draft and send Allocation letters	Jul-23		Service Team
		6.5	PPE reporting on Palliative Care Pharmacy posts activity and impact	Sep-24		Trusts/PCiP
7	**National Audit for Care at End of Life**	7.1	Plan and deliver NI Round 4 Findings Event	Mar-23		PCiP
		7.2	Agree NI Round 4 Summary Report	Apr-23		PCiP
		7.3	Update NACEL DPIA for Northern Ireland	Sep-23		PCiP/ PHA
		7.4	Prepare for close down of Rounds 1- 4 & arrange data transfer	Jan-24		PCiP/ PHA

		7.5	Participation in NHS NACEL Steering Group	Ongoing		PHA
		7.6	Preparation & return of Trust NACEL Recommendations Action Plans	Sep-23		PCiP/ Trusts
		7.7	Discussions with NHS Benchmarking re. future NI participation in 'new' NACEL	Dec-23		PCiP/ PHA
		7.8	Explore views re. new Quality Survey and potential for NI to opt in or opt out	Dec-23		PCiP/ NIBN
		7.9	Agree NHS Benchmarking NI Proposal for NACEL 24/25	Dec-23		PHA/ NHS Benchmarking
		7.10	Deliver 'new' NACEL info event for Trusts to determine NI participation	Mar-24		PCiP
		7.11	Seek funding source for NACEL 2024/24	Mar-24		PCiP/ PHA
		7.12	Deliver NACEL Warm Up event for NI	May-24		PCiP/PHA
		7.13	Update NACEL DPIA for Northern Ireland	Jun-24		PHA/NHSB
		7.14	Update Management of Outliers policy	Jun-24		PHA/NHSB
		7.15	Review and edit data specifications for use in NI	Jun-24		PCiP/PHA
		7.16	Participation in NACEL 2024/25 (Data Collection opens 1 July 2024)	Jul-24		Trusts
		7.17	Monthly progress meetings with NHS Benchmarking	Oct-25		PHA/ PCiP
		7.18	Development and testing of the NI Data Improvement Tool	Oct-24		NHSB
		7.19	NI Data Improvement Tool Induction sessions	Oct-24		NHSB
8	**SPC Workforce Planning Report Update in light of Covid**	8.1	SPC professional forums to submit impact of COVID on SPC Workforce rec	Mar-23		CEG
		8.2	Meeting with individual SPC Forum leads	Apr-23		PCiP
		8.3	Validate original education assumptions with UU and NIMDTA	Jun-23		PCiP
		8.4	Confirm SPC education Commssioning arrangements through Covid years with DOH	Jul-23		PCiP
		8.5	Draft SPC Workforce Planning Report Update in light of Covid	Jul-23		PCiP
		8.6	Share draft with PHA/ SPPG Leads for review and comment	Aug-23		PCiP
		8.7	Share draft with SPC Professional Forum leads	Sep-23		PCiP
		8.8	Share updated recommendations with CEG & regional PCiP Programme Board	Sep-23		PCiP
		8.9	Agree final narrative and format update report	Sep-23		PCiP
		8.10	Submit SPC Workforce Planning Report Update to DOH	Oct-23		PCiP

10	**Scoping and Costing a 7 day model for SPC Nursing**	10.1	Draft Terms of Reference for Working Group	Jan-24		PCiP
		10.2	Recruit membership to Working Group	Feb-24		PCiP
		10.3	Plan and run monthly Working Group meetings	Apr-25		PCiP
		10.4	Review regional SPC Working arrangements in line with projected service demands	Jan-25		7 Day Working Group
		10.5	Scope existing models of 7 day working services and examples of 7 day SPC services in other countries	Jan-25		7 Day Working Group
		10.6	Options appraisal of 7 day working models	Apr-25		7 Day Working Group/CEG
		10.7	Costing of preferred option	Apr-25		PCiP
		10.8	Collate findings and drfat report on 7 day model for SPC nursing in NI	Jun-25		PCiP
		10.9	**Following completion of 7 day SPC Nursing - consideration should be given to 7 day working for other members of the SPC MDT**	TBA		
11	**Regional Palliative Care 'State of the Nation' report**	11.1	Review of TYPEOLC Enhanced Access -Gap Analysis Report 2016	Dec-24		PCiP
		11.2	Review and update Locality Services Scoping Template	Jan-25		PCiP
		11.3	Completion of Locality Services Scoping Template	TBA		PC Locality Boards
		11.4	Validation of Scoping Returns, collation and drafting report	TBA		PCiP
		11.5	Locality review of findings	TBA		PC Locality Boards
		11.6	Finalise 'NI State of the Nation Report - Palliative Care Services'	TBA		PCiP
13	**Palliative Care Keyworker Quality Indicator Project**	13.1	Develop and agree DN Keyworker Quality Indicators	Mar-23		PHA/ PCiP
		13.2	Agree, print and distribute DN Palliative Care Keyworker Aide Memoire	Apr-23		PHA/ PCiP
		13.3	Trust DNs collate and submit PC Keyworker QI metrics	Monthly		Trusts
		13.4	Develop sharepoint to provide shared dashboard	Aug-23		PSSID
		13.5	Review 6 months data and identify key challenges and regional actions/learning			PHA/ PCiP
		13.6	Presentation to UU Palliative Care Keyworker	Sep-24		PCiP
		13.7	Explore discussions with PHA/DN Leads to update the Palliative Care Keyworker Role & Function Paper and consider Pal Care Needs Assessment tool for District Nursing	Mar-25		PCiP/PHA/ Trusts

14	**Regional Syringe Pump Guidance & Education**	14.1	Scope membership and seek nominations from relevant stakeholders	Jun-23		PCiP
		14.2	Draft and agree Task & Finish Terms of Reference	Jul-23		PCiP/ T&F Group
		14.3	Plan and run monthly T&F Group meetings	Ongoing		PCiP
		14.4	Set up Working Groups for section development (3 groups)			T & F Group
		14.5	Draft Section content	Dec-23		T & F Group
		14.6	Seek membership from Paedatric Palliative Care Network	Oct-23		PCiP
		14.7	Collate section content, proofreading and editing	Dec-23		PCiP
		14.8	Circulate draft guidance to stakeholders named in TOR for comment	Jan-24		PCiP
		14.9	Consider options for distribution (online and or printed) seek funding if required	Jan-24		PCiP/ T&F Group
		14.10	Consideration of comments received from stakeholders and make necessary amendments	Jul-24		PCiP/ T&F Group
		14.11	Distribution for final comment	Aug-24		PCiP
		14.12	Develop regional competency document and audit tool for infusion site	Sep-24		T&F Group
		14.13	Work with Paediatric colleagues to support development of similar regional guidance & competency document	Dec-24		T&F Group
		14.14	Liaise with designers and obtain quotes for design	Oct-24		PCiP
		14.15	Seek and secure funding source for design	Oct-24		PCiP
		14.11	Release final Syringe Pump Guidance, Education & Training document to network	Nov-24		PCiP
15	**Regional Syringe Pump Documentation**	15.1	Scope membership and seek nominations from relevant stakeholders	Jun-23		PCiP
		15.2	Draft and agree Task & Finish Terms of Reference	Jul-23		PCiP/ T&F Group
		15.3	Plan and run monthly T&F Group meetings	Ongoing		PCiP/ T&F Group
		15.4	Scope existing Syringe Driver documentation across providers	Oct-23		T&F Group
		15.5	Seek membership from Paedatric Palliative Care Network	Oct-23		PCiP
		15.5	Agree draft Regional Syringe Driver Documentation	Dec-23		T&F Group
		15.6	Pilot Regional Syringe Driver documentation	Mar-24		T&F Group
		15.7	Review feedback from pilot and make required amendments	Jun-24		T&F Group
		15.8	Arrange printing and distribution through BSO Regional Stock Lists	Nov-24		T&F Group

17	**Regional approach to Individualised EOL Care Plans**	17.1	Draft and submit Individualised EOL Care Plan Briefing to DOH Policy	Dec-22		CEG
		17.2	Meetings for consideration by DOH Professional Leads CMO and CNO	Sep-23		DOH
			DOH policy position - Workstream not to be progressed. Decision shared with PCiP Programme Board & CEG (Sep 2023)			
18	**Progressing Cancer Strategy Actions 47 -49**	18.1	Confirm Cancer Strategy funding for 23/24 (recurrent or non-recurrent)	Jun-23		PCiP
		18.2	Review Cancer Strategy Actions and align to PCiP Work Plan	Sep-23		PCiP/DOH
		18.3	Action 47 - follow up discussions with DOH to specify priortisation	Ongoing		PCiP
		18.4	Action 48 - See Workstream #13	Ongoing		PCiP
		18.5	Request permission from DO to direct 23/24 funding to OOH SPC Advcie service in line with Action 49	Aug-23		PCiP/DOH
		18.6	Action 49 - see Workstream # 10 & #23	Ongoing		PCiP
		18.7	Regular progress reporting to Cancer Strategy Programme Board	Ongoing		PCiP
19	**Encompass Palliative Care Workflow**	19.1	Participate in encompass Palliative Care eFCDG meetings (monthly)	Jun-24		Encompass/ members
		19.2	Develop scoping template to support encompass review of SPC assessments and forms nd circulate to SPC providers for completion	Mar-23		PCiP/ SPC providers
		19.3	Collate provider responses and report back to Palliative Care eFCDG	Apr-23		PCiP
		19.4	Input to encompass 1/2 workshop for PC inpatient build	May-23		PCiP/ SPC providers
		19.5	Review and update 'SPC Referral Reasons' to inform build	Aug-23		PCiP/ CEG
		19.6	Arrange encompass PC inpatient build demonstration for CEG	Sep-23		PCiP
		19.7	Follow up queries rasied at CEG re. placement of e-SPICT and use of outcome measures	Oct-23		PCiP
		19.8	Support build of DN Palliative Care KPI reporting build in encompass	Oct-23		PCiP/ PHA
		19.9	Explore plans for encompass training for hospices	Jan-24		PCiP
		19.10	Contribute to regional Encompass Palliative Care monthly meetings	Ongoing		PCiP/members
		19.11	Identify process with Digital Health Care NI for hospice to undertake full access feasibility scoping and communicate to hospices &	May-24		PCiP

		19.12	Hospices through the Hospice Alliance to submit a collaboartaive New Request Form to Digital Health Care NI	TBC		Hospices/ Hospice Alliance
		19.13	Escalate emerging concerns from clinicians re. functionality of epic care link for hospices through regional lines	Oct-24		PCiP
		19.14	Support Trust/clinical colleagues to work with encompass to develop palliative care patinet view and implementation of BHSCT palliative care co-ordination system to track and report palliative care patients at Trust level	TBC		Trusts/ encompass /epic
20	**Regional SPC Referral Form Update**	20.1	Expolore feasibility of starting this project in 2024 in line with plan for Regional ACP/ReSPECT implementation and encompass build functionality	Apr-24		PCiP/CEG
		20.2	Write to SPC Providers to request MDT support for development and piloting	TBA		PCiP
		20.3	Draft Task & Finish Terms of Reference	TBA		CEG
		20.4	Recruit Membership to Task & Finish Group	TBA		CEG
		20.5	Plan & run Task & Finsh Group meetings	TBA		PCiP
		20.6	MDT Review and edit of proposed Draft	TBA		T & F Group
		20.7	Updating of Regional SPC Referral Directory	TBA		T & F Group
		20.8	Alignment for new SPC Referral Form to encompass build	TBA		T & F Group
		20.9	3 month pilot from Jun 24 - Sep 24	TBA		SPC Providers
		20.10	Following pilot - Regional Go-live or Review and amend process	TBA		T & F Group/ SPC Providers
21	**Integrated Care System and PEOLC**	21.1	Faciliatate PEOLC Strategic Outcomes Framework Indicators Workshop process	Jan-23		PCiP
		21.2	Organise ICSNI presentation to PCiP Stakeholders at Priority Resetting Workshop	Jun-23		PCiP
		21.3	Respond to ICSNI queries re. data sources	Sep-23		
			Awaiting communication from ICSNI re. next steps			
23	**OOH Access to Specialist Palliative Care Advice**	23.1	Confirm Cancer Strategy funding can be directed to OOH SPC advice	Aug-23		PCiP
		23.2	Scoping of existing OOH SPC Advice services across Localities	Aug-23		PCiP/ PC SILs

		23.3	Request call data from existing services (where available)	Oct-23		PCiP
		23.4	Options appraisal to fill existing gaps in year	Sep-23		PCiP
		23.4	Present Gap Analysis and proposal to fill gaps to PC Service Team, CEG & PC SILs	Sep-23		PCiP
		23.5	Discussions with Localities where gaps exist	Sep-23		PCiP
		23.6	Draft Business Cases	Sep-23		PCiP/ SPPG
		23.7	Complete and Return Business Cases	Oct-23		Eligible Trusts
		23.8	Issue allocation letters	Oct-23		SPPG
		23.9	All locality collection and return of OOH SCP advice service (medic to medic) from start of allocation	Ongoing		Eligible Trusts
		23.10	Trusts to complete and return PPEs	Oct-24		Eligible Trusts
		23.11	Issue allocation letters for continuation in 24/25	Sep-24		SPPG
		23.12	Qtrly return and review of service activity	Ongoing		Eligible Trusts/ SPPG
			Agree next phases - Long term aim to move to a NI provided service for all HSC professionals caring for PEOLC patients in OOH periods	TBA		PCiP/ DOH/PC Locality Boards
25	**Improving Palliative Care in Care Homes**	25.1	Meet with PHA Care Home Nurse Consultant to discuss current challenges for pal care in Care Homes	Sep-23		PCiP
		25.2	Meet with RCN Independent Sector Nurse Managers to explore current challenges	Oct-23		PCiP/RCN ISNM Network
		25.3	Procure Page Tiger Licence for PCiP Programme and attend training			PCiP
		25.4	Scoping for Care Home Palliative Care Page Tiger	On hold		PCiP/ PHA
		25.5	Agree content and develop Palliative Care in Care Homes Page Tiger	On hold		PCiP
		25.6	Gaining clairty of VoLE process in Care Homes following Covid and training arrangements for care home staff	Dec-23		PCiP/PHA
		25.7	Redrafting Care After Death guidelines - inclusion of care home practices	Jun-24		NI Bereavement Network
		25.8	Regular meetings with RCN Independent Nurse Manager Network	Ongoing		PCiP/ RCN
			Further actions to be agreed as specifc regional needs emerge from ongoing engagement			PCiP
26	**Palliative Care Formulary**	26.1	Draft and agree PCF User Survey to support renewal of regional PCF subscription	Feb-23		PCiP
		26.2	Issue User Survey to regional PCF users for completion	Feb-23		PCiP
		26.3	Collate User Survey responses and report	Mar-23		PCiP
		26.4	Source and secure funding for Regional PCF Subscription for 23/24	Mar-23		PCiP

		26.5	Validation of existing 23/24 users with all providers leads	May-23		PCiP
		26.6	Monitor quarterly usage statistics	Ongoing		PCiP
		26.7	Update CEG on PCF Usage stats and need to increase usage	May-23		PCiP
		26.8	Members to encourage their PCF users to access the service	Ongoing		CEG/ Provider Leads
		26.9	Source funding stream for 24/25 renewal	Mar-24		PCiP
		26.10	User audit - Consideration of appropraiteness of current user allocations ahead and alternative user groups	Jun-24		PCiP/CEG
		26.11	Consideration of benefits of continuing regaional subscription and decision to be taken for 25/26 year	Sep-24		SPPG
		26.12	Inform CEG/providers of decision to not renew the regional subscription beyond Mar 2025. Providers to inform users and plan ahead for cancellation.	Jun-24		PCiP/CEG
		26.13	**CANCELLATION OF REGIONAL PCF SUBSCRIPTION**	Mar-25		SPPG
27	**Review of End of Life Care Operational System (ELCOS)**	27.1	Initial request for comments on required updates to the 2016 ELCOS from CEG	TBA		PCiP/CEG
		27.2	Collation of comments and review	TBA		PCiP/ CEG
			Next steps to be agreed following initial review by CEG	TBA		CEG
28	**Transitions to Adult Palliative Care Services**	28.1	Data collection - paediatric PC patients due to turn 16 in 2024	Nov-23		Paed PCN
		28.2	Scoping with networks and research of practice in other jurisdications	Feb-24		PCiP/ Paed PCN
		28.3	Drafting Briefing Paper for PCiP Programme Board and Paedatric Palliative Care Network	Feb-25		PCiP/ Paed PCN
		28.4	Workshop to establish Working Group/ Action Plan (subject to funding)	TBA		PCiP/ Paed PCN
			Further actions to be agreed following Workshop at 28.3			
29	**Regionally agreed patient level outcome measures for SPC services**	29.1	**Working Group Set up and Actions to be agreed at project initiation c. 2025**	2025		PCiP/ CEG
31	**Palliative Care Health Needs Assessment (Phase 2)**	31.1	Exploration of potential for Needs Assessment Collaborative Project	Dec-24		PCiP/ All members

32	**Belfast Locality Single Point of Access Project**	32.1	PCiP membership of Project Steering Group - monthly meetings	Jan-25		Belfast PC Locality Board
		32.3	PCiP membership of Service Model Workstream - weekly meetings	Jan-25		Belfast PC Locality Board
		32.3	Providing commissioning context and advice to Trusts and collaborative providers as Belfast Palliative Care Community Hub service model is developed	Jan-25		SPPG
		32.4	Invite Belfast Community Palliative Care Hub to present at Regional Board	Oct-24		PCiP
36	**Improving Palliative Care Approach in NIAS**	36.1	Re- establish PCiP programme pre-Covid links with NIAS	Aug-24		PCiP
		36.2	Review pre-Covid PCiP/NIAS proposals to improve PEOLC within NIAS and assess for appropriateness to progress or rethink in line with new needs	TBA		PCiP/NIAS
			Further actions to be agreed following review as at 36.2			
37	**Palliative Care Pharmacy Improvements**	37.1	Secure funding for 3 WTE Palliative Care Pharmacists across providers as per workstream # 6	Jun-23		PCiP/SPPG
		37.2	Recruit and integrate new Palliative Care Pharmacists into exiting service provisions	Dec-23		Trusts
		37.3	Future actions for PCiP to be crossreferenced with Regional Palliative Care Consultant Pharmacist Work Plan for 2024	Ongoing		PCiP/ BHSCT/ SPPG
38	**Pandemic Preparedness - Palliative Care**	39.1	Attend Regional Pandemic Preparedness Task & Finish Group meetings	Oct-23		PHA
		39.2	Meet with hospices to progress Business Continuity Plans	Aug-23		PHA/ Hospices
		39.3	Draft Pandemic Preparedness for Hospices Action Plan	Sep-23		PHA/ Hospices
		39.4	Circulate to Hospices and Palliative Care Service Team for comments	Sep-23		PCiP
		39.5	Review comments, edit and agree Pandemic Preparedness for Hospices Action Plan and submit to Taks & Finish Group	Feb-24		PHA/PCiP
		39.6	Trusts to agree Trust pandemic plans will include escalation plans to supporting the local hospice inpatient unit if staffing levels are comprised	Feb-24		Trusts/ Locality Boards
		39.7	Hospices to align Business Continuity plans to the Regional Pandemic Action Plan for Hospices	Feb-24		Hospices

40	**Hospice Monitoring Meetings**	40.1	Monitoring Meetings with Hospice Providers	Ongoing		SPPG/ Hospices
		40.2	Respond to RQIA Review of Independent Hospitals and Hospices Report recommendation # 18. See Workstream # 5	TBA		PCiP/Hospices
		40.3	Consideration of current Day Hospice Services and funding allocations	**Established new workstream # 47**		
		40.4	In - year hospice monitoring meetings arranged for Nov/Dec 2024	Dec-24		SPPG/ Hospices
48	**SPPG Review of Day Hospice Services**	48.1	Visits to Hospices to explore and better understand changes to Day Hospice post pandemic and models currently being delivered	Jan-24		PC Service Team Working Group / Hospices
		48.2	Sense check findings from each visit with respective hospices to inform next steps	Mar-24		PC Service Team Working Group / Hospices
		48.3	Explore how Day Hospice models have evolved elsewhere - meetings with Mitford Care Centre, Limerick and St Francis' Hospice, Dublin	Sep-23		PC Service Team Working Group
		48.4	Draft Briefing Paper to inform SPPG/PHA PC Service Team and next steps	Jun-24		PC Service Team Working Group
		48.5	SPPG finance to develop a Day Hospice costs template for hospices to complete with costs for delivering the 'new' models currently in place. Hospices to complete and return	Jul-24		SPPG Finance/ Hospices
		48.6	SPPG Finance to confirm 24/25 hospice allocations for Day Hospice in order tp QA cost template returns	Aug-24		SPPG Finance
		48.7	Review of current Day Hospice monitoing returns (22/23 & 23/24) against existing contract metrics	Jul-24		PC Service Team
		48.8	In year Monitoring meetings organised with providers to discuss	Nov/ Dec 24		PC Service Team/ Hospices
50	**Regional and locality assessment of palliative care provision against the National Ambitions Framework**	50.1	Initial regional review of Ambitions Framework in line with existing policy direction and PCiP work plan	Aug-24		PCiP
		50.2	Seek clarification of terminlogy from Adrienne Betteley (Co-chair National Ambitions Framwork) to alig with NI process and practice ahead of locality consideration	Oct-24		PCiP/ Macmillan
		50.3	Communication to Palliative Care Locality Board Co-chairs to consider current locality services provision and process and complete the National Ambitions Framework self -assessment	Nov-24		PCiP

		50.4	Discussion with Paediatric Palliative Care Network with regards to under 18 provision against National Ambitions Framework	Feb-25		PCiP/ Paediatric PC Network
		50.5	Palliative Care Locality Boards to complete National Ambitions Framework self- assessment tool	Feb-25		PC Locality Boards
		50.6	Collation of Locality Board returns to inform regional position and NI baseleine	Mar-25		PCiP

PRIORITY 3: Palliative Care Education & Training Framework

WS #	Workstream	Action Ref	Action	Timeline	Progress	Lead
16	**Advanced Communication Skills Training Project**	16.1	Support drafting of submission to Commission Advanced Communication Skills Project as per Cancer Strategy Action 53	Jan-23		PHA
		16.2	Support set up of, arranging meetings and minuting of Project Steering Group	May-23		PCiP
		16.3	PCiP representation at ACST Project Steering Group	May-23		PCiP
		16.4	Arrange user experience of communications with V4C members	Jan-23		PCiP
		16.5	Setting up ASCT Project Focus Groups	Mar-23		Project Lead/ PCiP
		16.6	Support development of ASCT data collection template	Feb-23		PCiP
		16.7	Act as link between ASCT Project and SPC profession groups	May-23		PCiP
		16.8	Source funding to support ACST Project Workshop	May-23		PCiP
		16.9	Preparation for ASCT Workshop at Tullyglass Hotel	May-23		Project Lead/ PHA/ PCiP
		16.10	Review and comment of Darft ACST Project Report	May-23		PCiP/ PHA
		16.11	Provide project management support to Dr McCloskey in interim role as Regional ACST Programme Lead	Mar-25		PCiP
		16.12	Work with ACST Project Lead to facilitate as many of the core SPC Team Professionals as feasible are trained in year	Mar-24		PCiP
		16.13	Continue to work with ACST Project Lead to ensure SPC professionals are included in future training opportunities and explore options and sustain models for delivering foundation/intermediate communication training to meet the needs of the those caring for PEOLC patients across care settings	Mar-25		ACST Project Lead/ Cancer Programme Board/ PCiP
		16.14	PCIP representation at Regional ASCT Oversight Group	Ongoing		PCiP

33	**Regional Palliative Care Education & Training Steering Group**	33.1	Draft Terms of Reference for 'PCIP Education & Training Steering Group'	Oct-23		PCiP
		33.2	Consider positioning of Steering Group in overall PCiP Structure	Oct-23		PCiP
		33.3	Recruit membership to Steering Group	Feb-24		PCiP
			Actions of PCiP Education & Training Group to be agreed following establishment of group (see Workstreams 44 -47)			
		33.4	Strenghen Steering Group membership with NIAS, Home Care and additional Care Home represntation	Oct-24		PCiP
34	**Post-graduate Education Pathways for Social Work, SPC AHPs & Pharmacists**	34.1	Scope exiting education for Palliative Care Social Workers and draft proposal for Postgraduate Education Pathway	Sep-23		NIAPCSW
		34.2	Scope exiting education for SPC AHPs and draft proposal for Postgraduate Education Pathway	TBA		SPC AHP Forum
		34.3	Scope exiting education for Palliative Care Pharmacists and draft proposal for Postgraduate Education Pathway	TBA		NIPCPG
		34.4	Seek recurrent funding for Specialist Award Level Postgraduate Diploma in Palliative Care Social Work	Sep-25		NIASPCSW /PCiP
39	**Non- medical Prescribing SPC Nursing Project**	39.1	Identify barriers to prescribing in the community	Sep-23		PHA
		39.2	Scoping of SPC Nursing non-medical prescribers currently unable to prescribe	Sep-23		PHA
		39.3	Meetings with hospice leads to discuss way forward	Aug-23		PHA
		39.4	Draft proposal under for pilot solution to be submitted to Integrated Presecribing Oversight Board	Mar-24		WHSCT/PCiP / SPPG
		39.5	Agree project governance and project group	Mar-24		WHSCT/PCiP / SPPG
		39.6	Deliver pilot project (6 months minimum)	Mar-25		WHSCT/ Foyle Hospice/ SPPG
		39.7	Monthly Pathfinder meetings	Ongoing		
		39.8	Develop communication processes between hospice and GP colleagues	Sep-24		
		39.9	Review prescription processes and agree with pathfinder members	Sep-24		
		39.10	MOIC collation of baseline data and data collection throughout pilot	Ongoing		
		39.11	Liaise with BSO to idetify process for hospice colleagues to get cipher codes and prescription pads	Ongoing		

40	**Developing proposal for Regional Career Framework for SPC Nursing**	40.1	Review SPC Nursing Workforce data submitted in 2017	Jul-23		PHA
		40.2	Discuss findings with SPC Senior Nurse Reference Group	Jul-23		SPCSNRG
		40.3	Prepare Hot Topic paper to request support to progress with CNO	Aug-23		PHA
		40.4	Seek support from Macmillan to progress formal scope of SPC Nursing Workforce	Dec-23		PHA
		40.5	Develop SPC Nursing Workforce Census Data Collection Template	Jun-24		PCiP
		40.6	Seek advice from Infromation Governance re. data collection template	Jun-24		PHA
44	**Develop Regional PEOLC training framework to support all tiers of staff currently caring for adults with PEOLC needs across all care settings**	44.1	Draft and agree workstream project plan	Jun-24		PCiP
		44.2	Based one previous regional work - draft initial PEOLC education and training framework to initiate dsicussions	Jun-24		PCiP
		44.3	Develop templates for Steering Group members to complete the 'Who' (Tier 1 & 2) needs trained and 'What' do they need training in scoping exercises	Jun-24		PCiP
		44.4	Steering Group members to complete the 'Who' and 'What' scoping exercises within their representative organisations/ forums and return	Aug-24		Steering Group members
		44.5	Returns from scoping exercises to inform Draft Framework - to be agreed as working draft by Steering Group	Oct-24		PCiP/ SG
		44.6	Proactively seek closer engagement with the Care Home & Home Care sector	Oct-24		PCiP
		44.7	Deliver specific care home/home care engagement event to inform draft framework (Teams event delivered 2 October 2024)	Oct-24		PCiP/NISCC/ IHCP
		44.8	Link with ACST Project Lead to explore links with development of other tiers of communication skills training	Sep-24		PCiP
		44.9	Invite ACST Project Lead to join Steering Group	Sep-24		PCiP
		44.10	Develop templates for Steering Group members to map existing education and training offerings against the working draft of the framework	Nov-24		PCiP
		44.11	SG members to work with their representative organisations/ forums to map existing offerings against the working darft of the framework and return	Jan-25		SG members
		44.12	Returns to inform where there is existing offerings which can be considered for standardisation/ scale and spread and to identify genuine gaps in provison	Feb-25		PCiP

45	**Identify opportunities to provide/ standardise training/ information for patients and carers**	45.1	Draft and agree workstream project plan	Jun-24		PCiP
		45.2	Initial discussions on re. education and training for patients and carers with outgoing V4C cohort	Jun-24		PCiP/V4C
		45.3	Brief Compassionate Communities NI Community of Practice on this workstream and seek involvement from those members	Jul-24		PCiP/ CCNI
		45.4	Scope and identify existing PEOLC service user and carer training courses from other countries	Sep-24		PCiP
		45.5	Enage with new cohort of Voices4Care NI members	Feb-25		PCiP/V4C
46	**Explore existing provision and advocate for pre-registration and postgraduate PEOLC education across professions**	46.1	Draft and agree workstream project plan once working draft of the framework has been agreed by Steering Group (October 2024)	Dec-24		PCiP
47	**Explore and make recommendations for SPC professionals to advance their skills through education**	47.1	Draft and agree workstream project plan	2025		PCiP/CEG

PRIORITY 4: Public Health Approach to Palliative Care

WS #	Workstream	Action Ref	Action	Timeline	Progress	Lead
3	**Annual Palliative Care Week**	3.1	2023 -Participation in AIIHPC Palliative Care Week Reference Group	Aug-23		All members
		3.2	2023 - Advertise Pal Care Week on PCiP website	Aug-23		PCiP
		3.3	2023 - Co-ordinate PHA/ SPPG/DOH internal comms for Pal Care Week	Aug-23		PCiP/AIIHPC
		3.4	2023- Plan, run and attend NI wide Palliative Care Week events	Sep-23		All members
		3.5	2024 - Participation in AIIHPC Palliative Care Week Reference Group	Aug-24		All members
		3.6	2024 - Advertise Pal Care Week on PCiP website	Aug-24		PCiP
		3.7	2024 - Co-ordinate PHA/ SPPG/DOH internal comms for Pal Care Week	Aug-24		PCiP/AIIHPC
		3.8	2024 - Plan, run and attend NI wide Palliative Care Week events	Sep-24		All members
9	**PCiP Website**	9.1	Update PCiP website in line with Accessibility requirements	Mar-25		PCiP
		9.2	Redesign information for public/staff section	Ongoing		PCiP
		9.3	Update useful contacts / resources / events	Ongoing		PCiP

12	**Interim Reprint of Your Life Your Choices Booklet**	12.1	PCiP permission from DOH for Interim reprint of YLYC	Apr-23		PCiP
		12.2	Confirm Macmillan content to support interim reprint and reinstate previous distribution process	Apr-23		PCiP
		12.3	Reconvene PCiP Advance Care Planning Resources Task & Finish Group to review and update content	May-23		PCiP
		12.4	Revisit and update 'Useful Contacts' section and link to PCiP website	May-23		PCiP
		12.5	Seek legal clarification re. ADRT status from DOH	May-23		PCiP
		12.6	Review booklet 'Inserts' as previously agreed in 2020	Jun-23		PCiP
		12.7	Submit content to DOH for agreement	Jun-23		PCiP
		12.8	Review and agree updated artwork, logos and legal disclaimers	Jun-23		PCiP/Macmillan
		12.9	Submit agreed content to Macmillan Editorial Team	Jul-23		PCiP
		12.10	Final editorial and schedule for printing	Oct-23		Macmillan
		12.11	Circulate final pdf and go-live date to PCiP network	Jan-24		PCiP
22	**PCiP collaboration with NI Bereavement Network**	22.1	PCiP represntation at NI Bereavement Network monthly meetings	Ongoing		PCiP
		22.2	Attend and contribute at website meetings every 2 weeks until Dec 2023	Jan-24		PCiP
		22.3	Assist with layout of content and wordpress queries	Dec-23		PCiP
		22.4	Assist with uploading website content	Dec-23		PCiP
		22.5	Assist with developing the NIBN logo	Nov-23		PCiP
		22.6	Co-ordinate CEG and RCN INMN input to review of Care After Death guidance	Jun-24		PCiP/CEG
		22.7	Membership of the Bereaved NI website editorial board	Ongoing		PCiP
30	**Inequalities in Palliative Care (seldom heard populations)**	30.1	Gather/Research exisiting data on inequalities in Pallaitive Care and Organisations with on Ethnicity, Deprivation, Homelessness, Prisoners, Learning Disabilities, LGBTQ+ to determine work in progress and identify gaps.	Feb-24		PCiP
		30.2	Establish links with regional organisations who work with hard to reach populations in each locality area	Ongoing		PCiP
		30.3	Presentation/ report on key challenges for hard to reach groups accessing palliative care services and proposal for actions to address	Jun-25		PCiP
		30.4	Shape the local plans that are needed to ensure fairness in care for those facing the last stage of their lives	Jun-25		PCiP/Locality Boards
		30.5	Explore options to engage with LGBT communities around death, dying and bereavement	Oct-24		PCiP/PHA
		30.6	AIIHPC commissioned to offer 3 x Pride in Death events in 24/25	Mar-25		AIIHPC

35	**Use of Marie Cuire Talk About Resources within PCiP work**	36.1	Re-establish links made in 2020 with Marie Curie Comms re Talk About Resources	TBA		PCiP
		36.2	Develop and agree MOU	TBA		PCiP/ Marie Curie
42	**Winter Preparedness**	42.1	Attend Winter Perparedness Roundtable	Oct-23		PCiP
		42.2	Disseminate information re. Winter Preparedness Seminar	Oct-23		PCiP
		42.2	Update PCiP webiste with public information on support available to people with life limiting illness and as a signposting resource for professionals	Nov-24		PCiP
43	**Dignity in Healthcare Conference (May 2024)**	43.1	Establish organising committee - agree date, scope and agree venue	Dec-23		Conference Committee
		43.2	Seek and secure funding input from HSC Trusts	Jan-24		Trust reps
		43.3	Prepare PHA Grant Application fro venue support	Feb-24		AIIHPC
		43.3	Book flights and accommodation for Prof Chocinov	Feb-24		BHSCT
		43.3	Issue save the date	Feb-24		AIIHPC
		43.3	Open event registration & booking system	Feb-24		AIIHPC

If you have any questions about the activities in this regional palliative care work plan please contact:

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Palliative Care in partnership

Palliative Care
in partnership

Palliative Care Keyworker

Role & Function
2017

Background

The Living Matters Dying Matters strategy (LMDM, 2010) recommended that ***'each patient identified as having end of life care needs should have a keyworker'*** (Recommendation 9)***.***

NICE and the General Medical Council both define the '*end of life'* as ***'people who are likely to (or may) die in the next year (12 months)'.***

The LMDM strategy also highlighted that '***as complexity and/or decline become apparent, the need for care to be planned, organised and delivered, often across care settings, will require significant co-ordination'***. The role of the palliative care keyworker is therefore crucial.

Around 15,000[i] people die each year in Northern Ireland and around 75% (11,250) of those will be expected deaths who could benefit from a palliative care approach. Research shows that 81%[ii] of people, given the choice, would prefer to be cared for and die in their own home. Therefore it is important to ensure that appropriate support, care and advice is in place locally to enable them to do so.

Purpose

This paper is an update to the original **'Definition and Competencies for Keyworker Function'** paper which was agreed by Living Matters, Dying Matters in 2012. The development of this paper has been led by the Palliative Care Project Management Team and updated in collaboration with Public Health Agency Nursing Leads, Regional District Nursing Leads and the Trust Palliative Care Service Improvement Leads, in line with regional priorities for best practice palliative and end of life care and has been approved by the Regional Palliative Care Programme Board – Palliative Care in Partnership on 8 February 2017.

The following paper sets out the regional definition, responsibilities, function and core competencies of the Palliative Care Keyworker role. It is not an overarching policy for delivery and these principles should be embedded into local policies and procedures to facilitate best practice palliative and end of life care at a local level.

Keyworker Definition

The Palliative Care Keyworker (the keyworker) is an identified individual with responsibility for planning and co-ordinating care for patients who (as a minimum) have been identified as likely to be in their last year of life. This should include co-ordinating care across interfaces (within and between professionals, teams and care settings), promoting continuity of care and ensuring that the patient and those important to them know how to access information and advice. The aim of the keyworker role is to ensure communication and co-ordination to ensure maximal quality of life and support the person to remain in their preferred place of care.

Role and Responsibilities of the keyworker

The role of the keyworker is to:

- Act as a main point of contact for person and those important to them
- Provide practical and emotional support to the person and those important to them
- Provide information, where appropriate, and ensure that it is timely and tailored to the person's needs and understanding
- Ensure the appropriate communication/discussions take place at the person's pace to allow them to have an active and informed role in their advance care planning
- Ensure the person's details are appropriately recorded on the local Trust Palliative Care Register/ co-ordination system
- Co-ordinate assessments, referrals and multidisciplinary team care planning to ensure appropriate interventions take place in a timely fashion
- Ensure that assessment, review and update of care plans takes place so that symptoms are managed and physical, emotional, and spiritual needs are met
- Ensure that systems and processes are in place to ensure handover of information on a 24 hour basis to all relevant services
- Ensure those important to the person and carers are aware of who to contact on a 24/7 basis for advice and support.
- Ensure that the carer/those important to the persons needs have been assessed (e.g. offered a carer's assessment and appropriate reviews)
- Co-ordinate and share information within and between care settings and services
- Act as an advocate for the person as appropriate
- Ensure that those important to the person/ carers are supported as necessary including what symptoms and signs to look out for and how these should be managed.
- Provide information and guidance to other professionals relating to the person and those important to them
- Co-ordinate appropriate care in the last weeks and days of life with the aim of facilitating the person to be cared for in their preferred place, where safe, practical and appropriate to do so
- Co-ordinate bereavement follow up.

Core Competencies

The keyworker should be competent in the following areas[1]:

- Overarching values and knowledge of Palliative and End of life Care
- Effective and appropriate communication

[1] Please refer to **Palliative & End of Life Care Competency Assessment Tool 2012 (Health and Social Care – Living Matters, Dying Matters)**

- Facilitating advance care planning (Advance Care Planning Level 2)[2]
- Awareness of the roles and responsibilities of all related professionals/services
- Co-ordination of systems and processes on a 24 hour basis.
- Holistic assessment[3] and care planning
- Symptom management, maintaining comfort and well being
- Co-ordinating care in the last days of life.

Keyworker Function

The keyworker should be named and recorded when (as a minimum) it is recognised that the person is likely to be in their last year of life, has palliative and end of life care needs and is placed on the GP palliative care register i.e. the green phase on the End of Life Care Operational System (ELCOS) onwards. This decision should be discussed and agreed as part of the multidisciplinary team meetings either in primary care or agreed in another setting and then communicated to primary care, respecting person's preference and considering continuity of care.

In cases where the person has a condition which may lead to a loss of capacity (i.e. such as dementia) is it important to identify the person as early as possible (ELCOS Blue Phase) in order to allow time for advance care planning discussion to take place and be recorded (if that is the person's wish).

The District Nurse will **typically** be the keyworker. However, there may be occasions when it would be appropriate for other specialist nurses or AHP professionals to be the keyworker, for example, where it has been agreed that these professionals are best placed to provide the keyworker function. On these occasions, there must be appropriate local procedures in place to ensure there is 24/7 support available for the person and those important to them.

The four operational elements of the keyworker function are:

1. **Identification:** Attending regular (preferably monthly) meetings with GP practices and the MDT team to proactively identify people who are likely to be in their last year of life. Allocating an appropriate keyworker for each person identified and activating palliative care as per ELCOS.
2. **Contact & Co-ordinating care:** Holistic assessment, referrals to services, co-ordinating care, providing advice and support to the person and those important to them. Recording the person's details on the local Trust Palliative Care Register/co-

[2] Please refer to **NI Wide Advance Care Planning Training/Implementation Guidance (Living Matters, Dying Matters 2015)**

[3] Holistic assessment should include assessment of the person's physical, social, emotional and spiritual needs e.g. using tools such as **eNISAT** or the **Palliative Care Aide Memoire.**

ordination system. Facilitating advance care planning discussions[4]. Ensuring local arrangements are in place and that the person and those important to them know who to contact of advice and support 24/7.

3. **Care in the last weeks/days of life:** ensuring person-centred care delivery and emotional support for the person and those important to them in the last weeks and days of life (ELCOS yellow and red phases). Supporting the person to achieve their preferred place of care, when practical and safe to do so.
4. **Bereavement follow –up:** Providing pre and post bereavement support to those important to the person. Including post bereavement visit, signposting to bereavement services, removal of equipment, notes and medications.

The role of the keyworker in other care settings

In Hospitals: When a person who has been identified as likely to be in their last year of life (as a minimum) is admitted to hospital, the hospital staff should make contact with the person's keyworker in the community (typically the District Nurse) to discuss continuing care and discharge arrangements.[5] During the inpatient stay the person and those important to them should have an identified staff member who will be their named contact for the time the person is in hospital.

If a person is identified as likely to be in the last year of life during a hospital stay then it should be recorded within the Regional Discharge Pro-formas and the GP Discharge Summary. Where immediate action is required the hospital should contact the local District Nurse to discuss keyworker arrangements on discharge.

In Hospices: : When a person who has been identified as likely to be in their last year of life (as a minimum) is admitted to a hospice or referred to hospice services, the hospice staff should make contact with the person's keyworker in the community (typically the District Nurse) to discuss continuing care and discharge arrangements (if appropriate) .[6] During the inpatient stay the person and those important to them should have an identified staff member who will be their named contact for the time the person is in hospice.

In Nursing Homes and other longer stay healthcare facilities[iii]: In terms of the four operational elements of the Keyworker role, the District Nurse will play a key role in the identification of residents in Nursing Homes and other longer stay healthcare facilities as part of the GP practice MDT meetings. Once identified, communication should be made with the registered nurses in the nursing home or other longer stay healthcare facilities and

[4] Please refer to ***'Advance Care Planning Operational Guidance for Health and Social Care Professionals in Northern'***

[5] Please refer to '***Guiding principles to enable effective discharge planning for adults from hospitals and transitional settings.' Section 4.2.3***

[6] Please refer to '***Guiding principles to enable effective discharge planning for adults from hospitals and transitional settings.' Section 4.2.3***

they will normally fulfil the other operational elements of the Keyworker role (Contact & Co-ordinating Care, Care in the last weeks/days of life and Bereavement follow-up).

Following identification, the registered nurse within the nursing home/longer stay healthcare facility will be the keyworker and be responsible for assessing and co-ordinating the on-going care needs of the person along with the GP and other members of the multi-disciplinary team. The registered nurse will liaise with other professionals including the District Nurse as required.

Keyworkers in Nursing Homes and long stay healthcare facilities should ensure there is clear communication from the nursing home to the District Nurse (or other appropriate community professional) to ensure the person is included on the local Trust register/co-ordination system (where local systems allow) once they have been identified (as a minimum) as likely to be in their last year of life.

Specialist Palliative Care Services

Local arrangements should be in place for the keyworker to make appropriate referrals to specialist palliative care services where the person has unresolved complex physical, emotional, social or spiritual symptoms despite previous interventions.[7]

Specialist Palliative Care professionals should not normally be the keyworker, unless there are particular circumstances which make them best suited to the role. In such cases, appropriate local arrangements should be in place to ensure the SPC professional can fulfil the keyworker role and for there to be 24/7 cover and co-ordination for the person and those important to them.

Monitoring and measures

Each person identified as likely to be in their last year of life (as a minimum) should be:

- Placed on the GP Palliative Care Register for QOF
- Registered on the local Trust Palliative Care Register/co-ordination system
- Allocated a keyworker
- Given the opportunity to discuss and record their advance care planning preferences
- Supported to achieve their preferred place of care, where practical and safe to do so.

[i] Approximate average using NISRA Recorded Place of Death Statistics 2012-2015
[ii] Office for National Statistics (UK) 2015
[iii] Other longer stay healthcare facilities for example the Neurology Unit at Musgrave Park Hospital or Thompson House, Lisburn.

[7] Please refer to '***Community and Inpatient Specialist Palliative Care Services Referral Guidance and Services Directory***'