Northern Ireland
Assembly

13. Committee Inquiry: Access to Palliative Care Services - Consideration of report

This agenda item will commence in closed session, with an indicative time of 4:45 PM

Northern Ireland
Assembly

Committee for Health

Report on Access to Palliative Care Services

Together with the Minutes of Proceedings of the Committee Relating to the Report, Minutes of Evidence, Written Submissions and Research Papers

Ordered by the Committee for Health to be printed XX xxx 2025

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COMMENCEMENT OF THE DEBATE IN PLENARY

Mandate 2022 – 2027 xx Report: NIA XX/XX

Membership and Powers

Powers

The Committee for Health is a Statutory Committee established in accordance with paragraphs 8 and 9 of Strand One of the Belfast Agreement, Section 29 of the Northern Ireland Act 1998 and under Assembly Standing Order No 48. The Committee has a scrutiny, policy development and consultation role with respect to the Department for Health and has a role in the initiation of legislation.

The Committee has power to:

- consider and advise on Departmental budgets and Annual Plans in the context of the overall budget allocation;
- approve relevant secondary legislation and take the Committee Stage of relevant primary legislation;
- call for persons and papers;
- initiate inquiries and make reports; and
- consider and advise on matters brought to the Committee by the Minister of Communities.

Membership

The Committee has 9 members, including a Chairperson and Deputy Chairperson, and a quorum of five members.

The membership of the Committee is as follows:

Alliance Party	Danny Donnelly MLA (Deputy Chairperson) Nuala McAllister MLA
Democratic Unionist Party	Diane Dodds MLA Alan Robinson MLA
Sinn Féin	Linda Dillon MLA Órlaithí Flynn MLA Philip McGuigan MLA (Chairperson)
Social Democratic and Labour Party	Colin McGrath MLA
Ulster Unionist Party	Alan Chambers MLA

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List of Abbreviations and acronyms used in the report

ACP	Advance Care Planning
AfC	Agenda for Change
AHPCC	Association of Hospice and Palliative Care Chaplains Northern Ireland and Donegal Regional Group
AIIHPC	All Ireland Institute of Hospice and Palliative Care
ALBs	Arms's Length Bodies
APM	Association for Palliative Medicine of Great Britain and Ireland
BASW NI	British Association of Social Workers Northern Ireland
BHSCT	Belfast Health and Social Care Trust
CPNI	Community Pharmacy NI
CTA	Community Transport Association
DN	District Nurse
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
DoH	Department of Health
EA	Education Authority
GP	General Practitioner
HSC	Health and Social Care Service
ICU	Intensive Care Unit
LD	Learning Disabilities
NHS	National Health Service
NIAS	Northern Ireland Ambulance Services
ONS	Office of National Statistics
OOH	Out of Hours
PCiP	Palliative Care in Partnership Programme
PEOLC	Palliative and end-of-life care
PCI	The Presbyterian Church in Ireland
PHA	Public Health Agency
PPC	Paediatric Palliative Care
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners Northern Ireland
RCNIPCN	Royal College of Nursing Northern Ireland Palliative Care Network
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
RoI	Republic of Ireland
RPMG	Regional Palliative Medicine Group Northern Ireland
RSPCNG	Regional Specialist Palliative Care Nursing Group
SPC	Specialist Palliative Care
SPPG	Strategic Planning and performance Group

Short Summary of Recommendations

The following is a short summary table of the Committee's recommendations. The full recommendations are provided in Conclusions and Recommendations.

Universal Access to PEOLC	
Recommendation 1	Northern Ireland introduce legislation to mandate the commissioning and funding of PEOLC.
Recommendation 2	The commissioning of PEOLC services be reviewed regarding capacity to meet a statutory duty of equitable PEOLC services.
Hospice Funding	
Recommendation 3	100% funding for hospices with an initial 50% for 2026-27 and a sliding scale increase over 5 years, based on cost of services.
Investment in PEOLC	
Recommendation 4	Immediate investment in a regional Out of Hours PEOLC workforce, generalist and specialist, to be rural proofed.
Recommendation 5	Increased investment in PEOLC pharmacy services with equitable Out of Hours provision prioritised, and rural proofed.
Recommendation 6	A PEOLC scoping exercise specific to SPC adult and children services, in order to expedite investment in MDT SPC services.
Recommendation 7	Increased investment in Paediatric services prioritised for SPC beds, Out of Hours community based cover and respite care.
PEOLC Pathways	
Recommendation 8	Urgent regional implementation of the Advanced Care Planning and the ReSPECT framework.
Recommendation 9	A 24/7 PEOLC telephone and online central point of contact established for co-ordination of PEOLC assistance.
Recommendation 10	All Hospital Emergency Departments have SPC teams, and systems, in place for rapid service access and safe discharges.
Recommendation 11	A fixed regional pathway framework and map of services established for continuity and coordination of patients' journeys.
Recommendation 12	A programme established that fully supports young people as they transition from children's PEOLC services.
PEOLC Tailored Pathways	
Recommendation 13	Investment in training and resources to remove barriers to PEOLC for vulnerable and protected characteristic groups.

Recommendation 14	Greater investment in research and innovation to remove barriers to PEOLC for our autistic population.
Recommendation 15	Stabilised and predictable funding of PEOLC services for our elderly population in every community-based environment.
HSC Staff Support	
Recommendation 16	The ‘Regional Individualised Last Days Care’ planning template embedded in all Trust hospital wards, as a matter of urgency.
Recommendation 17	PEOLC training of all HSC staff to support timely referrals for patients and diagnosis’ received in appropriate manner..
Integrated PEOLC Services	
Recommendation 18	Full read and write access of the Encompass IT system be given to all generalist and specialist PEOLC services.
Public Health Messaging	
Recommendation 19	The Public Health Agency resourced to successfully plan and implement public health messaging on PEOLC.
Hospices	
Recommendation 20	Hospices be included in strategic planning at central department level when it will impact hospice services and finances.
Recommendation 21	The Department provide support to Evora Hospice on its move to the new site for best outcomes for patients.
Governance and Accountability	
Recommendation 22	A permanent Regional Palliative Care Clinical Lead appointed. An interim appointed in the immediate term.
Recommendation 23	The Health Minster commit to and prioritise a programme of work with Executive Ministers to rural proof PEOLC services.
Recommendation 24	The Health Minster commit to a programme of work with Executive Ministers to remove societal barriers to PEOLC.
Recommendation 25	PEOLC services prioritised in ‘Transformation’, ‘Hospital reconfiguration’ and ‘invest to save’ agendas.
Recommendation 26	An internal policy branch with specific responsibility for PEOLC established in the Department.
Recommendation 27	A new regional PEOLC Strategy introduced by the Department which takes account of diverse locality needs.

Executive Summary

Background and Purpose for the Inquiry

1. In June 2024, the Committee for Health agreed to undertake an Inquiry following concerns that the hospice sector was facing significant funding challenges and that not all Palliative and end-of-life care (PEOLC) services were available to patients, and their families and carers, across Northern Ireland. The Committee was also aware that there had not been a Department of Health (DoH) strategy in place since the Living Matters Dying Matters Strategy in 2010.

2. The Committee was concerned that the healthcare system was failing to support patients at the most vulnerable time of their lives. Further, many individuals and families were facing long-term trauma caused by the difficulties they had experienced in trying to access services for their loved ones who had needed palliative and end-of-life care.

3. The Committee put the needs of patients and their families and carers at the forefront of the Inquiry and had the privilege of hearing from PEOLC patients, and families and carers, who generously shared their lived experiences, both good and bad. It is evident that we must do better. They are the reason that we need to see change in the way PEOLC services are provided.

4. The Committee learned early on in the Inquiry that the PEOLC sector has an exceptionally skilled workforce, both statutory and community, across Northern Ireland, who have a passion to keep improving access to high-quality PEOLC services for patients and families. Members found that not only does the sector understand the challenges facing PEOLC services, it also has many solutions to those challenges but is facing barriers to affect the change that is needed.

5. The Committee is grateful to the Minister and DoH officials for their cooperation throughout the Inquiry. This includes the timely provision of responses on issues which Members deemed as urgent.

6. The report shines a spotlight on this area of the health care system in order to assist the Minister and the Department, and the relevant Arms's Length Bodies (ALBs), and meet our shared goals of high quality care and outcomes for patients and their families and carers. The Committee looks forward to continuing to work together to bring about much needed change.

Palliative and End-of-Life Care (PEOLC)

7. The World Health Organization (WHO) states palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.

8. PEOLC is an approach that improves the quality of life of patients, both adults and children, and their families, who are facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification,

correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. PEOLC improves the quality of life of caregivers as well.

9. PEOLC offers a support system to help patients live as actively as possible until death. On 12 June 2025, a patient who had been receiving palliative care since April 2021, following a diagnosis as a result of an emergency admission to the Ulster Hospital, attended the Committee to give oral evidence to the Inquiry and stated,

> *“What does "palliative care" mean to me? To me, palliative care is me living my best life with cancer, living well through my pain management, through my treatment management and having a holistic approach to what I need for my overall well-being going beyond my physical symptoms.”*

10. PEOLC is multidisciplinary, involving generalist and specialist providers. Generalist care is delivered by GPs, hospital doctors, nurses, care home staff, and social workers. Specialist palliative care (SPC) is the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. SPC teams include palliative medicine consultants, clinical nurse specialists, and allied health professionals.

11. All medics, generalists, should be able to provide palliative care to the majority of patients who are facing the last few days, weeks or months of their life without high levels of complexity, and many patients can live well until they die peacefully, requiring only generalist palliative care. If a patient’s needs cannot be met by generalists, that is where specialist palliative care comes in. Specialist teams will work alongside hospital teams to get a patient’s symptoms under control so that they can be discharged back into the community or alongside GPs, and District Nurses (DNs), and live comfortably at home.

12. When patients experience issues that cannot be controlled by specialists in a hospital or the community, a specialist inpatient unit or hospice is required. A consultant in palliative medicine for over 16 years, who works between the Mater Hospital and the Northern Ireland Hospice, stated to the Committee,

> *“Over the years that I have worked in specialist palliative care, I have seen many patients being admitted to the Northern Ireland Hospice inpatient unit with intractable symptoms… wanting to be dead because life had become so miserable that it was no longer worth living.*
>
> *However, with the right balance of medication and holistic support, I see these people transformed within days to people who are comfortable, clear in their thoughts once more, often able to get out of bed, able to have important conversations with their loved ones… They still have a limited time to live. We have not changed that, but we have given them the opportunity to live well until they die.”*

13. In a specialist palliative care unit, the aim is to control those symptoms well with access to holistic care through multi-disciplinary specialist teams and the use of

complex medication regimens and discharge the patient, but some patients will end up spending the last days of their life in a specialist unit.

14. Palliative care is not a specialty for older people. Many dying people leave behind young families. The Committee was told,

> *"To know that the person you love died peacefully with comfort and dignity and that you had the opportunity to tell them that you loved them and say goodbye properly helps to ease the rawness of bereavement, and it allows those bereaved to recover sooner and be able to continue living their lives without crippling memories of unnecessary suffering."*

Committee Approach

15. The Committee held a public consultation from 4 November 2024 to 17 January 2025, on access to palliative care services, and invited written evidence by email and through two separate questionnaires on Citizen Space:

    I. patients, families, carers; and
    II. healthcare organisations and professionals.

16. The Committee is grateful for the written evidence it received which formed a major part of this report's findings. Written evidence was considered from xx organisations, xx health professionals, xx academia, xx 'lived experience'. Section xx of the report provides themed summaries of this evidence. Submissions are included in the appendices.

17. The Committee also commissioned research from RaISe, the Assembly's research branch. Six research reports provided context for the stakeholder evidence gathered. These are included in the appendices.

18. The Department briefed the Committee on 16 January 2025. The Committee then held 18 oral evidence sessions, hearing largely from HSC statutory bodies and the independent hospice sector. However. at the meeting on 12 June 2025, a patient who was receiving palliative care attended and gave oral evidence on their experience of accessing services. Official Reports of the oral evidence sessions are included in the appendices.

19. On 12 June 2025, the Committee also hosted a small 'lived experience' forum and received oral evidence from xx individuals who shared with Members their experience of caring for loved ones who had needed palliative and end-of-life care. The testimonies heard at the forum can be found on the Inquiry web pages. The Official report and further detail of the forum is included in the appendices.

20. The Committee visited the five independent hospices in Northern Ireland: NI Hospice, Marie Curie, Foyle Hospice, Evora Hospice and the Children's Hospice. The Committee also visited St Francis Hospice in Dublin.

21. By visiting hospices, Members were given the opportunity to view their facilities and also meet with consultants, nurses, and multi-disciplinary teams and see

first-hand the nature of caring for palliative care patients. Members also had the privilege of meeting with patients in In-patient Units to hear their testimonies.

22. The Committee wrote to the Minister on a range of issues during the Inquiry, including:
    - January 2025: detail of the Public health Agency Needs Assessment on short breaks, and confirmation on legal requirement on commissioning palliative care services in Northern Ireland;
    - March 2025: palliative care patients access to 24-hour services, a joined up approach to 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) documentation across all trusts and in community and hospital settings, assessment of the reasons for a 9% increase in excess death rates since the covid pandemic, consideration of ensuring all pharmacies have qualified prescribers within their staffing compliment, funding plan to improve community transport, work which has taken place with other departments such as Education and Infrastructure to improve the transport infrastructure and make better use of transport resources such as EA buses which are not in use during school holidays, plans to continue income support for carers following the death of a person in their care;
    - April 2025: failure of the Department to implement the 'Advanced Care Planning: For Now and For the Future' launched in 2022 and widespread concern on the lack of implementation of the ReSPECT document and regional DNACPR;
    - May 2025: proposal for a 'Regional Last Days Care Bundle' or 'Individualised Care Plan' embedded in hospital wards that gives clear prompts for doctors and nurses when reviewing patients in their last hours/days and that can serve as an aide memoire to support the delivery of good last days care;
    - May 2025: the status of the Department's palliative care scoping exercise and the Department's current plans and design for the audit, including a timeline for progress of the audit; and
    - June 2025: the National Lottery funded Programme which is carried out by Cruse Bereavement Support in schools working alongside Education Authority Critical Incident Teams play an important role in Department of Health Advance Care Planning.

The Committee also wrote, in June 2025, to the Education Minister and Education Authority on the bereavement programme being added to the school curriculum.

Universal Right to PEOLC

23. It is clear to the Committee that PEOLC is an acute service and, as such, must be universally accessible across Northern Ireland and a priority of the Executive. However, the Committee heard compelling and consistent evidence from stakeholders that palliative care is not being prioritised by government in Northern Ireland.

24. The Committee identified a number of key themes that highlighted there were significant gaps in the provision of adult, young adult, and children's PEOLC services across Northern Ireland. While this is all too common across all services in the Health system, it was highlighted to the Committee that in end if life care you have just one chance to get it right for the patient and their families and carers.

25. Where services are available, stakeholders consistently acknowledged that care is high quality and centred on patient needs. However, access remains inequitable. Urban areas are generally better served than rural communities, and provision varies across Health and Social Care (HSC) Trusts.

26. Further, there is a lack of confidence across the PEOLC sector in the commissioning process. The current system lacks transparency and clarity around decision-making on services.

27. The Committee found strong evidence to substantiate the claims by the PEOLC sector that legislation to mandate the commissioning and funding of services is required to ensure equitable access to PEOLC services across Northern Ireland.

Opportunities Missed

28. The Committee shares in the frustrations of the PEOLC sector of the many missed opportunities both for improved quality of care and to prevent trauma to patients and families.

29. The failure to implement the Advance Care Planning (ACP) and the ReSPECT process, following its launch in 2022, has caused distressing circumstances for patients, their families and carers, and also healthcare staff.

30. The Committee heard of many examples of proven sector-led best practice initiatives which have not been rolled out regionally.

31. DoH has been cautious in endorsing a 'Regional Individualised Last Days Care' template in Trust hospital wards which would guide generalist clinical staff in addressing the full spectrum of patient needs for palliative care. This causes concern of a misalignment between departmental decision-making and international best practice.

32. The palliative care sector has consistently identified the absence of a national clinical lead in Northern Ireland as a major barrier to effective service delivery.

33. The Committee sees the absence of a branch team within DoH with a remit specifically for PEOLC as having further affected proper representation and policy development for this sector.

Key Findings

34. When the Committee considered all the evidence it had received, it identified a number of key themes that highlighted there were significant gaps in the provision of services across Northern Ireland. While this is all too common across all services in the Health system, it is particularly serious for those patients in palliative care and their families.

35. The Committee heard many examples of patients being having to be treated and indeed dying in Emergency Departments as there was no services available out of hours.

36. The Committee received research that highlighted that in 2022, estimated expenditure on healthcare for people in their last year of life was approximately £350m. 56% of that spend (£195m) was in relation to emergency admissions, by comparison only 4% (£14m) of that spend was in Hospice. While we appreciate that some patients will need to be admitted to hospital on an emergency basis, the Committee believes that patients should be treated in the most appropriate place and in most circumstances this should be in the community and at home.

37. Members agree that there should be support for patients and families that allows patients to be treated with dignity and respect in their preferred place, whether that be at home or in Hospice care and that when emergency care is required end of life patients receive the timely care they need.

38. The Committee welcomes the Minister’s intention to shift services left into the community. The Committee believes that palliative care would be a prime opportunity for the Minister to commence that shift left. The Committee believes that by giving palliative care focus and the appropriate level of funding there is the ability to transform services for patients and their families and for services to be delivered at home and in the community.

39. In addition, by improving services for patients, we will see a significant decrease in the need for more costly emergency care where patient outcomes are poorer. This will have a wider effect on the health system and free up valuable resource to address other system pressures.

Patient and family perspective

40. Evidence received in the consultation and through meetings with patients and families highlighted significant areas where there needed to be better support. Evidence outlined significant differences in services provided to patients and families across Trust areas. The evidence also outlined some of the key barriers in accessing services, these included:

    - Lack of communication
    - Unaware of services
    - No services provided in certain areas

41. The evidence received from patients and families highlighted that the lack of focus and funding for palliative care was resulting in significantly poorer health outcomes and was resulting in trauma for families.

42. One of the significant issues raised by patients and families was the lack of communication with families in decisions made about the treatment of patients and being clear in what the patients and families want. This issue can be largely dealt with by bringing forward the work on Advanced Care Planning.

43. The Committee understands that this work has been advanced to a point by the Department, but there has not been resource available to put this in place. The Committee believes that Advanced Care Planning needs to be implemented as a matter of urgency.

44. The Committee would also recommend that the ReSPECT process and form be implemented as a matter of urgency. The Committee heard many examples of confusion in relation to patients wishes and how new forms and conversations had to be had with patients and families when they moved between services. The ReSPECT process will provide clear and personalised recommendations for a person's clinical care and treatment in a future emergency.

45. Another significant issue raised by patients and families was in relation to the lack of out of hours support. Families outlined the difficulties they faced when they had to seek advice and support outside of weekday 9-5 hours. This ultimately resulted in increased instances of patients having to attend very busy Emergency Departments, which are not the most suitable place for patients with palliative care needs.

46. The Committee heard many good examples of support being provided to patients and families. This included a 24/7 helpline, out of hours nursing support and "just in case" boxes. However, these services are only provided in some areas of the system and are not available across all of the region. This further highlights inequality of access to services, where some services are available in some areas but not in others. More needs to be done to provide support to patients and families to provide treatment in the most appropriate place. Further out of hours support will further reduce the need for patients to attend Emergency Departments and emergency admissions therefore easing the pressure on the hospital system.

47. The Committee would recommend as a matter of urgency that additional out of hours support be provided to patients and families, this would include the full roll out of a 24/7 helpline, out of hours nursing support and "just in case" boxes across all areas.

48. Over the period of undertaking the Inquiry, Committee Members heard from families on a number of occasions of the quality of the services their children received in the Children's Hospice and how valuable the respite service was to their families. However, they did highlight that there was difficulty in accessing respite services at the Children's Hospice due to resourcing issues and funding cuts to services.

49. Members saw first-hand that the quality of the facilities that there are in the Children's Hospice and where disappointed to hear that while the Children's Hospice has the ability to increase respite services, the Department has

decommissioned services and have cut funding meaning the Hospice cannot provide the much needed respite to children and their families. As a matter of urgency, the Department should work with the Children's Hospice to identify how they can fully utilise the facilities at the Children's Hospice and provide the much needed respite care to children and families.

Increase need/future proof

50. Recent analysis by Marie Curie (2023), estimated that approximately 90% of people who died in Northern Ireland between 2017 and 2021 would have benefitted from palliative care. This is in contrast to the current planning estimate that 75% would benefit from palliative care. Therefore in Northern Ireland we are already working on an underestimated need for palliative care. The Office for National Statistics further projects that Northern Ireland will experience the largest proportional increase in deaths requiring palliative care of any UK nation, with a 32% rise expected between 2023 and 2048.

51. This outlines the need to increase the focus placed on palliative care and put the correct structures in place that will ensure that as demand for palliative care rises, the systems are in place to be able to provide patients and families with the holistic care that is needed at end of life.

52. The Committee welcomes that the Executive have placed the need to improve support to those coping with death, dying and bereavement into the Programme for Government. The Committee's recommendations will outline opportunities for the Health Minister and the Executive to improve that support to patients and families.

53. During evidence the Committee noted that Northern Ireland was the only region on these islands that does not have a clinical lead for palliative care. A clinical lead is crucial for a number of reasons, including policy advocacy, education and training and the need to link policy with quality of care and a holistic approach to treatment.

54. The Committee would urgently recommend that the Minister appoint an interim Clinical Lead, who could look initially take forward a number of work streams while looking at the role of the clinical lead. The role of the clinical lead could include the following:

    - Leadership of the Palliative Care in Partnership Borad
    - Consideration of service specification
    - Consideration of minimum standards of service
    - Ensure there is consistency across the system
    - Development of Strategy/Implementation Plan

55. The Committee agrees with evidence that there is a need for co-ordinated strategic direction. There is currently no adult strategy for palliative care. Previous strategies and reviews – such as the RQIA review and the Palliative Care in Partnership Programme – have identified key priorities. However, implementation remains outstanding. A new strategy is required to provide the framework that will

ensure the needs of our population are met now and as demand for services increases.

56. The Committee is clear that any strategy must include clear and measurable goals and have an associated detailed implementation plan. The strategy must be evidence based and should provide framework for issues such as workforce planning, future need, training across professions, education, data collection and the funding model and mechanism.

57. The Committee is disappointed that the scoping exercise that the Department advised was going to be taken forward has only just commenced. Officials advised the Committee in January 2025 that the exercise was to be completed in 3 to 6 months.

58. It is frustrating that the Department is still not fully aware of the services provided and commissioned across Northern Ireland. The Committee believes that the delay in commencing this scoping exercise further outlines that there is not sufficient importance given to palliative care by the Department. The Committee recommends that the Department look at its staffing structures and consider how it can place palliative care as a priority within the Department.

59. The Committee also has some concerns in relation to how services are commissioned by the Strategic Planning and Performance Group in the Department and specifically how commissioning of services links with needs in our communities. It would appear that there is a lack of planning in the commissioning of services and many successful pilot programmes are unable to be extended or rolled out.

60. There needs to be a review of how services are commissioned. We need to move beyond making annual incremental funding uplifts and to focus on strategic commissioning that will reflect changing needs, greater complexity and the need for flexible, responsive care. This work can link in with the role of the clinical lead, service specification and minimum standards, and a requirement to work with key stakeholders to ensure that the needs of the community are made known and services commissioned accordingly.

Funding

61. The final key theme is in relation to funding of palliative care. Northern Ireland has the highest per capita expenditure on end-of-life care in the UK, estimated at £40,410 per person in the last year of life. A large share of this expenditure is directed towards unplanned hospital care, while hospice care accounts for approximately 4 per cent. This distribution contrasts with evidence suggesting that community-based care can be more cost-effective and better aligned with patients' preferences. While nearly 80 per cent of people express a wish to die at home or in a hospice, only 44 per cent do so, indicating a potential disconnect between system investment and outcomes.

62. We spend more on expensive unplanned hospital care rather than investing resource into providing services in the more cost-effective community services, which is where patients want their treatment.

63. In our questionnaire we asked health professionals and organisations whether the current model of funding for palliative care was sufficient and sustainable, only 1 response from 98 responses indicated that it was. The sector is very clear, there current model is not sufficient nor is it sustainable in the medium to long-term as demand will increase.

64. In evidence the Department advised that it provided 50% funding of in-patient services commissioned for adults and 30% funding for in-patient services for children in hospices. This means that a significant proportion of funding must be raised by these charities in order to provide a service. The system has become reliant on the charitable sector to provide essential healthcare services.

65. When we visited the Hospices and when they gave evidence, Hospices outlined that the 50% and 30% provided were based on the cost of a general medical bed in a hospital and were not linked to the actual cost of providing the service. Hospices indicated that the funding provided was around 40% of cost for adult services.

66. This model of providing funding based on the equivalent cost of a general medical bed in a hospital is outdated. It does not take into account the specialist care provided in a hospice setting and the economies of scale that a general medical bed has when compared to much smaller units.

67. Indeed, in a response from the Minister in relation to questions on the cost of providing services in the in-patient units run by Trusts, the Department indicated that the Bed Day Cost at the reported occupancy in Macmillan Palliative Care Unit in Antrim was £1148, which is significantly higher than the approximately £370 paid to Hospices. This highlights inequity across the system and how the funding model for in-patient services is outdated.

68. In evidence, officials advised that moving children’s services to 50% funding would cost an additional £700k per year. An official stated *“£700k would make a massive difference in the whole space of palliative and end of life care for children*”. However, the official outlined that funding is not available in the Department’s budget. The Committee visited St Francis Hospice in Dublin, where Members learned more about the move to 100% funding by the Irish Government for palliative care services and saw firsthand the benefits of that for patients and families.

69. The Department indicated that the additional cost of moving to 100% funding in Ireland was 18m Euros (£16m). The Committee believes that this investment on in-patient services would be an invest to save initiative that would ultimately see a reduction in patients being admitted to hospital in emergency circumstances, freeing up beds and services in our hospital sites.

70. The Committee would recommend that there be an immediate move to a true 50% cost of in-patient service in both the adult and children's services. This would require SPPG to liaise with each of the hospices to identify the cost of providing the service and then moving to provide 50% of that cost. This should be in place for the start of the 2026/27 financial year. The Committee would also recommend that there be a planned incremental move to 100% funding for in-patient services.

71. In relation to community services and other services commissioned by SPPG and Trusts, the Committee would again recommend that same incremental move to 100% funding of existing services.

72. The Committee would note that any new services or services being rolled across all areas as a result of this inquiry should have 100% funding from SPPG/Trusts. The role of charities in this sector are vital. Not only do they provide high quality palliative care services to patients and families, they are a valuable source of innovation, research and best practice. However, if we do not change the model of funding for services provided we run the risk of these charities having to cut services and close beds. We need an efficient and sustainable funding model that provides for the needs of our population.

Introduction

73. At an informal planning meeting in June 2024, the Members of the Health Committee discussed the Committee's priorities for the session ahead. At the meeting the Committee agreed to undertake an Inquiry on Access to Palliative Care Services.

74. Committee Members were aware of the significant challenges that were facing the hospice sector and there was evidence of some services not being available to all patients and families across Northern Ireland. The Committee was concerned that patients and families were unable to access the necessary support in coping with death, dying and bereavement and that this was causing further difficulties for patients and long-term trauma for families. The Committee was also aware that there had not been a strategy in place for a number of years since the previous Living Matters Dying Matters Strategy in 2010.

Aim and objectives

75. The Committee objectives of the Inquiry were to:

- evaluate the current state of PEOLC services in Northern Ireland, the range of services available, geographical distribution, and the quality of care provided;
- examine funding structures for hospices, government contribution and commissioning processes, charitable donations, and any other sources of funding;
- investigate accessibility of PEOLC services across geographics and demographics in Northern Ireland;
- explore the level of coordination between different healthcare providers and the integration of PEOLC with other health services;
- identify the main challenges and barriers faced by hospices and trust care providers, including financial, operational and regulatory issues;
- assess future needs and demands for PEOLC and emerging trends; and
- assess the level of support provided to a patient and carers or families throughout the patient's journey.

Context

76. The WHO considers PEOLC a public health issue, focusing on reducing suffering, preserving dignity, and improving quality of life. Leading healthcare bodies recognise it as a basic human right. It focuses on improving quality of life for individuals with life-limiting illnesses by managing symptoms, addressing psychosocial needs, and supporting families. End of life care is a component of palliative care provided when curative treatment is no longer an option.

77. While commonly associated with cancer, palliative care now extends to conditions such as cardiovascular disease, respiratory disorders, neurological conditions, and dementia. Services are tailored to the patient's needs and

delivered in various settings, including hospitals, hospices, care homes, and private residences.

78. PEOLC plays a critical role in supporting individuals with life-limiting conditions, ensuring dignity, comfort, and quality of life in their final stages. Northern Ireland faces significant challenges in delivering these services due to evolving health trends, demographic shifts, and increasing demand for services.

79. The patterns of illness and mortality among adults are shifting and chronic conditions and ageing populations are increasing demand for palliative care. Advances in healthcare have extended life expectancy, yet this has also resulted in a greater prevalence of complex, long-term conditions requiring sustained support. Additionally, end-of-life trends highlight the need for integrated services that prioritise patient-centred care. For children, life-limiting illnesses present distinct challenges, requiring specialised paediatric palliative care models tailored to their needs.

80. The current evidence highlights the necessity of providing appropriate care to all individuals, irrespective of age, location, diagnosis, or socioeconomic status. An estimated 90% of those who could benefit from palliative care do not receive it. This unmet need results in lower quality of life for patients, increased avoidable hospital and emergency department admissions, and greater use of life-extending measures.

81. Access to PEOLC not only offers holistic support for patients and their families but also enables individuals to die in their preferred place. Additionally, it has the potential to alleviate pressure on the acute hospital sector. The COVID-19 pandemic further exposed vulnerabilities in end-of-life care provision, highlighting the need for resilient and adaptable health and social care services.

82. The causes and nature of illness are changing; we are living longer and survival from diseases is prolonged. In Northern Ireland there were 17,254 deaths in 2023, with two thirds of deaths in people over the age of 75 years. The average age at death was 75.3 years for males and 79.9 years for females. Of these deaths, 27 per cent were attributable to cancer, and 23 per cent and 12 per cent to circulatory and respiratory diseases respectively. The most frequent cause of death (for all persons) was dementia (12 per cent; 2,026 people) with the majority of deaths occurring in hospitals (47 per cent), followed by home (38 per cent), nursing homes (eight per cent), and hospices (four per cent).

83. Although life expectancy growth has slowed considerably in Northern Ireland, the overall population is to rise to 1.93 million by mid-2047. Over this period, the population of those aged 65 years+ will increase by 49.6 per cent (between mid-2022 and mid-2047), whilst those aged 85 years+ is estimated to increase by 122.2% over the same period. This increase in the number of elderly people will lead to an increase in the number of people living with chronic disease and multiple conditions. This will result in an increase in demand for palliative and end of life services.

84. Increasing multimorbidity and degenerative conditions mean that end of life can be characterised by a prolonged period of decline rather than a sudden illness. Chronic diseases (such as asthma, diabetes, coronary heart disease, hypertension, stroke, cancer COPD and dementia) are a major cause of morbidity and mortality in Northern Ireland. The prevalence of most chronic conditions increases with age and is accelerated by deprivation, which will mean an increase in the percentage of the population with one or more of these conditions.

85. Health policy makers have a strong interest in developing a better understanding of how they can improve end of life care. Studies have found that in the months leading to death, the need and the costs of care increase substantially, with the bulk of these expenditures coming from high-cost individuals, such as those with persistent chronic conditions. In addition, there are serious concerns that the quality of care at the end of life falls short of expectations. As more people reach old age with chronic conditions, improving the quality and efficiency of care at the end of life will continue to grow as a priority policy area.

86. This highlights the need for action to be taken now and the structures and systems that need to be put in place and developed now and planned for accordingly. If we fail to implement change now our health system will be in a much worse position with a significant increase in demand for end-of-life services which we will not be in a position to provide.

Services in Northern Ireland

87. PEOLC is multidisciplinary, involving generalist and specialist providers. Generalist care is delivered by GPs, hospital doctors, nurses, care home staff, and social workers. Specialist palliative care (SPC) is the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. SPC teams include palliative medicine consultants, clinical nurse specialists, and allied health professionals. Originally, this type of care was developed to provide support to people with cancer nearing the end of life. There is emphasis in policy on community-based SPC teams supporting people with more complex palliative care needs, with generalists providing wider care.

88. Hospices play a key role in PEOLC, providing inpatient, outpatient, and community-based support, although it can also be provided in other settings such as prisons. They offer medical care alongside psychological, social, and spiritual support for both patients and families. In Northern Ireland in 2022-23:

    - 16% of hospices’ total service activity in Northern Ireland was delivered in an inpatient unit;
    - 74% of hospices’ total activity was delivered at the person’s place of residence;
    - 52,000 visits were made by specialist palliative care nurses and doctors to hospice patients at home;
    - 11,000 visits were made by generalist healthcare staff to hospice patients at home (including nurses, healthcare assistants, social workers and carers);

- 12,000 outpatient appointments were made by hospices for physiotherapy, counselling and other support services;
- 17,000 days and nights of inpatient care were provided by hospices; and
- 2,300 appointments were provided to patients' families, friends and carers, including counselling and bereavement support.

89. The Committee's survey for patients, families and carers showed that services were accessed right across the health system, including at home, in hospital, at hospices, in the community and with GPs. Over 32% of respondents outlined that they access the majority of their services through their GP.

90. Key components of PEOLC include management of physical symptoms as well as social, psychological and spiritual care and provision for documentation of their values, goals, and preferences for future care in the form of ACPs.

91. ACP allows individuals to document their values, goals, and preferences for future care. ACP aims to minimise unnecessary hospitalisations, avoid futile treatments and enhance comfort. Early ACP discussions have been deemed crucial, particularly for those diagnosed with dementia. Research suggests ACP can improve end-of-life care quality, reduce stress, anxiety, and depression in relatives, and lower hospitalisation rates and costs.

92. Early integration of palliative care has been shown to reduce unnecessary hospital admissions and the use of intensive interventions, promoting home-based care that many patients prefer. This can result in lower costs by providing care that aligns with peoples' needs and preferences, reducing unnecessary hospitalisations, diagnostic and treatment interventions, and inappropriate intensive and emergency department care.

Policy in Northern Ireland

93. The responsibility for delivering and overseeing PEOLC services in Northern Ireland is shared across multiple stakeholders. The Department of Health, Health and Social Care Trusts, and partners from the voluntary and community sectors.

94. The most recent strategy Living Matters Dying Matters (LMDM, 2010) defined PEOLC as "the active, holistic care of patients with advanced progressive illness". LMDM identified 25 recommendations to improve PEOLC through developing, commissioning and delivering a model for quality PEOLC. The strategy sought to improve public awareness of palliative care, enhance workforce capacity, and ensure equitable access to services, while promoting choice and dignity for individuals at the end of life.

95. Transforming Your Care (2011) further supported the work of LMDM and identified 7 key principles to inform future palliative care service design and implementation. From 2013-2016 the Transforming Your Palliative and End of Life Care (TYPEOLC) programme, a partnership between Marie Curie, Strategic Planning and Performance Group (SPPG), Department of Health and the Public Health Agency (PHA) worked towards the enhancement of PEOLC through engagement with key stakeholders including Health and Social Care, and independent providers and voluntary and community sector representatives.

96. The 2016 Regulation and Quality Improvement Authority (RQIA) Review assessed the effectiveness of the strategy's implementation. The review acknowledged that progress had been made in several key areas, including the integration of palliative care across care settings and improved collaboration between healthcare professionals. However, it identified critical gaps, particularly in the consistent delivery of services and equitable access to care across Northern Ireland. The RQIA made several recommendations, including the need for enhanced data collection, greater workforce training, and improved public engagement to address ongoing stigma and misconceptions about palliative care.

97. In September 2016, the previous LMDM and TYPEOLC structures were brought together to form the Palliative Care in Partnership (PCIP) programme. The PCIP programme management support has been sponsored by Macmillan from June 2018. The PCIP Programme mandate is to take forward the work initiated by the LMDM implementation board (from 2010 to 2016) and the TYPEOLC Regional Steering Group (from 2013 to 2016), and regional priorities and work plan for 2019 and beyond.

98. The aim of the PCiP programme is to provide regional direction so that everyone identified as likely to benefit from a palliative care approach (regardless of condition) is:

- Allocated a palliative key worker
- Has the opportunity to discuss and record their Advanced Care Plan decisions; and
- Is supported with appropriate generalist and specialist palliative care services.

99. The strategic direction for children's PEOLC services in Northern Ireland is set out in A Strategy for Children's Palliative and End-of-Life Care 2016-2026 and contains 23 objectives. These include:

- families receiving planned and emergency short breaks;
- access to 24/7 multidisciplinary community services and direct access to a 24/7 crisis and specialist palliative care and end of life services, including access to medicines for symptom relief;
- a regional protocol to facilitate discharge and transfer for chosen place of death;
- provision of bereavement services; and
- development of a minimum dataset to support children's palliative care service.

100. A progress report (June 2021) noted that substantive work to progress the various objectives within the strategy did not commence until 2019, at which point a Paediatric Palliative Care Network (PPCN) was formally convened, and that the COVID-19 pandemic had impacted on many areas of work. The network includes clinical and nursing leads from all Health and Social Care Trusts and the Northern Ireland Children's Hospice.

Policy in other jurisdictions

101. The policy landscape of PEOLC across the UK and the Republic of Ireland is characterised by a shared commitment to person-centred care, yet each jurisdiction has developed its own unique approach to addressing the complex needs of individuals facing life-limiting illnesses. All strategies recognise the importance of tailoring care to the individual needs and preferences of patients and their families.

England

102. England's approach to palliative care has been significantly shaped by the Health and Care Act of 2022, which mandates that Integrated Care Boards (ICBs) commission palliative and end-of-life care (PEOLC) services. This legislative change ensures that palliative care is embedded within the broader health and care system.

103. The NHS England PEOLC team has produced statutory guidance for ICBs based on the National Palliative and End of Life Care Partnership’s Ambitions for Palliative and End of Life Care for Local Action 2021-2026.This guidance is further supported by a suite of technical documents on commissioning and funding approaches, aimed at standardising and enhancing the quality of palliative care services nationwide.

Scotland

104. Scotland's approach to PEOLC is characterised by its emphasis on early identification of care needs and the integration of services across sectors to ensure better outcomes for adults and children, as well as their families and carers. Scotland is currently in the process of refining its strategy with the 'Palliative Care Strategy: Palliative Care Matters for All' (2025-2030), which builds upon the foundations laid by previous frameworks.

105. Key objectives included improving early identification of care needs, integrating services across sectors, and enhancing workforce development. Scotland has also made notable progress in embedding palliative care within primary care settings and promoting the use of anticipatory care planning.

Wales

106. Wales has adopted a nationally coordinated strategy through its 'Palliative and End of Life Care Delivery Plan (2017-2020)' and subsequent updates for children, young people and adults. A distinctive feature of the Welsh approach is its commitment to co-designing services with patients and families, ensuring that the voices of those most affected by palliative care policies are heard and incorporated into service development. The establishment of regional palliative care networks has improved consistency in service delivery across health boards and local authorities.

Republic of Ireland

107. The Republic of Ireland has recently launched its National Adult Palliative Care Policy, which outlines four strategic objectives focused on delivering the

right care, in the right place and time, by the right people, while ensuring good governance. This policy is notable for its emphasis on expanding specialist services and addressing the needs of non-cancer patients. The proposed use of comprehensive metrics to track progress, including hospital death rates and carers' views on the quality of end-of-life care, demonstrates a commitment to evidence-based policy implementation and continuous improvement.

Funding

108. PEOLC in Northern Ireland operates under a hybrid funding model, comprising statutory funding and charitable contributions.

- although there has been an indicative commitment to cover 50 per cent of costs through statutory sources, ambiguity remains regarding which services are included, leading to regional variation in commissioning;
- block grants offer predictability but are not routinely adjusted for local demographic shifts, changes in patient complexity, or inflation, which may lead to misalignment between funding and need; and
- this approach has been associated with recurring deficits across the sector, estimated at £17.3 million annually, and increased dependence on voluntary fundraising to cover operational and capital costs.

109. While this approach reflects the sector’s long-standing partnership between public and voluntary sectors, it has been associated with challenges for workforce stability, innovation, and long-term planning. Multi-year funding arrangements have been identified to support provider capacity for effective planning, staff retention, and service development in response to population needs.

110. Current commissioning arrangements involve multiple stakeholders without a standardised framework, which can add to the complexity of governance and accountability. The absence of comprehensive data on service delivery, outcomes, and population need may limit the ability to commission care strategically and equitably. Strengthening data collection and sharing could support more informed, outcome-focused decision-making across the system.

111. Hospices, like other parts of the health and social care system, face financial pressures linked to inflation, staffing costs, and wider economic changes, including the reintroduction of employer National Insurance contributions (NICs). These pressures have contributed to some reductions in service provision. If such pressures persist, there may be an increased likelihood that more patients will access care through acute settings rather than hospices or community services, which are often considered appropriate and cost-effective alternatives.

112. Despite these pressures, Northern Ireland has a highly skilled PEOLC workforce and a strong base of community support for hospice services. With more integrated planning, improved data use, and a sustainable funding model, there may be opportunities to strengthen the delivery of high-quality, patient-centred care.

Hospice Funding – Adult Services

113. The Department of Health's SPPG is responsible for commissioning palliative care services in Northern Ireland, including regular engagement with hospices to ensure the delivery of contracted specialist palliative care. This commissioning framework is underpinned by a longstanding funding model that has shaped the landscape of adult hospice care for over two decades.

114. Since 2004/05, adult hospice inpatient services have operated under a 50:50 funding arrangement, with the Department of Health and charitable sources each contributing half of the agreed service costs. This model was extended to community-based hospice care in 2005/06. Importantly, these agreements apply to the costs of commissioned services rather than the total running costs of each hospice, leaving hospices to bridge the gap through fundraising and other sources. The reliance on multiple funding streams, including Health and Social Care Trusts and the voluntary sector, can result in a complex and sometimes fragmented commissioning landscape.

115. Recognising that the 50:50 funding model has been in place for nearly two decades, the Department of Health proposed a review in 2021. This review, intended as a co-production exercise, aimed to inform future funding arrangements, define the scope of specialist adult palliative care, and assess service capacity considering population needs. However, financial and resource constraints delayed implementation.

116. While the 50:50 model has provided a basis for hospice funding, variation in service provision and access has been observed across Northern Ireland's HSC Trusts. The mixed model - relying on statutory, local government, and charitable contributions - can contribute to differences in service availability and integration. The absence of multi-year budgets may constrain investment in workforce development and service improvement, while limitations in data infrastructure may affect efforts to standardise quality.

Children's Services

117. The Northern Ireland Children's Hospice (NICH) is currently the only provider of specialist palliative, respite, and end-of-life care for children aged 0–19 with life-limiting or life-threatening conditions. Each year, it supports approximately 2,300 children, nearly half of whom are under one year old, reflecting the complexity of paediatric palliative care needs.

118. Services are delivered through Horizon House (inpatient care), 24/7 community teams, Hospice-at-Home nursing, and family support. NICH collaborates with HSC Trusts to coordinate care across hospital and community settings. However, funding constraints have affected the service's ability to respond to increasing demand.

119. The Department of Health funds NICH through Service Level Agreements covering only part of costs

- Bed nights – approx. 30% of costs
- Hospice at Home – 50% of costs
- Family/Bereavement Support - 41% of costs

- Community Support Teams - 43% of costs

120. This places significant pressure on NICH to raise the necessary funds to deliver much needed services. It leaves many services at risk and results in short-term decision making and difficulties with long-term planning.

Key Issues and Findings

Cradle to Grave

121. The Regional Palliative Medicine Group Northern Ireland (RPMG), highlighted to the Committee that the NHS's original vision was to provide care from cradle to grave. The Association for Palliative Medicine of Great Britain and Ireland (APM) stated, we fall short, offering only to the very old, not to the grave.

122. In Northern Ireland, there is a heavy reliance on charitable hospices to provide palliative and PEOLC. This essential care is often funded through community fundraising efforts like bake sales and sponsored walks, instead of government funding. The Trust Bereavement Co-ordinators Northern Ireland, made the point that if the public were asked to finance intensive care units (ICUs), there would be widespread outcry. They argued that despite the NHS being founded on the principle of providing care from cradle to grave, care at the end of life is severely lacking, particularly outside of elderly care.

123. The Evora Hospice Care emphasised that while palliative care should be universally accessible, there is a lack of policy direction and this indicates palliative care is not a priority in government.

A Legal Framework

124. A recurring theme was the call for a legal right to palliative care. It was acknowledged that legislation alone would not solve all challenges but would raise the profile of palliative care, ensure consistent commissioning across Trusts, and help secure equitable access. The RPMG stated that, there are gaps across the system which have never been addressed over many years and have continually got worse. If Northern Ireland is serious about addressing these gaps, then there needs to be a recognition of the legal right to Palliative Care.

125. Marie Curie pointed out that, Scotland is exploring a legal right to palliative care, similar to that in England and Wales. The hospice urges policymakers in Northern Ireland to catch up with other jurisdictions.

126. The Northern Ireland Hospice and Northern Ireland Children's Hospice stated that, such legislation would guarantee that patients in Northern Ireland have access to the palliative care they need and deserve, ensuring better healthcare outcomes for individuals at the end of life.

127. The Northern Ireland Paediatric Palliative Care Network had heard reports of positive developments in Canada, in that when legislation for paediatric palliative

care was introduced in that part of Canada, it helped to drive progress on the services that they could develop there.

128. The Presbyterian Church in Ireland (PCI) believes, the absence of a legal requirement for commissioning palliative care services creates a significant barrier to equitable access to care across Northern Ireland.

Recommendation 1: Northern Ireland introduce legislation mandating the commissioning and funding for palliative and end of life care. If the Committee finds the Department of Health unwilling to commit to bringing legislation forward, the Committee will consider a Committee Bill on PEOLC.

Commissioning

129. Marie Curie spoke of disjointed commissioning with a lack of transparency around how funding benchmarks are set by the commissioners for both in patient unit and community services, and no recognition of actual costs required to deliver services. The NI Hospice described an absence of accountable commissioning. There is a need to improve clarity around commissioning goals and decisions to ensure effective service provision. The RPMG views current funding for palliative care as not transparent or evidence based.

130. Hospice UK stated, hospices struggle at times to understand how funding allocations are made up by commissioners (e.g. the proportion for In-Patient Units versus Day Hospice versus Community). Hospices appreciate the potential for cost pressures to be addressed in year, and recognise that in recent years some additional funding has been made available. However, the funding provided has not met the financial impact of cost pressures, and at times there has been no transparency over how the decision on funding allocations has been made.

131. The BHSCT believes that commissioning should be considered regionally to ensure equity and transparency and that review of current commissioning is needed to provide a responsive solution to new and expanded problems that the sector faces.

132. Both the BHSCT and APM noted the disbanding of Quality and Outcomes Framework (QOF) points post-Covid has led to a reduction in funding and support for GPs providing palliative care. APM advocates for a model where GPs are involved in commissioning palliative care services similar to Clinical Commissioning Groups in other parts of the UK, with palliative care being a statutory requirement.

133. RCGP stated, current palliative care provided by GPs is carried out as part of General Medical Services contract, thus strengthening palliative care should be achieved by an improved General Medical Service resource or at the very least a separately commissioned enhanced service.

Recommendation 2: The Department review commissioning of palliative care services to ascertain capacity to meet a statutory duty of commissioning of

equitable palliative care services in Northern Ireland, and to provide responsive solutions to new and expanded problems of the palliative care sector.

Hospice Funding Policy

134. Marie Curie explained, hospice funding arrangements are complex and there is also a lack of longer-term budgeting (single year contracts only, as a result of current 1 year budget setting) which is compounded in some cases by significant delays in contract completion and an inconsistent approach to contracting across settings.

135. Hospices are funded centrally by the DoH for inpatient unit services and commissioned by each Trust individually for community nursing services according to their budget and requirement for palliative care. Both services are funded approximately 50% through statutory funding, with the remaining shortfall sought from charitable giving and public donations.

136. However, in reality Hospices actually receive closer to 40% of their income from statutory funding. Marie Curie stated, there is a lack of recognition of over-performance against contracted delivery, funding arrangements do not reflect cost pressures and there is an assumption that fundraising will be able to meet growing gaps between statutory funding and charitable contribution.

137. DoH funding policy for the independent hospice sector was set 20 years ago. This policy has not been reviewed in more recent times and with fundraising income reducing, it is becoming increasing unsustainable to rely on fundraising to cover half of hospice care costs. This would be an unthinkable proposition for any other basic healthcare service.

138. The Hospice Alliance NI collectively met with the Health Minister in December 2024, to highlight the strategic challenges facing organisations. Hospice UK stated, to ensure the long-term sustainable funding of the hospice sector we support the Hospice Alliance NI position that: “It is time to move on from the long-running debate about 50% funding”.

139. Evora Hospice stated, a vital service reliant on local fundraising is not a secure funding model. Last year Evora Hospice received 34% of its income from Strategic Planning and performance Group (SPPG) - this % already excludes the costs we incur to generate its own income. On average its income from SPPG has increased by 2% each year. Its costs to deliver services is impacted by significantly increasing costs. This includes pay awards to staff to ensure parity with staff in the HSC, and other increasing running costs. The financial revenue model means it is very difficult to address other issues such as infrastructure to appropriately deliver services in.

140. NI Hospice stated, research undertaken by Marie Curie projects a 32% increase in demand for palliative care in Northern Ireland by 2048, compared to 2023. Funding pressures are putting current services at risk of being scaled back.

Improved service delivery agreements should be implemented, with standardised contract templates across all Trusts, to include:

- Multi-year contracts. This would result in hospices being sustainable and reliable partners to the NHS, enabling hospices to offer their workforces the benefits of working within stable organisations;
- Agenda for Change uplift applied to full contract value. Pay awards are the biggest risk to hospices' cost base. Providing NHS grade service requires NHS grade remuneration in order to attract and retain the highest quality of staff. This would remove the need for hospices to ask for 'pressures monies' during end of year monitoring rounds; and
- Service Specific KPIs & volume-based remuneration. Establish agreed service levels in line with NHS metrics, with agreed per service unit reimbursement levels. Current 50% reimbursement of an NHS General Medical Bed is insufficient to cover the true cost of care.

141. The All Ireland Institute of Hospice and Palliative Care (AIIHPC) stated, if hospices become fully state funded, the fundraising from the public would still be needed to support measures such as innovations in patient care, capital builds, additional comfort services for patients and their families, education and research stating an example of this can be seen in the RoI, where hospices are now fully state funded.

142. Foyle Hospice stated, if the Ireland model was adopted - that is 100% funding of hospices apart from their income generation costs - local fundraising could be used for innovation, additional services, comfort services, education and research. In fact, this model in effect already exists in parts of Northern Ireland which creates a very significant fairness and equity issue.

143. The AHPCC believes, it is vital to stop the funding of hospices coming from charitable sources, but providing that statutory funding is at a sufficient level of funding and better than currently being offered in other sectors.

144. NI Hospice highlighted that, constant financial instability and risk diverts attention away from providing clinical care and prevents meaningful development and growth. Without multi-year budgets, long-term planning and meaningful service development are impossible, leaving clinical needs unmet and communities underserved. The APM stated, financial instability prevents hospices from maintaining services, retaining skilled staff, and fostering innovation. It also forces unnecessary competition for limited funds, fragmenting care and hindering collaboration.

145. The AIIHPC noted, it has been positive that one off sources of funding have been provided to the sector by the DoH but the lack of longer-term consistency of funding negatively impacts on consistent service delivery. Evora Hospice Care pointed out, 'pots' of money become available every now and then. For example, for support worker for 18 months. Whilst this is to be welcomed it is not an approach that should be used to sustain services, rather it should be used to try, for example new ways of working or to enhance a service etc.

Recommendation 3: The Department move to 100% funding for hospices, with an initial 50% for 2026-27, and a sliding scale increase over 5 years and based on cost of services. The Department must liaise with each Hospice and begin to standardise contract templates across all Trusts, to include:

- **a. Multi-year contracts;**
- **b. Agenda for Change (AfC) uplift applied to full contract value; and**
- **c. Service Specific KPIs & volume-based remuneration.**

Recommendation 20: Hospices be included in strategic planning at central departmental level which will impact services and hospice finances.

Recommendation 21: The Department work closely with Evora Hospice to provide support to the hospice's move to a new site to ensure the success of the project and best outcomes for patients.

National Insurance Rise

146. The APM emphasised, the National Insurance rise is shrinking funding further in hospices, general practice and nursing homes which together all contribute to the vast majority of palliative care services as a whole. The APM stated, there is a disproportionate hit to this sector. Marie Curie pointed out, hospices also have to absorb the recent Employers National Insurance contributions hike, and unlike English counterparts, will not avail of the £100 million funding announced for the hospice sector in December 2024. These additional costs have a considerable ongoing impact on Hospices in NI.

147. For Marie Curie reported, the additional £300,000 employer NICS costs will steer funding away from the delivery of services, and unless it can be raised through fundraising, there is a high chance that services will be impacted. On top of that, all independent hospices here will have to find extra income to cover these additional costs and will ultimately be competing against each other for the same charitable pound from a limited pool of supporters in a small nation of under 2 million people.

148. The PCI agreed, the increased national insurance contributions announced in the 2024 autumn budget will adversely and disproportionally affect GPs, the Hospice sector and nursing homes. PCI's Council for Public Affairs had written to the Chancellor expressing concerns regarding the negative impact this increase will have.

Out of Hours Care

149. The BHSCT stated, there has been no new commissioning monies for SPC teams in recent years. Out of Hours (OOH) medical remote advice is provided by a private company. The majority of calls happen over the weekend, indicating that a 7-day service/hospital presence would be well used.

150. The Trust Bereavement Co-ordinators and Evora Hospice Care reported significant gaps in palliative care availability outside of regular working hours, including weekends and public holidays, which affects both acute and community care settings.

151. The RSPCNG identified a significant gap in out-of-hours palliative care services, particularly for symptom management in rural areas. This lack of service can be a barrier to patients returning home, and the absence of 24-hour care services makes it difficult for some patients to receive timely support.

152. Life and Time Nursing Agency highlighted that the demand for out-of-hours palliative care often exceeds the available service provision, leading to strain on both statutory and voluntary services. The agency’s "organic model of care" has proven essential in addressing this gap, indicating a clear need for a more robust response during these times.

Recommendation 4: Immediate increased investment in a regional Out of Hours PEOLC workforces, generalist and specialist, particularly in rural areas, to ensure equitable access to services for all patients in a timely manner.

PEOLC Pharmacy

153. Marie Curie stated, community and palliative pharmacy play a critical role in keeping the patient stabilised in the home setting and also in the hospital setting, especially at discharge. It is important that these functions continue to be resourced to support patients. Community pharmacy is also a vital support to unpaid carers who play a pivotal role in caring for loved ones in their home setting.

154. The Northern Ireland Palliative Care Pharmacists Group identified a range of issues within pharmacy services for palliative care, including the following gaps in the provision of service:

- a lack of equitable access to palliative care medicines in primary care, in the evenings and at weekends;
- no overnight access in primary care, to the controlled drugs regularly used in palliative care outside of Belfast;
- a lack of anticipatory medicines for end-of-life care available in every patient’s home when they are needed;
- not all areas of Northern Ireland have access to a funded specialist palliative care pharmacist with input for community patients;
- not all Trusts or hospices have equivalent specialist palliative care pharmacist input;
- no seven-day palliative pharmacy service for hospitals or hospices;
- nursing homes could keep stocks of non-controlled palliative medicines, not just named-patient supplies; and

- a lack of guidance to patients, carers and healthcare professionals on how to access palliative care pharmacy services within and outside normal working hours.

155. Community Pharmacy NI (CPNI) explained that**,** in Belfast different arrangements are in place as palliative care is provided by the Belfast on-call pharmacies, whilst other areas in Northern Ireland do not have a community pharmacy palliative care on-call service. This inconsistency across the region creates a gap of service, and could cause confusion for patients, community pharmacy, Out of Hours, and GPs. A consistent approach to service delivery will create equity for patients requiring palliative care and ensure easier messaging for the public and healthcare professionals.

156. CPNI stated, there are 509 community pharmacies across Northern Ireland, and many of these pharmacies are placed in rural locations. These pharmacies provide much needed access to healthcare and support, and in many instances can be the prevalent form of healthcare provision the patient has available to them. Community pharmacy is therefore an ideal setting for the expansion and exploration of further services in palliative care.

157. All community pharmacies will provide general palliative care to the patients that need it. This will be through the procuring and dispensing of palliative medicines, and advice and support to both the patient and their families. There are the additional 61 pharmacies that provide the enhanced palliative care service and that are required to stock certain palliative medicines in order to meet the needs of palliative patients on a timely basis.

158. A number of pharmacies across Northern Ireland also provide a palliative care on-call service, to facilitate emergency palliative care. This involves developing relationships with district nursing, hospice staff, OOHs, and secondary care.

159. There are no current roles for pharmacy technicians in palliative care in Northern Ireland. The Northern Ireland Palliative Care Pharmacists Group explained, in other jurisdictions pharmacy technicians working in palliative care have reduced medicines wastage, reduced staffing pressures, improved use of patients' own drugs, and their understanding of their medication and increased awareness of medication incidents.

160. The Northern Ireland Palliative Care Pharmacists Group pointed out that, funding should be made available for specialist palliative care pharmacy posts in line with the Palliative Care in Partnership Workforce Planning document (2020), including the role of the pharmacy technician in palliative care.

161. The Northern Ireland Palliative Care Pharmacists Group highlighted that, pharmaceutical wholesalers do not keep sufficient stocks of some medicines used in palliative care, so when these are needed for patients in community or in hospices, there are delays in obtaining them while they arrive from England. This includes commonly prescribed medicines such as morphine injection, as well as more specialist medicines like furosemide injection.

162. The Northern Ireland Palliative Care Pharmacists Group states, Northern Ireland does not yet have a primary care Electronic Prescription Service (EPS), unlike other areas of the UK. Patients/carers need a physical HS21 prescription which causes delays to accessing medicines.

163. The Northern Ireland Palliative Care Pharmacists Group recommended including palliative care in core training for undergraduate, Foundation Year, postgraduate pharmacists and provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in.

164. The Northern Ireland Palliative Care Pharmacists Group stated, in recent years, there has been an expansion of pharmacy services in Trusts and hospices. This has led to all Trusts and hospices having at least some dedicated palliative care pharmacy input. However, this could be improved by GPs, hospices and community pharmacy access to Encompass. Whilst hospitals are using electronic administration records, community services are still utilising paper-based versions which leads to complications at the interface of secondary and primary care.

165. CPNI noted that, community pharmacy currently do not have read/write access to the Northern Ireland Electronic Care Record (NIECR)**,** which would be beneficial to record any interactions with palliative care patients and/or other healthcare professionals involved in their care so that there would be full oversight across both primary and secondary care.

166. Access to Encompass would also be important to improve governance and communication between all sectors. This would allow community pharmacy a better awareness of the patients that are undergoing palliative care and enable pharmacists to better support these patients. Creating more opportunities for shared learning across sectors would also help improve integration.

Recommendation 5: Immediate investment in pharmacy services within PEOLC services, to include:

a. **an Electronic Prescription Service;**
b. **clear pathways on how to access palliative medicines outside normal working hours (in collaboration with the 24/7 PEOLC single central point of access);**
c. **regional roll-out of proven sector-led best practices such as ‘Just in Case’ boxes, and nurse prescribing;**
d. **specialist palliative care pharmacy roles introduced in all Trusts in Northern Ireland;**
e. **pharmaceutical wholesalers to keep sufficient stocks of certain PEOLC medicines;**
f. **include PEOLC in core training for undergraduate, Foundation Year, postgraduate pharmacists; and**
g. **provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in.**

General Palliative Care (GPC) Services

167. The APM pointed out that, General Palliative Care is provided by predominantly GPs and district nurses and states this service is under-valued, under-resourced and has got expectations out-with capacity. Long gone are the days when at end-of-life the GP visited you numerous times and increasing in frequency the closer to death you became.

168. The RMPG stated, fair funding should be reviewed for GPs. They require appropriate renumeration to resource themselves to be able to provide essential palliative services. The current funding for palliative care is not sufficient, nor transparent or evidenced based.

169. The Royal College of General Practitioners Northern Ireland (RCGP) believes, funding for all care in community is inadequate. Primary care teams are underfunded, in particular general practice is only allocated 5.4% of the total health budget. GPs play a key role within a community team delivering palliative care, and they need to have time and resource dedicated to doing so. Protecting palliative care is becoming increasingly difficult with an ever-squeezed resource, practice instabilities, contract hand backs and recruitment and retention issues that prevail in general practice.

170. The RCGP stated, current investment in community (district) nursing teams is wholly inadequate, and workforce/workload issues are leading to intolerable strains on these teams who provide the majority of palliative care. Where care is particularly complex and the need for specialist palliative care input is required, this can be limited by capacity and availability of such primary care teams. In a palliative care setting, capacity to react to need in the quickest and most effective way is integral to being able to deliver a quality service.

171. Marie Curie reported significant problems with the recruitment and retention of GPs in Northern Ireland, which has had severe consequences for palliative care patients and their families. GPs serve as a crucial point of access to palliative care, and delays in access to GPs can have devastating consequences for patients in acute need.

172. Both NI Hospice and Macmillan Cancer Support (Macmillan) emphasised that an optimal workforce, integrated and well-resourced community end-of-life care has proven to improve patient experiences and reduce avoidable ED admissions. However, community-based palliative care remains underfunded and insufficiently supported.

173. The Belfast Health and Social Care Trust (BHSCT) reported that community general palliative care is inadequately funded and without specialist support, patients with cancer at the end-of-life are more likely to experience multiple unplanned emergency care episodes, extended hospital stays, and a lack of continuity in care.

District Nurses (DNs)

174. The BHSCT and RCGP state that, district nursing teams are under-resourced relative to DoH recommendations, leading to gaps in end-of-life care provision, overwhelming workloads and putting strains on the services that provide the majority of palliative care in the community.

175. The Royal College of Nursing (RCN NI) emphasises the essential role of DNs in providing palliative care in the community. DNs are the key workers in many end-of-life cases, often providing the most consistent and up-to-date care for patients at home. In some Trust areas, 24-hour palliative care provided by DNs has been a vital service. This service reassures families by providing continuous support, ensuring that care is prioritised, particularly during the night.

176. Trusts and hospitals have developed Advanced Nurse Practitioners (ANPs) in palliative care, which has been a positive step toward enhancing service delivery. However, the RCN NI notes that access to university training programs required to develop and expand these roles across Northern Ireland is limited, primarily due to commissioning constraints. This lack of access to training opportunities further restricts the expansion of the palliative care workforce, which is essential to meet the needs of an aging population with increasing demand for end-of-life care services.

177. The RCN NI further highlights the reduction in the availability of specialist practice qualifications in palliative care. This reduction limits the ability of nurses to advance in their practice, hindering professional development and the capacity of the nursing workforce to meet the growing demand for specialist palliative care.

Specialist Palliative Care (SPC) Services

178. The APM emphasised the critical importance of SPC as an essential healthcare service that should be fully funded through Health and Social care (HSC) and noted it has been underfunded for a prolonged period, with the majority of funding for hospices and inpatient units in Northern Ireland being reliant on charitable donations rather than statutory support. This underfunding has resulted in significant challenges for service delivery.

179. The British Association of Social Workers Northern Ireland (BASW NI) highlighted the limited number of hospice beds in Northern Ireland. As a result, patients often face difficulties accessing SPC units. The shortage of available beds leads to situations where individuals are unable to be admitted to hospices in a timely manner, forcing some patients to reach crisis points at home. These patients may experience severe pain and infections, further complicating their care. In some cases, patients attempt to avoid EDs due to long waiting times and the stressful, high-pressure environment of these facilities.

180. The Trust Bereavement Coordinators also underlined the severity of this issue, stating that limited bed capacity in SPC units has resulted in patients dying while on waiting lists. This situation reflects the urgent need for more accessible and adequately resourced SPC services to prevent unnecessary suffering and ensure timely care for individuals nearing the end of life.

181. Moreover, APM pointed out that the palliative care workforce within hospitals has stagnated, in stark contrast to the exponential growth seen in other specialties, such as oncology. This lack of expansion within the SPC workforce contributes to difficulties in meeting the increasing demand for specialist care, exacerbating pressures on existing services.

182. The Northern Ireland Hospice and RPMG emphasised the critical need for investment in the community SPC workforce. As more individuals choose to receive care at home, there is an urgent demand for a sustainable, multi-disciplinary community workforce. Training, education, and the creation of regional career development pathways are essential to building this workforce and meeting the increasing demand.

SPC District Nursing

183. Marie Curie pointed out that most community SPC nursing roles are only partially funded through statutory sources, with a considerable reliance on charitable donations to sustain these essential services and this funding gap presents ongoing challenges in maintaining the workforce required to provide adequate palliative and end-of-life care for the people of Northern Ireland.

184. The Regional Specialist Palliative Care Nursing Group (RSPCNG) undertook an exercise in 2023 to review data collated in 2017 regarding SPC nursing workforce predictions. This found there had been a 44.5% turnover of staff either retiring or leaving the service. This loss of knowledge and skills is difficult to replace without appropriate proactive workforce planning. The current funding model makes it challenging to sustain an adequate workforce across all disciplines.

185. The RCN NI reported that, there has been little investment in increasing the capacity of the palliative and SPC nursing workforce. Surprisingly, a recent review of the SPC workforce recommended that the current training arrangements were sufficient to meet workforce requirements by 2024. However, this assessment overlooks the significant need for increased capacity to provide quality palliative care, particularly as demand continues to grow.

186. According to the RCN NI, workforce shortages are a critical issue with high vacancy rates in nursing that significantly impact the delivery of palliative care in both acute and community settings. They are often the key workers for terminally ill patients. In addition to providing services in private homes, DNs also work within care homes, where they deliver palliative care alongside nursing teams, often with support from Trust and hospice nurses.

187. One of the notable challenges is that SPC in the community continues to be a five-day, Monday-to-Friday service. Significant investment is required to enhance the workforce's ability to provide care beyond these hours. Without such investment, the risk of burnout and turnover among the current workforce will increase, further exacerbating recruitment and retention issues in this essential field.

Multi-Disciplinary Teams

188. BASW NI highlighted the significant pressures faced by hospital social workers due to high caseloads, which often result in missed opportunities to provide the necessary support to palliative patients and their families. The current resource limitations within hospital settings are insufficient to meet the increasing demand for social care services, impacting the quality of support provided to individuals at the end of life.

189. RCN NI noted that DN teams often step in to fill the gaps in social care when providing end-of-life care (EOLC) at home. This additional responsibility puts further strain on the already limited district nursing workforce. The expectation of high-quality palliative care services is understandably high, with patients and families relying on healthcare professionals to deliver comprehensive, compassionate care during the critical end-of-life phase.

190. The Evora Hospice Care called for more resources to community core teams (DN, Physio, OT etc) for generalist support palliative patients and their families.

Psychological and Spiritual Needs

191. The AIIHPC Psychological, Social, and Spiritual Care Research and Special Interest Group (PSSCR SIG) emphasised that the WHO (2020) defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”.

192. Research by the PSSCR SIG highlighted the importance of addressing psychological and spiritual distress in palliative care. These aspects are integral to providing holistic care, yet there is currently uncertainty among clinicians about how to identify these needs and where to refer patients for further support. The AIIPC PSSCR SIG’s research emphasises the need for clearer pathways to assess and manage emotional and spiritual distress throughout a patient’s journey.

193. A significant issue is the lack of access to specialist mental health and spiritual care professionals, such as psychologists and chaplains, across palliative care services. The AIIHPC PSSCR SIG stressed the urgent need for workforce planning to ensure that specialists with the necessary competencies are available to manage complex emotional and spiritual distress, particularly as patients near the end of life. Additionally, many staff members report not having received formal training on how to address these needs effectively.

194. The AIIHPC PSSCR SIG called for the creation of evidence-based pathways for addressing emotional and spiritual distress. Funding cuts to services are seen as a significant barrier to providing holistic care, particularly in the voluntary and community sector, which plays a key role in supporting patients' emotional and spiritual well-being.

195. Marie Curie and the BHSCT, highlighted the need for more comprehensive training for the palliative care workforce. Key areas identified for training include advance care planning, breaking bad news, and enhancing communication skills to ensure that patients and families are supported through difficult conversations.

196. The AHPCC underscored the vital role of chaplains in providing spiritual care to patients, families, and staff in palliative settings. Chaplains are integral to the multidisciplinary teams, offering spiritual support regardless of religious beliefs, and supporting staff in delivering spiritual care. Volunteers also play a crucial role but are not always available as dedicated resources.

197. Just as there are assumptions about palliative care, so too the general public sometimes assume that chaplains only provide religious care. It is quite a revelation when they discover otherwise. Chaplains are there for patients, those who are important to them, staff and volunteers to provide spiritual, religious and pastoral support.

Recommendation 6: The Department carry out a scoping exercise specifically for the Specialist Palliative Care sector. That is, SPC in Emergency Departments, SPC in-patient units in hospitals and hospices, SPC in the community, paediatric SPC and MDTs. This exercise must give an understanding of total service provision needed in the SPC sector, including out of hours, and be kept separate from any work on scoping generalist PEOLC. To support a future increased investment in SPC workforce needs, to remove waiting lists for SPC services and support training.

Paediatric Palliative Care Services

198. The NI Children's Hospice raised concerns about the current strategy for paediatric palliative care, stating that it is not adequately funded. Progress made in the Regional Paediatric Palliative Care network has been largely reliant on the goodwill of professionals involved, rather than a structured, well-funded approach. This reliance on professionals' dedication underscores the uncertainty and instability in the current funding model, which impacts the sustainability and expansion of services.

199. The RCN NI stated that, paediatric palliative care remains underfunded, leading to significant barriers in service delivery. One major issue is the availability of SPC beds for children, with only six beds open out of a total of ten at the Children's Hospice due to limited funding. This limited bed capacity further restricts access to critical care for children in need, especially as demand continues to rise. The NI Children's Hospice stated that research indicates that the number of children with palliative care needs is expected to grow in the coming years.

200. The NI Children's Hospice pointed to a significant shortage in medical leadership for paediatric palliative care, noting that currently they have no paediatric palliative care consultant and medical leads only have one Programmed Activity (PA) per week dedicated to this important area. This lack of dedicated leadership and insufficient medical staffing limits the effectiveness of

the services provided, potentially leading to fragmented or inconsistent care for children who require palliative support.

201. The NI Children’s Hospice suggested, comparing the paediatric palliative care services in Northern Ireland with those in other regions highlights significant gaps in service provision. That benchmarking these services would demonstrate the considerable development needed to bring Northern Ireland’s services in line with other areas that offer more comprehensive and well-resourced care.

202. The NI Children’s Hospice stated that, similar to adult services, there is a lack of community-based, out-of-hours cover for paediatric end-of-life care. In Northern Ireland, care often depends on the goodwill of staff or a reliance on ramping up independent services to fill the gaps. This lack of consistent out-of-hours care places significant strain on families and healthcare professionals and can lead to challenges in ensuring that children receive the care they need in a timely and coordinated manner.

203. The Northern Ireland Children's Hospice highlighted the diverse role of nurses in children's palliative care, where staff provide not only end-of-life care but also ongoing care for children with life-limiting or life-threatening conditions, from before birth to the end of life. This includes both inpatient and community-based services, which have a regional scope.

204. Supported short breaks should be a key component of paediatric palliative care. Unlike adult palliative care, where respite options may be more widely available, supported short breaks for children with life-limiting conditions are significantly underprovided in Northern Ireland. This lack of provision limits the ability of families to access necessary respite care, placing further strain on parents and caregivers who are providing full-time care for their children.

205. The Northern Ireland Paediatric Palliative Care Network highlighted Paediatric Palliative Care sees families from before the child's birth right up until they are 18 years of age. When a child and family receive that diagnosis, it aims to improve quality of life; to support families emotionally and practically; and to help children to live as well and for as long as possible. It is a long-term, holistic approach; it is not just about the final stage. The World Health Organisation definition from 2013 is:

- palliative care for children is the active total care of the child’s body, mind, and spirit, and also involves giving support to the family;
- it begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease;
- health providers must evaluate and alleviate a child’s physical, psychological, and social distress;
- effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited; and
- it can be provided in tertiary care facilities, in community health centres, and even in children's homes.

206. The Northern Ireland Paediatric Palliative Care Network states, children with cancer are known to oncology services and probably get a better level of palliative care support. Not ideal, but it is a better level than what other groups of children receive.

207. Those with severe neurodisability or rare genetic conditions are far less well served in paediatric palliative care.

208. There are no dedicated funded paediatric palliative care teams or end-of-life teams anywhere in Northern Ireland, but that was recommended by the NICE quality standards from 2016. It recommended that there should be a core team that includes a paediatric palliative care consultant, which is a consultant who has specific, specialist training in paediatric palliative care; a nurse with expertise in paediatric palliative care; a pharmacist with expertise in specialist paediatric palliative care; and experts in child and family support who have experience in end-of-life care. That would include social, practical, emotional, psychological and spiritual support.

209. Most work in end-of-life care specifically for children is carried out by community children's nursing teams in each Trust area, as well as by specialist nurse teams from, for example, the children's hospital in. Those teams are not funded properly. They work on goodwill, working above and beyond to provide that service out of hours and at weekends. This is an ongoing problem in paediatric palliative care.

210. In addition, no consistent medical cover is funded for children receiving end-of-life care. That is not a sustainable model, and families are often left vulnerable. Families who want to remain at home with their child during end-of-life care have questioned why there is not the specialist input that, they feel, is vital.

Recommendation 7: Paediatric palliative care services prioritised and invested in to provide:

- **a. adequate funding of SPC beds for children:**
- **b. a dedicated paediatric palliative care consultant in the NI Children’s Hospice;**
- **a. an increase in medical leads Programmed Activity (PA) per week;**
- **b. additional support for ‘non-cancer’ conditions in children;**
- **c. increased investment in community-based, Out-of-Hours cover for paediatric end-of-life care;**
- **d. adequate provision of supported out-of-home respite; and**
- **e. a strategic approach to building capacity and resources to meet growing demand in paediatric palliative care.**

Advance Care Planning Policy/Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

211. The RSPCNG stated that the ‘For Now and for the Future’ Advance Care Planning Policy and the ReSPECT framework and regional ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR), needs to be implemented widely, ensuring that the public understands the importance of early planning for end-of-life care.

212. The RCN NI stated that it has previously highlighted concerns about the delay in the framework. and emphasised the emotional distress and frustration experienced by patients and families due to the repeated conversations that occur across various healthcare settings.

213. Many patients are forced to have multiple discussions with different healthcare professionals about their healthcare wishes and preferred place of end-of-life care, which not only adds to the burden on patients but also contributes to inconsistent care. The absence of a unified approach exacerbates the challenges patients face in articulating their wishes for care.

214. Additionally, the RCN NI pointed out the lack of a recognised DNACPR form that can be used consistently across all care settings. The hope was that the ReSPECT form would resolve this longstanding issue, particularly within community settings. The delay in implementing the ReSPECT form has left a gap in ensuring standardised documentation, causing further confusion and uncertainty for both patients and healthcare professionals.

215. RSPCNG stressed that the delay in implementing the Advance Care Planning policy and ReSPECT document has far-reaching impacts. The absence of a clear framework for advance care planning leaves many individuals uncertain about their future care preferences, particularly in emergency situations. This lack of guidance can increase stress and anxiety for both patients and their families, particularly when critical decisions need to be made quickly.

216. The AIIHPC underscored that advance care planning should be integrated into the healthcare journey of all adults, regardless of their stage of illness. AIIHPC suggests that if advance care planning were approached similarly to birth planning, where individuals are encouraged to make plans from the outset, it could normalise conversations around death and dying. Introducing education on palliative care at both the primary and secondary school levels could provide individuals with a foundational understanding of end-of-life issues, making it easier to have informed and open discussions about care preferences in the future.

217. This approach could lead to a broader societal shift, where individuals feel more comfortable discussing their healthcare wishes and end-of-life plans, reducing the stigma and taboos that currently exist around such topics. It is essential that advance care planning becomes a routine part of healthcare, not something only discussed at the end of life or in times of crisis.

Recommendation 8: Regional implementation of the Advanced Care Planning (ACP) and the ReSPECT framework as a matter of urgency. The Department

provide the PEOLC sector with a detailed timeline, including its inclusion in Encompass.

Referral Pathways to Palliative Care

24/7 Single Point of Contact

218. Foyle Hospice, the WHSCT, and the Evora Hospice Care, highlighted the need for a single point of access for palliative care services, particularly for out-of-hours support. At present, the system is fragmented, leading to frustration and confusion for patients, families, and healthcare providers alike. A unified access point could streamline communication, reduce confusion, and ensure that patients can quickly receive the necessary care and support. This would also allow for standardisation of service delivery and ensure that quality improvement initiatives are more easily implemented across the region.

219. Marie Curie supported the introduction of a single point of contact for people with terminal Illness and their carer's, whether at a regional based or offered at an individual HSC Trust level. A streamlined point of contact is critical for patient safety and managing the expectations of both patients and carers, who are often under immense emotional and psychological stress. A single contact number would provide a direct route to the appropriate services, helping to alleviate confusion and stress in already difficult circumstances.

Clear Referral Pathways

220. Marie Curie emphasised the need for clear referral pathways that facilitate rapid transitions from condition-specific services to palliative care when appropriate. To address these issues, a greater recognition and understanding of palliative care within disease-specific disciplines such as oncology, cardiology, and neurology is crucial. Establishing well-defined and efficient referral systems would streamline the process, reduce delays, and ensure that patients receive the most appropriate care in a timely manner.

221. The RCGP advocated for a more homogenous approach across Northern Ireland, where the entire population has access to the same palliative care services. A fixed regional pathway should be established to ensure equity of access to services. This pathway would allow healthcare providers to easily refer patients to the appropriate service, while also accounting for the diverse needs of different communities. Such integration would help ensure that all patients, regardless of location, receive the care they need in a consistent and equitable manner.

Continuity and Co-ordination

222. The WHSCT highlighted the lack of coordination and communication across the multiple services providing care to patients during their palliative and end-of-life phases. This fragmentation can result in missed opportunities for timely and holistic care, as various healthcare providers may not be fully aware of each other's involvement with the patient.

223. Fermanagh Community Transport reported that its members often experience frustration when having to repeatedly explain their symptoms, interactions with healthcare professionals, and medications to various providers within the primary, secondary, and specialist care sectors. This lack of coordination and the need to repeat information hinders the smooth delivery of care and adds to the emotional and logistical burden on patients and their families.

224. Marie Curie emphasised that palliative care is an interdependent ecosystem, with various components of the healthcare system working together to support patients and their families. For this ecosystem to function optimally, primary, secondary, and tertiary care sectors must collaborate seamlessly. This requires better coordination and integration between different disciplines and care providers. The lack of this cohesion currently limits the effectiveness of palliative care services and can lead to fragmented and inconsistent care delivery.

Reliance on Emergency Departments

225. The RPMG and Macmillan reported that there are difficulties for patients in accessing unscheduled secondary care, with the only common route being through ED attendance. This reliance on EDs as the main point of entry for palliative patients, particularly in times of crisis, is not only inconvenient but also often inappropriate for those at the end of life. Many patients would prefer to avoid emergency settings, and yet these are often the only available pathways for urgent care.

226. Marie Curie noted that when patients and carers experience a crisis, they often turn to GP Out of Hours services. However, these services frequently direct them to either call an ambulance or go to the ED themselves, which may not be suitable for palliative patients nearing the end of life. This situation is further complicated by a lack of specialist advice and support for out-of-hours GP staff, particularly when a patient’s cancer diagnosis is mentioned.

227. The BHSCT added that some patients have been re-directed to EDs upon mentioning their cancer diagnosis, mainly due to the lack of specialist guidance and the absence of patient records, making it difficult for GPs to make informed decisions on appropriate care. These challenges are exacerbated by the unmet need for specialist palliative and end-of-life care in EDs, resulting in poorer outcomes for many people with advanced cancer who require urgent care.

228. Marie Curie noted that workforce shortages impact both generalist and specialist palliative care services, affecting critical roles such as nursing, allied health professionals (AHPs), general practice, palliative care consultants, community pharmacy, and social care providers. When there are gaps in one area of the system, such as primary or community care, patients may be left with no alternative but to present at Emergency Departments (EDs). The absence of appropriate alternatives leads to inpatient admissions, which can have negative consequences on patient outcomes, including delayed or less effective care during their end-of-life journey.

Recommendation 9: A 24/7 PEOLC single central point of access established to co-ordinate:

a. **a 24/7 telephone and online helpline for patients and their families and carers;**
b. **emergency out-of-hours palliative care expertise services;**
c. **provide advice and assistance on referral pathways to HSC staff; and**
d. **provide advice and assistance on referral pathways for pre- and post-bereavement services.**

Emergency Departments

229. Both the NI Hospice and Macmillan Cancer Support stressed the need for funding to support in-reach palliative care services to EDs. The Trust Bereavement Coordinators agreed that EDs should have designated palliative care professionals to provide expert care to patients in crisis.

230. The BHSCT called for faster access to palliative care teams in the ED for assessment, imaging, or direct admission, emphasising that hospital palliative care teams could provide this service.

231. BASW NI pointed out a gap in identifying palliative patients in acute care settings, which can lead to unsafe discharges and a failure to provide the necessary palliative care support in the community.

Recommendation 10: Hospital Emergency Departments to have Specialist Palliative Care teams and systems in place to ensure PEOLC patients have rapid access to ED processes such as assessments, imaging and admission and that patients needing palliative care are identified before being discharged from EDs and relevant palliative care packages arranged.

Integration of Palliative Care Services

232. Marie Curie highlighted that, generalist palliative care is typically provided by primary care services, including GPs, district nursing, community pharmacy, and domiciliary care. Specialist palliative care is generally delivered by specialist teams, such as specialist nurses, doctors, and pharmacists, often based in hospices and hospitals, with some community outreach depending on the provider. This fragmentation of care across different sectors, including public sector Trusts, independent sector hospices, and private and public sector social care providers, leads to a lack of integration and creates opportunities for patients to fall through the gaps in service provision.

233. The RCGP highlighted a disconnect between palliative care services across different geographical areas and between primary and secondary care providers. This fragmentation can make it particularly difficult for GPs to help patients navigate the complex palliative care system.

234. In some regions, there are multiple community palliative care services, each with overlapping and unique roles, leading to confusion among healthcare providers as to which service they should refer patients to. This lack of integration and clarity may result in patients missing out on critical services due to the lack of uniformity across the region.

235. Foyle Hospice pointed out that, the integration of services varies significantly across Northern Ireland. While hospices and HSC palliative care units generally have a good approach to service delivery and outreach, the timing of referrals from other specialists often affects the quality of care. In some cases, referrals arrive too late to make the maximum impact on patient care. To improve this, hospices need more adequate support to enhance their effectiveness in reaching and supporting patients at critical times.

236. NI Hospice noted that the involvement of multiple provider organisations, coupled with variation in service delivery across different regions increases the likelihood of duplication of services. As it currently stands, the HSC system is complex and presents multiple entry points for patients, with varying levels of care at different stages. This complexity increases the likelihood that patients will fall between the gaps in service provision, as coordination between these different services is often lacking.

Recommendation 11: A fixed regional pathway framework and map of services established to support equity of access to services by continuity and coordination for patients at intersection points of services within and across all HSC interfaces. Ensure that every PEOLC patient's journey is planned and recorded and includes pathways to assess and manage emotional and spiritual wellbeing. Encompass must be integrated into the framework.

Transitions for Young People in PEOLC

237. The Northern Ireland Paediatric Palliative Care Network states that young people from the age of 14 upwards are poorly served in palliative care. There is a grey area between paediatric and adult services in many areas, and, again, families often feel vulnerable in that situation. Transition can be a big problem for any child with any health condition, but, for children and young adults with a life-limiting condition and complex health issues, it poses further problems due to the need, often, for multi-speciality input, advance care planning and increased technological needs, such as breathing support and feeding support, and creates a fear of how they will fit into adult support services.

238. For those families, there is often no clear lead or equivalent doctor in the adult world who will take on the care and look at a holistic approach for them. That is a big problem, because, as Fraser recognised in her 2020 paper 'Make Every Child Count', the mortality risk for children with life-limiting conditions increases when they reach young adulthood. We should focus on improving a child's journey into the adult world as a target area.

Recommendation 12: A programme established that fully supports young people as they transition from children's PEOLC services to adult services.

Tailored Care in Palliative Services

Mental Health Issues

239. The Trust Bereavement Co-ordinators stated, for individuals with serious mental illness, there is a noticeable lack of specialist palliative care support. Mental health conditions significantly affect the palliative care journey, yet there is insufficient expertise and tailored services available to address these patients' needs at the end of life.

240. Marie Curie highlighted, late diagnosis and delayed palliative interventions are often reported by individuals with mental health issues. The mental health dynamics present in these individuals can directly affect their palliative care, making timely and tailored interventions essential to improving patient outcomes.

241. The AHPCC agreed, people with mental health conditions may face late diagnoses, and their palliative interventions can be delayed due to the mental health dynamics at play. While there may be some support for patients, there is often a lack of support for their loved ones and carers, affecting their emotional well-being during bereavement and throughout the care process.

242. Macmillan highlighted that disparities exist based on socio-economic status and mental health.

Learning Disabilities

243. The RCN NI stated that a significant gap exists for people with learning disabilities (LD) in accessing appropriate palliative care. While LD nurses play a key role in providing end-of-life care to individuals with learning disabilities, they often lack the necessary palliative care training. This results in reactive rather than proactive care and missed opportunities for early intervention.

244. Furthermore, ACP is not routinely implemented for this group, and concerns remain regarding the inappropriate application of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders for individuals with learning disabilities.

245. RCN NI stated highlighted the risk of people with learning difficulties struggling to understand how to access PEOLC services, and even when they do, the services are not tailored to their specific needs. Marie Curie highlighted, current palliative care services are not designed to meet the unique needs of

individuals with learning disabilities, making tailored care essential to ensure equitable access.

Autism

246. The AHPCC noted that, research from other healthcare areas indicates that there are gaps in services for autistic individuals, and it is anticipated that similar gaps exist in palliative care. The cultural issues surrounding death within the autism community are poorly documented, and there is a longstanding misunderstanding of autism within healthcare provision.

247. The Independent Autism Reviewer for Northern Ireland stated, there is limited specific research on autism and palliative care, but existing research in other healthcare sectors suggests significant barriers to access. These barriers likely extend to palliative care services as well.

248. Effective adaptations and accommodations for autistic individuals in palliative care are often low-cost or no-cost solutions, but there is a clear need for greater investment in research and innovation to develop more equitable services for Northern Ireland’s autistic population.

Aging Population

249. Marie Curie notes**,** older people, particularly those over the age of 85, are less likely to access palliative care compared to those under 85. With the number of individuals over 85 projected to double in the next 25 years, there is an urgent need to identify and address the specific palliative care needs of this aging population.

250. The Rural Community Network highlighted, 13% of UK population have “ultra-low” digital skills. Within that group, there are concerns for older people as two thirds of this group labelled as having ultra-low digital skills were over 70 years old. One look at the Census Data for 2021 shows us that there are high numbers of people over the age of 65+ living rurally.

251. In addition, Rural Local Independent Advice Providers have indicated their concern for males, over the age of 55 regarding their digital literacy. The Network stated, it urges the Department to be mindful of this when engaging on complex medical topics.

Marginalised Groups

252. Marie Curie stated, training is also needed to address the barriers faced by marginalised groups, such as those from diverse ethnic backgrounds, LGBTQIA+ communities, or those facing socio-economic challenges to ensure that care is inclusive and accessible to everyone.

253. The AHPCC stated, spiritual care, though a core dimension of palliative care, remains the least developed and most neglected aspect. Gaps exist in the provision of spiritual support for diverse groups, including: LGBTQ+ Individuals. Access to palliative care can be more challenging for LGBTQ+ individuals, and opportunities for spiritual, religious, and pastoral support may be overlooked.

254. Marie Curie highlighted, other groups, such as individuals who are homeless, those in prison, and people with sensory impairments (sight or hearing), face significant barriers in accessing palliative care services. These barriers are even more pronounced when individuals belong to multiple marginalised groups. The failure to adequately address these needs exacerbates inequalities.

255. RCN NI stated that often struggle to understand how to access services, and even when they do, the services are not tailored to their specific needs.

256. Macmillan stated, inequities in palliative care provision are evident in the challenges faced by refugees, asylum seekers, and people in rural areas. A notable issue is that terms such as “palliative care” do not always translate effectively across languages, which can result in people being unaware that they are approaching the end of life, thus missing out on crucial care.

257. Marie Curie stated, people from racialised communities in Northern Ireland are less likely to access palliative care services, and often at later stages of their illness. Clinicians may also be ill-equipped to support these communities adequately, contributing to significant disparities in care. The failure to address cultural differences and barriers to communication only worsens the issue.

Recommendation 13: Remove barriers to PEOLC services for vulnerable and protected characteristic groups through investment in training and resources that will help ensure:

a. **people over the age of 85 are adequately supported to access palliative care;**
b. **individuals with serious mental illness gain access in a timely manner and receive tailored support as they access services;**
c. **people with learning disabilities or complex needs gain access in a timely manner and receive tailored support as they access services; and**
d. **barriers faced by marginalised groups in accessing palliative care are addressed.**

Recommendation 14: Remove barriers to PEOLC services for Northern Ireland’s autistic population through greater investment in research and innovation.

Nursing Homes and Care Homes

258. The PCI emphasised the need for stabilised and predictable funding for community-based palliative services to ensure that older people, regardless of the type of care home they live in, can receive dignified and effective end-of-life care.

259. The BHSCT highlighted the ongoing issue of underfunding for hospital and community-based SPC teams which has made it difficult to meet the growing demand for palliative care, particularly for the aging population in care homes.

260. Despite the significant need for palliative care in these settings, there has been no substantial investment in the workforce in recent years. As a result, resources are stretched thin, and the care provided is reactive rather than proactive.

261. The recommendations from the SPC Workforce Planning Report Northern Ireland 2017-2024 have not been implemented, further exacerbating the difficulties faced by care homes and community teams in providing comprehensive palliative care services.

262. The RCN NI highlighted significant issues within the care home sector related to the lack of recognition of increased patient acuity and the enhanced skills, training, and competencies required to deliver PEOLC services. The regional rate paid to care homes does not reflect the time and resources needed to deliver these services effectively.

263. The RCN NI suggested that with appropriate training and additional support, care homes could play a crucial role in facilitating quicker discharges from hospitals and preventing unnecessary hospital admissions for patients receiving PEOLC. By addressing these gaps, care homes could better manage patients' end-of-life needs within the comfort and familiarity of their own living environment.

264. Foyle Hospice raises concerns about the lack of capacity in non-specialist care settings to care for individuals with ongoing care needs who no longer require hospice-level care. As palliative patients often have complex needs that change over time, finding appropriate settings for those who no longer need the intensive support of a hospice but still require ongoing care can be challenging. The shortage of resources in non-specialist settings limits the ability to provide continuous, quality palliative care in these circumstances, leaving many individuals without suitable care options.

265. The PCI argued that there should be consideration given to reforming the distinctions between residential care homes and nursing homes. The current system can create barriers to delivering high-quality palliative care, particularly for older individuals who may not require hospital care but still need specialised support in a care setting.

Recommendation 15: Stabilised and predictable funding for community-based palliative services to ensure that older people, regardless of the type of care home they live in, can receive dignified and effective end-of-life care, to include:

- **a. recognition of increased patient acuity and the enhanced skills, training, and competencies required to deliver PEOLC services:**

b. levels matching recommendations from the Specialist Palliative Care Workforce Planning Report Northern Ireland 2017-2024 implemented, to help resolve the difficulties faced by care homes;

c. the regional rate paid to care homes reflect the time and resources needed to deliver these services effectively;

d. appropriate training and additional support, to ensure care homes play a crucial role in facilitating quicker discharges from hospitals and preventing unnecessary hospital admissions for patients receiving PEOLC; and

e. consideration given to reforming the distinctions between residential care homes and nursing homes.

Regional Last Days Care Bundle' / 'Individualised Care Plan' on Wards

266. SHSCT advised the Committee of the proposal by palliative care clinicians for a 'Regional Last Days Care Bundle' or 'Individualised Care Plan' with clear prompts for doctors and nurses when reviewing patients in their last hours/days and that can serve as an aide memoire to support the delivery of good last days care. A simple but effective core tool to provide good last days of care in hospital wards.

267. The prompts would include physical symptom prompts for example, review of previous medications, symptom review, treatment and observation reviews, mouth care prompts and hydration assessment. But would also include prompts to discuss spiritual and social needs with patients/families and discuss what 'normal dying' looks like. It could be a single template or one for doctors and one for nurses.

268. The Committee engaged with the Department on the matter but learned there was no work in progress in the health system for implementation. Specialist Palliative care clinicians feel that response falls short of expectations and called for the Department to meet with them the matter.

Recommendation 16: The 'Regional Individualised Last Days Care' planning template embedded in all Trust hospital wards, as a matter of urgency. The Department to meet with the clinicians leading this initiative, in the immediate term.

HSC Staff Understanding

269. The WHSCT emphasised that many healthcare professionals have misconceptions about palliative care and are often confused about the roles of generalist and specialist palliative care teams. This confusion can delay access to appropriate care and hinder collaboration between different service providers.

270. Hospice UK pointed out that there is often insufficient understanding among the broader HSC workforce regarding the full scope of palliative care services. As

a result, patients, especially those with conditions like neurological diagnoses or complex multi-morbidity combined with frailty, may not be referred for palliative care in a timely manner. In contrast, cancer patients are more likely to receive appropriate referrals for palliative care, highlighting a disparity in the recognition of when palliative care is needed.

271. Foyle Hospice and the Evora Hospice stated that late diagnosis is common. These delays result in patients not receiving the appropriate care and support at the right time, ultimately impacting their quality of life and end-of-life journey. The hospices stress the importance of early identification and appropriate training to ensure that all patients, regardless of their diagnosis, receive timely and appropriate palliative care.

272. Marie Curie highlighted that the majority of patients listed on the palliative care register have a cancer diagnosis, yet many non-cancer patients, particularly those with respiratory or circulatory diseases, are not being identified and are missing out on essential palliative care. Given that cancer accounts for only 27% of deaths in Northern Ireland, many patients with conditions like dementia are not being recognised for palliative care, which could significantly improve their quality of life.

273. The RCN NI and RSPCNG both noted that many healthcare professionals fail to recognise when they should refer a patient to specialist palliative care or are unaware that they are delivering generalist palliative care. This can contribute to patients not receiving the right care at the right time, resulting in worsened symptoms and increased distress.

274. Similarly, Marie Curie highlighted that there is an issue with unwillingness to refer patients to palliative care. This is compounded by a lack of recognition regarding the benefits of early referral and intervention. Marie Curie stressed that delayed referrals mean that patients often present with more complex symptoms that require specialist palliative care. Early identification and generalist palliative care in a primary care setting could prevent this, offering patients better support for a longer period and potentially avoiding unnecessary pain and distress.

275. According to PCI, hospital doctors and GPs are often unclear about when and how to utilise palliative care services, with some clinicians struggling to address the topic of palliative care due to stigma or discomfort.

276. The Evora Hospice noted that the language used to describe palliative care can be confusing, both for HSC staff and the public. The lack of standardised terminology contributes to misunderstanding and complicates communication between healthcare providers and patients. The Evora Hospice recommends that language related to palliative care should be agreed upon in any future strategies or action plans to ensure clarity across all stakeholders.

277. Marie Curie reported cases where patients have received their terminal diagnosis in an Emergency Department, which is a highly inappropriate environment for delivering such difficult news.

278. Moreover, the APM draws attention to an existential challenge for palliative care in Northern Ireland related to the assisted dying debate. It is crucial to distinguish between palliative care and assisted dying services. Palliative care focuses on providing comfort and support to patients with life-limiting conditions, while assisted dying involves ending life. There is a risk that some patients may misunderstand the role of palliative care, leading to unrealistic expectations about the services it provides.

Recommendation 17: HSC staff supported to help prevent late PEOLC referrals, to include:

- **a. appropriate palliative care training of all HSC staff to ensure early identification and timely referral to palliative care;**
- **b. appropriate palliative care training to prevent terminal diagnosis being given in inappropriate environments such as EDs;**
- **c. standardisation of palliative care language and appropriate training of all HSC staff and palliative care staff to remove confusion;**
- **d. include palliative care in core training for undergraduate, Foundation Year, postgraduate pharmacists and provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in; and**
- **e. a consultant training scheme.**

Integrated IT Systems

279. BHSCT, APM, and RSPCNG agreed that, while the Encompass system has made progress in linking hospitals and community services, it remains incomplete. Hospices are currently not integrated into the system, and many GPs lack direct access to it. This lack of access and integration creates barriers to effective communication, particularly the timely sharing of clinical information across organisations and Trusts. There is a clear need to fast-track the IT integration across all services, ensuring that hospices are fully included in this system to facilitate a seamless and safe transfer of care.

280. Evora Hospice and Foyle Hospice both emphasised the need for all hospices in Northern Ireland to be integrated into Encompass as soon as possible. They argue that hospices must have the appropriate training and full access to the system to enable effective data sharing and patient referrals. Foyle Hospice notes that, at times, hospices are seen as “external” to the system, which can lead to issues around trust and collaboration. This disconnect underlines the importance of bringing hospices into the Encompass system to ensure that patients are referred to the most appropriate service in a timely and coordinated manner.

281. Trust Bereavement Coordinators stressed the importance of a shared IT system for palliative care services to ensure continuity of care. They argue that a unified system would allow for better tracking of patients’ care across different

services and improve communication among healthcare providers, reducing the risk of information gaps.

282. Marie Curie stressed the need for significant improvements in real-time data sharing and coordination in recording details of terminally ill patients. Encompass is seen as a potential solution to address these issues, but it is essential that hospices are included as early as possible in the system's integration. The introduction of a discovery stage to explore this potential is welcomed, as it could provide a clearer path towards a more connected and coordinated palliative care system.

283. Marie Curie pointed out that hospices in Northern Ireland play a significant role in providing palliative and end-of-life care, supporting around 11,000 people each year, with a major focus on home-based care. They note that approximately 74% of hospice care is delivered in patients' homes, with 62% of the care being specialist palliative care and 38% generalist care. Given their substantial reach and workforce, hospices need to be digitally connected to the broader health and social care system. This requires access to patient records through existing systems like NIECR and the new Encompass system.

284. Life and Time Nursing Agency highlighted another gap. The NIECR is not accessible to all care providers, which hampers timely information sharing. This lack of access to up-to-date patient records creates challenges for care coordination, particularly for patients with complex needs or those receiving care across multiple services.

285. Both WHSCT and Marie Curie underscored the need for an IT system to effectively record and communicate advanced care planning documentation across all professionals involved in palliative care. This is particularly important for ensuring that patient wishes and care plans are respected and followed through.

Recommendation 18: Full read and write access of the Encompass IT system is given to all generalist and specialist PEOLC services.

Public Understanding of PEOLC

Misconceptions

286. The AIIHPC asserted that, the lack of understanding about the full range of palliative care services means that people may be missing out on the opportunity to improve their quality of life. When people are unaware of the breadth of services available, they may not seek them until it is too late, reducing their overall quality of care.

287. A common misconception, as noted by the RCGP, is that the public often associates palliative care only with end-of-life care. While this is an important component, palliative care can also help patients live better by improving their quality of life at various stages of illness. This misperception limits the willingness

of individuals to seek palliative care earlier, which can have a significant impact on patient outcomes.

288. The APM further identified a misunderstanding regarding palliative care inpatient units. These are sometimes perceived as places where lives are deliberately shortened, which is completely inaccurate. In reality, early referral to palliative care has been shown to not only improve quality of life but also extend life. Once patients and families experience palliative care's true purpose is to help people “live as well as they can until they die” they become strong advocates for its benefits.

289. The Evora Hospice observed that palliative care is often seen as a service exclusively for cancer patients, whereas individuals with other conditions can also have significant palliative care needs. The lack of a comprehensive palliative care strategy, in contrast to the cancer strategy, further complicates this perception. Additionally, there is a general lack of understanding regarding the different roles within specialist palliative care and the services provided by organisations like Marie Curie and Macmillan.

Paediatrics

290. The Northern Ireland Paediatric Palliative Care Network stated, there is a widespread misconception, amongst the public and healthcare professionals, that palliative care is synonymous with end-of-life care, but, in paediatrics, that is far from the truth.

Barriers to Public Understanding

291. According to the AIIHPC, the primary barriers to public understanding of palliative care are:

- fear and taboo surrounding death, which makes it a difficult topic to discuss openly;
- reluctance to engage with palliative care before it is needed, as it is often associated only with end-of-life care;
- lack of knowledge about the depth and breadth of services available and how they can improve quality of life; and
- inadequate funding and resources dedicated to promoting palliative care and engaging with communities to improve awareness.

292. The PCI notes, palliative care is delivered in discrete locations such as hospices, as opposed to the quality of end of life being strengthened by early identification, correct multi-disciplinary assessment and management of pain and other problems whether physical, psychosocial or spiritual in a range of care and domestic settings. There is an unwillingness amongst the public to engage in issues surrounding morality, death and dying.

293. The PCI identified several factors contributing to the lack of understanding of palliative care:

- lack of a clear definition of palliative care, given the variety of service providers and approaches involved;

- lack of regional ownership or leadership to define and clarify palliative care services in Northern Ireland; and
- cultural and societal change.

294. The RSPCNG highlighted the disparity in access to palliative care, especially for vulnerable groups such as those in social deprivation, prisons, homeless populations, and individuals with learning disabilities or mental health issues. A lack of awareness among both the public and professionals prevents these individuals from accessing vital services.

Death Literacy

295. The APM pointed to the cultural tradition of ‘the wake’ in Irish communities, where families would gather to celebrate life and openly discuss death. However, as these traditions become less common, the opportunity for natural and open conversations about death and dying also diminishes. The medicalisation of dying, which turns it into a feared event rather than a natural part of life, exacerbates the public's misunderstanding of palliative care.

296. The Rural Community Network highlighted the reluctance to discuss end-of-life care in rural communities, where such topics are often considered taboo.

297. The Trust Bereavement Co-ordinators echoed this sentiment, stating that death remains a taboo subject in Northern Ireland, and the fear surrounding it prevents the public from seeking more information or understanding about palliative care until they are faced with it personally.

Public Health Campaigns

298. The WHSCT supported the idea of a widespread public education or awareness campaign to improve understanding of what palliative care services can provide and when they should be accessed.

299. The CPNI notes the ability of community pharmacy to disseminate information to patients can be seen in the Living Well Service. It is CPNI’s view that community pharmacy could be a key enabler for the promotion of palliative care services to help improve the knowledge of patients and their families of the facilities that they can access.

300. The RPMG highlighted the failure to implement key initiatives, such as Advance Care Planning launched in 2022, which includes the ReSPECT document and Regional ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR), which could significantly improve public understanding. The lack of workforce planning also means that there are insufficient resources to educate the public effectively about palliative care.

301. The Evora Hospice stressed the importance of a public health education programme focused on death, dying, and palliative care. The aim is to normalise these conversations and make the public more comfortable with discussing end-of-life care. While some initiatives have been attempted, they have not gained the traction needed due to lack of funding and resources. Compassionate

communities and Advance Care Planning could be effective models for engaging communities in these discussions.

Recommendation 19: The Public Health Agency (PHA) resourced sufficiently to successfully plan and implement public health messaging initiatives required for public understanding of palliative and end of life care services.

A Palliative Care Clinical Lead

302. The WHSCT highlighted that there is no regional leadership within the Executive or DoH for palliative care to advocate for and commission services for palliative care. The WHSCT supports a Palliative Care Policy that brings responsibility and accountability and agrees with a clinical lead for palliative care services in Northern Ireland.

303. Hospice UK raised concerns regarding the absence of a national clinical lead for palliative care in Northern Ireland. They suggested that such a role, with the authority to address long-outstanding issues, would provide the necessary direction and accountability to drive meaningful changes within the system.

304. Marie Curie also advocated for the creation of a Palliative Care Lead within the DoH to oversee palliative care in Northern Ireland. They argue that the lack of this senior role, which exists in other jurisdictions, contributes to a lack of awareness and profile for palliative care. The proposed role would provide governance, oversight, and strategic direction at the departmental level, ensuring the integration and prioritisation of palliative care services.

305. The APM highlighted that the current leadership structure for palliative care in Northern Ireland has proven ineffective, particularly due to the lack of authority and accountability to drive change. The existing structure has limited clinical engagement, and its influence is confined to a subcommittee without the power to initiate significant reforms.

306. The APM called for a fresh approach, advocating for the appointment of a National Palliative Care Clinical Lead who would report directly to the Minister of Health. This leader would be responsible for commissioning palliative care services across Northern Ireland and ensuring that services are adequately funded and aligned with regional needs. Additionally, the APM suggests that the role should be supported by dedicated civil servants tasked with overseeing palliative care policy.

307. The RPMG noted the ongoing challenge in Northern Ireland, where many healthcare professionals are working diligently but are hindered by a perceived lack of leadership, direction, and the inability to implement change. The absence of a clinical lead has resulted in frustration among both staff and patients, as the lack of cohesive leadership prevents the system from evolving to meet the growing demand for palliative care.

308. NI Hospice asserted that a robust strategy, underpinned by a clear policy and funding commitment, would provide the opportunity for clearer and more accountable regional leadership. A national clinical lead, empowered to make impactful decisions, would play a crucial role in shaping the direction of palliative care services and ensuring that resources are allocated effectively.

309. Foyle Hospice also supported the call for a clinical lead, stating that such a position could facilitate greater integration of services across the region. They note that Northern Ireland is the only region in the UK that does not have a dedicated palliative care clinical lead, which is a critical gap in the system.

Recommendation 22: The Department appoint a National Palliative Care Clinical Lead for Northern Ireland who would report directly to the Minister of Health and be able to affect PEOLC policy, and commissioning of services. The Clinical Lead cochair the Palliative Care in Partnership Programme (alongside the Strategic Planning and Performance Group and Public Health Agency CEOs) and be an ambassador for the palliative care sector of Northern Ireland. An interim regional clinical lead be installed with immediate effect.

PEOLC in Rural Communities

Geographic Disparities

310. Life and Time Nursing Agency and the NI Hospice noted that rural communities in Northern Ireland are often less well-served than their urban counterparts when it comes to palliative care. The population in urban areas tends to have greater access to services, while rural areas are forced to identify gaps and develop innovative solutions to fill them, often in partnership with existing services. This reliance on informal solutions can lead to inconsistent care across different regions. The disparity can lead to inequities in care, particularly for those in the later stages of life.

311. The region’s infrastructure, particularly the lack of rail services and limited public transport options, poses significant challenges for residents of rural areas in accessing palliative care services. The Fermanagh and Omagh District is particularly affected, with poor road networks and limited transport options hindering residents' ability to reach healthcare facilities. These issues are compounded by the high levels of illness and an aging population, which require immediate attention from policymakers to ensure that healthcare is both accessible and equitable.

312. The Fermanagh and Omagh District **Council** highlights the challenges faced by residents in accessing palliative care due to geographical factors, including long travel distances and poor road infrastructure. The Council stresses that individuals in rural parts of Fermanagh often have to travel extensive distances to access care, further compounding the financial and emotional burdens placed on families during end-of-life care. Transport poverty is a particular issue, with a significant percentage of households in the district lacking access to a car, making it even more difficult to reach healthcare facilities.

313. The Fermanagh and Omagh District Council also calls for a reconsideration of the small level of palliative care provision in the region and the lack of care available at the South West Acute Hospital (SWAH). Despite the hospital's modern facilities, the absence of a dedicated palliative care ward and limited services in rural areas means that patients must travel to distant hospitals, increasing travel times, costs, and distress. The Council urges the DoH to address these disparities and ensure that healthcare decisions consider the unique needs of rural areas.

314. The Rural Community Network suggests that the DoH should engage in rural-proofing and border-proofing palliative care services to ensure that these communities are not left behind. Rural-proofed services must be developed to ensure that healthcare professionals are fully aware of the challenges rural communities face and can tailor their services accordingly.

'Rural Premium'

315. Rural Community Network explained the concept of the 'Rural Premium'. This refers to the additional costs incurred by rural patients and their families due to the need for extended travel times and often the necessity for family members to take time off work. Even though some financial assistance is available through schemes such as the Hospital Travel Costs Scheme, the true cost of rural travel is often hidden, which can make it difficult for families to cope.

316. Rural Community Network also pointed out that, under the Hospital Travel Costs Scheme, there are limitations regarding reimbursement for travel expenses. For example, patients may only be reimbursed for the cheapest mode of travel, such as a bus fare, even if they are too ill to take public transport. This fails to consider the lack of suitable public transport options in many rural areas, such as Fermanagh, where limited bus routes and no train network create additional barriers.

317. The Trust Bereavement Co-ordinators reported that travel-related expenses, including fuel, taxi fares, and parking fees, place a substantial financial burden on patients and their families, particularly those in rural areas. In many cases, these costs can quickly accumulate, adding to the emotional and physical strain of managing a terminal illness.

Infrastructure

318. The Rural Community Network called for DoH and the Department for Infrastructure to work more closely. In addition to the provision of dedicated transport services, there is a call for improvements in transport infrastructure to address critical gaps, particularly in underserved rural areas. Creating more direct routes and simplifying travel links between regions would alleviate the burden of long and convoluted journeys. Infrastructure improvements would help ensure equitable access to healthcare services, including palliative and end-of-life care.

Transport

319. The Community Transport Association (CTA) reported a significant increase in demand for transport related to palliative and end-of-life care, particularly in rural regions that are farthest from regional specialist palliative care centres. As the demand for palliative care services grows, especially in rural communities, transportation has become a critical issue. Many individuals in these areas face long travel distances to access specialist care, and the current transport services often do not meet the specific needs of these patients.

320. Despite the increased demand, transportation is often not adequately planned or funded as part of the overall palliative care pathway. The CTA emphasises the need for transportation services to be addressed from the outset of care planning, integrated into the care pathway, and appropriately funded. Without this, patients and their families face additional challenges, including the financial burden and emotional strain of travel, which can further complicate their access to essential care services.

321. Fermanagh Community Transport highlighted, charitable organisations are being expected to step into the breach and deliver essential transport services on the basis of good will, the community in terms of fundraising, volunteer drivers in terms of their time and resources and staff in terms of woeful terms and conditions of employment when compared to their colleagues in Health and Social Care, the Education Authority and Translink.

322. The transport provided is critical to access palliative and end of life services by so many patients and their families, yet it is viewed outside of the palliative care ecosystem and seen as something which can operate on the basis of good will and short-term charitable funding. This does not sit comfortably with the principles of access, quality and dignity, with one’s access subject to the potential fundraising capacity and volunteering propensity and availability within any given local community.

323. The Community Transport Association (CTA) stated, the transportation element, in particular, is underfunded and often neglected in the broader funding structure. There is a lack of coordinated funding and long-term planning for the transport needs of palliative care patients. This leaves patients in limbo and often results in disjointed, unreliable service delivery.

324. The Evora Hospice advocated for the integration of transport services into the care pathway, ensuring that transportation needs are met at every stage of a patient’s journey. They stress the importance of designing transport services that are specifically tailored to the unique needs of palliative care patients. This includes professionally managed transport services that offer safety, comfort, and reliability for patients with complex medical needs. Dedicated transport services would help ease the physical and emotional toll of travel, ensuring that patients can access care without additional strain.

325. Evora Hospice recommends the establishment of dedicated medical transport services to accommodate the specific medical and emotional requirements of terminally ill patients. They should offer flexible scheduling, including options for later appointments, to ease the burden on rural patients who often face long and

arduous journeys to healthcare facilities. These services should also be equipped to handle medical equipment and provide the necessary support for patients during transit.

Inflexible Appointments

326. The Rural Community Network stated, one of the challenges for rural patients is the inflexible nature of appointment scheduling, which often does not take into account the significant travel time required to reach healthcare facilities. Providing greater flexibility in appointment scheduling is essential to reduce the strain on patients and their families. Flexible appointment options, such as later appointment times or scheduling that prioritises travel considerations, would significantly improve access to care for patients in remote areas, ensuring that they can attend necessary appointments without added stress or discomfort.

GP Surgeries

327. The Rural Community Network also pointed to difficulties in accessing primary care in rural areas. Rural GP surgeries are under significant strain due to large catchment areas, increasing patient numbers, and limited resources. Many people in rural areas report problems getting GP appointments, which adds further pressure to their ability to access palliative care services.

328. Additionally, the closure of rural GP surgeries and the reduction of local healthcare services (e.g., Pain Clinics) have increased the need for patients to travel further for treatment. This has created additional barriers to care, especially for those with severe health issues, who may find it difficult to make long trips to regional centres.

Disjointed Service

329. The Rural Community Network and Fermanagh Community Transport highlight the disjointed nature of palliative care services in rural areas. Many patients in southwest Fermanagh, for example, are required to travel to Belfast or Altnagelvin Area Hospital for end-of-life care or diagnostic procedures, even though these services could easily be provided locally.

330. Furthermore, patients often have to travel for brief appointments, such as short review sessions, which could be conducted digitally to save time, money, and effort.

Regional Planning

331. While a regional model could improve communication and service coordination, the Rural Community Network argues that such a model must be designed to serve rural areas equitably. Moreover, rural patients must not be excluded from regional services simply because they live outside urban centres.

332. Fermanagh Community Transport and Rural Community Network call for a more strategic approach to planning palliative care services in rural areas. There is a pressing need for a deliberate and thoughtful policy that addresses the unique challenges of rural communities, particularly as the population ages and

the demand for palliative care increases. Equity-based planning is crucial to ensure that palliative care is accessible and of high quality, regardless of location.

Cross-border Access

333. Another challenge highlighted by the Rural Community Network is the cross-border access to palliative care services. In some cases, rural patients living close to the border may find it more convenient to access palliative care services in the Republic of Ireland.

334. For instance, patients in Belleek, Co. Fermanagh, may find it easier to access hospice care in Ballyshannon, Co. Donegal, but are required to travel to Derry City instead. This raises the question of whether cross-border cooperation in palliative care could reduce barriers for patients living in border areas.

At-home Palliative Care

335. The Rural Community Network pointed out, in rural areas, at-home palliative care is an essential service and tends to be provided by charities such as Marie Curie. Even where the Trust is providing Hospital Specialist Palliative Care, in most cases it is a 9-5 service. It should not be the case that the NHS are reliant on charities to fulfil their role.

336. Charities supporting people to access Palliative Care Treatment in the manner in which Marie Curie or Easilink do, should not be reliant on annual funding. Their staff should be sufficiently paid and resourced. Whilst the format of charitable fundraising might work well in cities or larger towns where fundraising is more easily achieved, in rural areas it is much harder to fundraise as well as to hire staff to take up positions.

Recommendation 23: The Health Minster commit to working with other Executive Ministers on rural proofing equitable access to palliative care services in Northern Ireland:

- **a. address the ‘Rural Premium’ incurred by rural patients and their families;**
- **b. integrate transport services as a care pathway critical to rural communities;**
- **c. examine cross-border co-operation opportunities for communities to access palliative care more easily; and**
- **d. charity staff supporting rural palliative services sufficiently paid and resourced.**

Financial Hardship as a Barrier

337. The Western Health and Social Care Trust (WHSCT) stated that, poverty is a critical barrier preventing equitable access to palliative care services. This includes not only the direct financial costs of care but also the broader socioeconomic impacts, which further disadvantage those already experiencing poverty.

Vulnerable Groups

338. Hospice UK recognised that, financial hardship is a significant barrier for many individuals in accessing palliative care. This is particularly true for vulnerable groups, including those with protected characteristics, who face additional challenges when navigating the complex healthcare system. Financial hardship exacerbates the difficulty of managing the costs associated with end-of-life care.

Rural

339. The Rural Community Network reported that, a significant number of people die in poverty, with an increasing trend over recent years. The number of people dying in poverty in Northern Ireland has risen from 2,000 in 2019 to 3,300 in 2023. Both working-age adults and pensioners are affected, with pensioner poverty almost doubling from 10% to 19% since 2019. The Network has proposed two actions that could alleviate this issue: guaranteeing a pension-level income for those of working age living with a terminal illness and introducing a social tariff for energy bills to help reduce the cost burden for patients nearing the end of life.

340. According to the Rural Community Network, the most deprived areas in Northern Ireland are predominantly rural, which further exacerbates the challenges faced by individuals in these areas when seeking palliative care services. Fermanagh and Omagh, for example, is home to several of the most deprived areas, where access to healthcare is already a significant issue. Socio-economic factors, such as poverty, limited public transport, and inadequate healthcare infrastructure, prevent rural populations from receiving timely and adequate palliative care.

341. The Fermanagh and Omagh District **Council** highlights the challenges faced by residents in accessing palliative care due to geographical factors, including long travel distances and poor road infrastructure. The Council stresses that individuals in rural parts of Fermanagh often have to travel extensive distances to access care, further compounding the financial and emotional burdens placed on families during end-of-life care. Transport poverty is a particular issue, with a significant percentage of households in the district lacking access to a car, making it even more difficult to reach healthcare facilities.

Loss of Employment Income

342. Marie Curie, which provides palliative care services across Northern Ireland, emphasised the financial challenges faced by individuals with a terminal illness. These challenges include the loss of employment income and the rising cost of living, particularly for households that must accommodate additional medical equipment and energy consumption. Research indicates that 1 in 5 people in their last year of life are living in poverty in Northern Ireland, with this number rising to 1 in 4 for those in fuel poverty. The current social security system does not adequately address the financial needs of terminally ill individuals, both of working age and pension age, leaving many families in a vulnerable position.

Unpaid Carers

343. Research has shown that unpaid carers, who often play a crucial role in supporting individuals with terminal illnesses, are more likely to experience financial insecurity and poor physical and mental health. Carers of end-of-life patients, especially those who are older, female, and have lower education levels, are significantly more likely to live in poverty. There is a strong call for strengthening employment rights for carers, including better access to statutory leave, pay, and flexible working practices to alleviate the financial pressures they face.

Psychological Distress

344. In addition to financial hardships, individuals diagnosed with a terminal illness often face significant psychological distress, which can be compounded by financial concerns. The impact of anxiety, depression, and hopelessness is particularly severe for those with pre-existing mental health conditions. Many individuals with terminal illnesses do not receive adequate palliative care for their mental health, and there is a need for improved training for healthcare professionals in addressing the mental health needs of terminally ill patients.

Compassionate Communities

345. Compassionate Communities Northern Ireland impressed on the Committee the need for a public health approach to palliative care that addresses public awareness and education and requires a whole-system approach to care. The Compassionate Communities international movement is a public health approach focused on improving palliative and end-of-life care in communities.

346. Compassionate Communities cares for people where they live, work, learn, pray and play. It emphasises a shared responsibility for care. Collaboration between local residents, organisations and healthcare services is seen as critical to enabling support for individuals and families facing serious illness, death and dying.

347. Compassionate Communities explained the 95% rule. The assumption held in communities is that a person living with advanced illness or frailty spends 95% of their time with healthcare professionals. Conversely, typically, they spend 5% of their time receiving treatment and 95% of their time in their homes and communities.

Bereavement

348. BASW NI calls for improved family support and services, both pre- and post-bereavement. The organisation advocates for counselling, emotional support, and respite services to be provided in-house as part of specialised palliative care services. These services should also be integrated with statutory services, particularly in children's social care. Emotional support for parents, especially in cases involving children with terminal illnesses, is seen as crucial to preventing the need for extensive post-bereavement counselling.

349. Marie Curie highlights a pressing need for statutory bereavement leave to be extended in Northern Ireland, ensuring that all close relatives, including carers, are supported during this challenging time. Additionally, they advocate for a statutory requirement for employers to implement a bereavement policy. They also emphasise the overwhelming reliance on the Voluntary and Community Sector to provide bereavement and emotional support, though these services are under significant pressure due to funding constraints and rising demand.

350. Foyle Hospice refers to the UK Commission on Bereavement's estimate that at least five people are affected by each death. As a compassionate organisation, Foyle Hospice staff provide support not only to patients but also to a significant number of their loved ones during difficult, emotional times. They follow up with relatives after the death of their loved ones, and volunteer chaplains assist when appropriate.

351. Macmillan reports that at the statutory level, capacity pressures are limiting Trusts and primary care teams' ability to offer sufficient bereavement support, including follow-up services for carers and loved ones. The charity sector is also facing challenges in meeting demand, with some individuals experiencing long waiting times for one-on-one support following a referral.

352. These delays can cause psychological distress and physical health complications, which in turn place additional strain on already overburdened mental health services. Macmillan stresses the importance of pre-bereavement and bereavement support, especially for carers and loved ones of those with non-curative cancer. They also emphasise the need for comprehensive support that acknowledges younger people affected by cancer mortality, including children.

353. RCGP recommend improved availability of psychological services for both patients and their families, particularly grief support for families. They believe that strengthening this support would enhance the overall palliative care service, providing better assistance to bereaved families.

354. Carers NI emphasises that bereavement support should be available to all family members and carers from the moment they recognize the need, which may arise even before the person they are caring for has passed away. Additionally, Carers NI highlights that post-bereavement support for carers is a critical gap in public policy, as many carers do not receive support from the state after the death of the person they cared for. This gap includes financial, emotional, and employment-related support.

355. The Trust Bereavement Co-ordinators state bereavement services are heavily reliant on charitable funds to maintain staffing, and in areas where this is not feasible, services may be withdrawn, leading to inequitable provision of support. Furthermore, bereavement support for families who have lost a baby, child, or young person is often inconsistent, with availability varying based on the circumstances surrounding the death and the geographic location of the family.

356. Cruse Bereavement Support described to the Committee a service that is funded through the National Lottery. Cruse go into schools perhaps after a number of deaths of parents, grandparents or maybe even children from the

school, be that sudden or unexpected or a death that they knew was going to happen. Cruse also work alongside the Education Authority's critical incident response team.

357. Cruse also provide bereavement support in communities where there have been sudden unexpected deaths, through community groups, sports clubs etc. These services have developed over the past 20 years and have been completely funded by the National Lottery. Cruse would like to see death, dying and bereavement included in the school curriculum.

Recommendation 24: The Health Minster commit to working with other Executive Ministers on programme for government initiatives to help remove barriers to PEOLC, for Northern Ireland to:

- **a. embrace the Compassionate Communities model that encourages communities to support their members through end-of-life experiences, dying, death, and bereavement, and support death literacy programmes in the public arena and public bodies such as Libraries NI;**
- **b. streamline death, dying and bereavement education in school curriculums, including programmes tailored to special education schools;**
- **c. remove financial hardship and poverty as a significant barrier for many individuals to access palliative care, particularly vulnerable groups, and those with protected characteristics;**
- **d. ensure financial support for unpaid carers and families of individuals receiving palliative and end of life care, including reviewing the timescale of Carer's Allowance ending after a person dies, implementing statutory Carers' Leave for employers to allow carers more flexibility to balance work with their caregiving responsibilities;**
- **e. increase support for front-line staff in homeless shelters dealing with challenging issues to meet the needs of individuals in their care;**
- **f. increase support for front-line staff in prisons dealing with challenging issues to meet the needs of individuals in their care needing palliative care; and**
- **g. streamline programmes to assist patients and their families and carers where there is a language or culture barrier for access to palliative and end of life services including bereavement services.**

Transformation

358. The Association of Hospice and Palliative Care Chaplains Northern Ireland and Donegal Regional Group (AHPCC) made the point**,** when palliative care is properly embedded in the delivery of health care so much money will be saved such as through reducing inappropriate ED admissions. When people witness ‘good deaths’ there is less demand on specialist bereavement support services and improved death literacy. When staff are fully trained to deliver palliative care there is better morale.

359. Marie Curie highlighted, while efficiencies and collaboration will need to be a focus of this transformation, funding will also be needed. A requirement within funding criteria to collaborate and work across services, Trust boundaries and sectors may create the framework to drive this necessary change and address protectionism of existing service models that can hold innovation back. Funding needs to support and promote transformation. The way people live and die is changing and we need to change how we support them.

360. Demand has increased, and with extreme pressures on the public purse, there is an ever greater need to innovate, and to work collaboratively and efficiently. A lack of recurrent budget means services can only plan for the short term to meet immediate need without an ability to support longer term strategic service planning, vital for innovation and transformation. RCGP stated, with planned transformation and the shift of care from secondary care into the communities, the already inadequate funding for these services will be even more stretched.

361. Marie Curie and RPMG noted that a lack of appropriate care packages in the community can delay the discharge of palliative patients from hospitals or hospices. This leaves patients in institutional care longer than necessary, preventing them from dying at home as preferred. Marie Curie stressed the need for greater investment in workforce planning, particularly for domiciliary care, to support hospital discharge and reduce unnecessary admissions.

362. The RSPCNG identified a significant gap in out-of-hours palliative care services, particularly for symptom management in rural areas, and this can be a barrier to patients returning home. Further, there is a significant lack of trained and supported domiciliary care workers to help individuals stay at home, a crucial preference for many at the end of life.

363. PCI’s Council for Social Witness (CSW**)** highlighted that, access to community services that support patients requiring palliative care to remain in their homes is inconsistent across Northern Ireland, creating disparities in care.

364. The RCN NI also stressed the need for ongoing education and training for generalist nurses to ensure they are equipped to provide quality palliative care, particularly as specialist nursing support is often limited. A comprehensive, accessible, and responsive education package is needed to maintain the training and competencies of these generalist nursing staff, with access to updated education programmes, such as advanced communication skills and breaking bad news training and guidance.

365. Foyle Hospice and Hospice UK stated, a well-supported hospice sector is a key enabler of moving more palliative and end of life care into the community. Hospices are delivering more services in the community and whilst commissioners have indicated this is the approach they wish to see, that message is then undermined by the fact that it seems a majority of funding is calculated on the basis of IPU beds. Hospices struggle at times to understand how funding allocations are made up by commissioners (e.g. the proportion for In-Patient Units versus Day Hospice versus Community).

366. The AHPCC stressed the value of hospice community services, which provide a range of support from chaplains, nurses, physiotherapists, reflexologists, social workers, and counsellors. However, additional funding is necessary to enhance these services and expand their reach.

Ambulance Services

367. Northern Ireland Ambulance Service Health and Social Care Trust (NIAS) noted, ambulance services throughout the UK are keen to link with palliative care services as they often receive urgent / emergency calls to patients suffering an acute deterioration in their symptoms.

Resolved at Home

368. In many cases it may be more appropriate to direct patients to or liaise with palliative care services in order to resolve issues at home rather than the traditional response of bringing a patient with a palliative care need to an already busy emergency department that may not be best suited to meet their needs. The journey and the experience within a pressurised ED system has the potential to be detrimental to a patient's comfort and dignity.

369. NIAS has made inroads into accessing palliative care teams in a number of Trust areas which has shown benefit for patients but has only able to directly access specialist palliative care teams in a minority of Trust locations.

GP Referrals

370. NIAS further noted, arrangements for access to palliative care services differ across the five acute Trust areas. Only in a minority can the ambulance service directly access teams while in the remainder this is only achievable through contacting the patient's GP to request a referral is made. This can be a lengthy process, impacting ambulance operational availability, and requires extra and arguably unnecessary steps as the same information is ultimately being passed to the palliative care team. This also adds additional workload to the pressurised primary care system where a direct referral could be made without their input.

Direct Referral Pathways

371. In developing a large number of direct referral pathways for a wide range of conditions, NIAS frequently faces concerns that the specialist services will be "swamped" with inappropriate referrals, but this has proven not to be the case as new patients are not being generated, just a more direct route of access to services for existing patients in line with the approach of "Right patient, right place, right time".

372. NIAS believes integration can be improved by clear regional agreement on levels of service provision / access arrangements and the ability to accept referrals from a wider range of healthcare professionals.

Recommendation 25: The Department review PEOLC within Transformation and Hospital reconfiguration agendas and invest to save initiatives. To include consideration of:

- **a. all Trusts aligning with the NIAS initiative that patients are directed to, or liaise with, palliative care services and resolve issues at home rather at an already busy Emergency Department that may not be best suited to meet their needs;**
- **b. remove the need for ambulance teams to contact the patient's GP to request a referral is made;**
- **a. increased investment in District Nurses to ensure community general palliative and end of life services adequately funded, to improve patient care at home on a more consistent basis and reduce preventable ED visits and hospital admissions;**
- **c. increased investment in training and supporting domiciliary care workers to help individuals stay at home, a preference for many at end of life, and assist discharge of palliative care patients from hospital wards;**
- **d. investment in specialist palliative care community teams to improve patient end of life choice and timely discharge of palliative care patients from hospices and hospital wards; and**
- **b. investment in palliative care services as 'preventative' policy in terms through a sustainable multi-disciplinary team workforce and prehabilitation services.**

Recommendation 26: The Department establish a branch with specific responsibility for the adult, young adult and paediatric specialist palliative care sector as an acute service within palliative and end of life care services. The branch must work closely with specialist palliative care professionals to prioritise and have oversight and governance of quality-of-care indicators for specialist palliative care in hospitals, hospices, care homes, Emergency Departments and patients' homes. The branch to also be an important partner for collaboration on department policy of generalist palliative care services in primary care, including a 'shift-left' agenda and be responsible for the collation of robust data to inform palliative care services, projected population needs and ensure data-led policy and decision-making.

Palliative Care in partnership programme (PCiP)

373. Marie Curie noted that, the PCiP is often cited as a solution to many of the issues raised within the hospice sector, but the lack of recognition of its resource constraints undermines its ability to deliver effectively. Marie Curie agreed with the programme's objectives, but PCiP is significantly under-resourced to meet the demands of care. The scale of the need for palliative care in Northern Ireland is vast, and the current resources allocated to the programme are insufficient to achieve its full potential. The staff within the unit are highly skilled and experienced, but there are simply too few of them to meet the demand.

374. Hospice UK acknowledged the ambitions of the PCiP but points out that existing priorities set by the programme have not been delivered on schedule due to limited resources. This delay in meeting key targets further underscores the need for increased investment and support for the programme if it is to fulfil its potential.

375. Life and Time Nursing Agency suggested that while the PCiP is an excellent model with a well-established network, it currently relies heavily on individuals driving the agenda for integration. More work is needed at the local level to promote and advance integration efforts.

376. Life and Time believes that the PCiP's regional work plan, along with Programme Board Members and the Clinical Engagement Group, provides a solid foundation for integration across palliative care services, but further efforts are needed to ensure these systems are fully realised and implemented across all areas.

377. RSPCNG stated that while integration of palliative care exists within the region, it is not standardised, and there is room for significant improvement. The PCiP has established a good framework by bringing together multiple providers of palliative care, but its effectiveness is hindered by limited funding and an insufficient number of staff dedicated to the programme.

378. RSPCNG emphasises that while the structure provided by the PCiP is a valuable starting point, the impact of the programme needs to be assessed and its structure strengthened. Ensuring timely delivery of the programme's work plan is essential for improving patient care.

379. It has been noted in recent years at the Palliative Care in Partnership Programme (PCiP) Board meetings that a national clinical lead could significantly impact the effectiveness of palliative care services.

A PEOLC Strategy

380. A joint letter from the hospices advised the Committee, the current palliative care strategy is substantially out of date. Since it was published, the number of people over 65 has risen by a quarter, care needs have become increasingly complex and research shows that demand for palliative care will increase by at least third by 2048

381. The BHSCT states, the Living Matters/Dying Matters strategy (2010) had no funding stream and therefore it was not fully implemented. A new 10-year strategy with realistic aims, objectives and funding, would provide clear direction, coordination and accountability for delivery of services.

382. The AIIHPC's members highlighted the need for a clear policy/strategy for Northern Ireland regarding palliative care, along with an implementation plan with key deliverables and detailed activities and timelines, a review panel and accountable parties.

383. Foyle Hospice states, it is clear that an overarching vision for palliative care is urgently needed and would like to see a commitment to the development and implementation of a new palliative care strategy for adults and children in Northern Ireland. This is fundamental to address ongoing issues and enable improvement, including greater integration of services.

Benchmarking

384. The Evora Hospice emphasises that Northern Ireland's palliative care policy lags behind UK regions and RoI, with an outdated strategic approach and the most recent palliative care strategy, "Living matters, Dying Matters," expired over a decade ago. The publication of the RoI Government's strategy starkly illustrates the disparity in approaches but population issues are the same and demographic challenges are the same.

385. The hospice believes long-term costs of ignoring the need for a strategic approach to ensuring that the dying (irrespective of postcode or financial status) can receive compassionate and professional end of life care is huge and supports the implementation of a palliative care strategy, including the Integrated Palliative Care Model.

386. RCN NI advised of its Members' frustration due to a lack of a regionally updated strategy in line with the UK and the RoI, supported by the commissioning of recurrent funding.

387. The Hospices joint letter advises, while the development of a strategy requires time to engage across all palliative care services, one immediate decision that could be taken which would support the development of a future strategy and provide short-term focus on addressing outstanding issues would be the appointment of a clinical lead for palliative care. Northern Ireland is the only nation across the British Isles not to have a clinical lead for palliative care.

388. The Hospices joint letter further advises, if you look to the RoI, full funding for charitable hospices was delivered last year but an 'in-principle' commitment to that funding was made years before it could be practically delivered. The hospices agree this level of funding should be the aspiration for hospices in Northern Ireland and wish to see an 'in-principle' commitment to that as soon as possible.

389. Marie Curie states, Northern Ireland is the only jurisdiction across the UK and Ireland that is failing to prioritise palliative care and end of life support at the strategic policy level.

390. Marie Curie welcomes the new NI Cancer Strategy's inclusion of a Palliative and End of Life outlining how services could meet the needs of this cohort, but states we now urgently need a new palliative care strategy for everyone, to address any malignant versus non-malignant imbalance.

Hospices

391. Marie Curie believes hospices should also be included in strategic planning at central departmental level which will impact services and hospice finances. This should include Agenda for Change discussions which hospices need to financially plan and fundraise for.

Sustainable Funding

392. The hospices advise, hospices in Northern Ireland provide an exceptional level of care for local communities, with around two thirds of people who die each year supported by charitable hospices. This level of support provides enormous benefit to the wider health and social care system as well as to patients and families. However, that also means that a failure of the hospice sector could have absolutely massive ramifications for the government and the people of Northern Ireland both in terms of patient care and financial impact. A sustainable funding model for hospice care is essential to ensure that these services are protected and continue to provide invaluable care across the region.

Quality Indicators

393. The RSPCNG states, quality indicators need to be developed for acute services similar to community services to monitor the delivery of care. Quality indicators should be used across all care settings (generalist and specialist) to assess performance and measure patient outcomes.

394. The RSPCNG would like to see a Strategy that emphasises robust governance structures to monitor both generalist and specialist palliative care, ensuring it is forward-thinking, inclusive, and adaptable. The Strategy should include performance indicators.

Transformation

395. Marie Curie states, there has been a lack of focus on the need to transform services to meet growing demand and changing patient needs, as people live longer but with more complex symptoms (so unhealthy life expectancy increasing), presenting later in their journey and also for some conditions, contracting them earlier. This highlights the current strategy Living Matters Dying Matters, written some 15 years ago, is completely outdated and unfit for purpose and a new palliative care strategy is urgently needed.

396. There is a critical need to draft a new PEOLC Strategy to better meet patient and carer need, deliver best practice and advancement in palliative medicine, and fit within new models of service planned through the HSC transformation programme.

397. Hospice UK states, the shift towards more services delivered at home and in the community is continuing. Place of death is also shifting in Northern Ireland which brings with it different demands. In 2011, 26.3% of deaths occurred at home whereas by 2021 33.5% of deaths occurred at home. Hospice services shifted substantially during the pandemic and continue to be delivered differently, and reshaped on an ongoing basis to meet local need.

Bereavement

398. There is strong support for a new Strategy to include bereavement support to those that are important to the deceased person.

Rural Proofing

399. The Rural Community Network asks for a specific rural dimension to any new Strategy. Rurality and deep rurality are major issues in terms of access to palliative care and end of life services, with those patients and families who live at the greatest distances from our major regional health centres often experiencing the greatest challenges and complexities when it comes to accessing the different elements which can make up the care offering.

400. The Rural Community Network highlights that rural transport is an afterthought (if a thought at all) and it has developed within an uncoordinated historical policy, strategy and practice vacuum. Transport is a critical element in the palliative care support ecosystem and as such it should be afforded the status and investment it merits based on the contribution and difference it makes.

401. The Rural Community Network states we need a deliberate and thoughtful policy and strategy which endeavours to build a palliative ecosystem from the perspective of patients (present and future) and their families.

Transport

402. Fermanagh Community Transport highlights transport is critical to access palliative and end of life services by so many patients and their families, yet it is viewed outside of the palliative care ecosystem and seen as something which can operate on the basis of good will and short-term charitable funding. This does not sit comfortably with the principles of access, quality and dignity, with one’s access subject to the potential fundraising capacity and volunteering propensity and availability within any given local community.

Data Led Approach

403. The NI Hospice calls for baseline data of projected population need across the age span to include antenatal data and baseline data of current service provision to include generalist and specialist palliative care.

404. The WHSCT highlights there is no population health analysis of palliative care needs within Northern Ireland which feeds into being a barrier for equitable services across Northern Ireland. There is no clear public health data on palliative care to demonstrate impact.

405. Hospice UK states, any strategic review should include: population based needs assessment (for example, using data available through Hospice UK); clear mapping of need, and who has responsibility for commissioning services to meet that need; clarity on the service specification required; and measurement of impact, with outcome measures encompassing qualitative as well as quantitative indicators.

Paediatrics

406. The NI Children's Hospice states, the current strategy is not funded and progress achieved in the Regional Paediatric Palliative Care network has relied on the goodwill of professionals. Research demonstrates that the number of children with a palliative care need will continue to grow. We need to be building for this growth. As with Adult Services, there is little or no community-based out of hours cover for end-of-life care. Care often relies on the goodwill of staff or a ramping up of independent services to plug the gap.

407. In addition, supported short breaks, a key element of paediatric palliative care, and distinct from adult palliative care are underprovided in Northern Ireland, compared to other regions.

408. The Northern Ireland Paediatric Palliative Care Network states that, up-to-date data on how many children in Northern Ireland live with life-limiting conditions is needed. Other parts of the UK have done that work. For example, in Scotland, there was the Children in Scotland requiring Palliative Care (CHiSP) study. To develop and drive paediatric palliative care forward, accurate data is needed.

Carers

409. Carers NI states, it wants any new palliative care strategy to specifically recognise the unique challenges faced by unpaid carers providing care and support for someone with a terminal illness, approaching the end of life, at the time of death, and following it through bereavement and grief. This should include recommendations and identify specific support for such as access to training, respite care, financial support, mental health support and bereavement services.

410. Unpaid carers play a key role in palliative care and should be considered as equal partners alongside health and social care practitioners in the care they provide to the person they are looking after. This should include all decision-making around the care of the terminally ill person. Carers should also be explicitly referenced in governance frameworks and innovation initiatives. Their insights can inform practical improvements in care delivery. Any new strategy on palliative care should clearly state their position as equal partners in care.

NI Executive

411. Marie Curie emphasises that beyond clinical care, socio economic and other societal factors also play an important role in patient well-being at end of life and this requires support in other Executive Departments, such as welfare support or funeral and death administration provided by local councils. We are a long way from all sectors, providers, disciplines and Departments working seamlessly together.

412. The Rural Community Network calls for DoH and the Department for Infrastructure to work more closely. In addition to the provision of dedicated transport services, there is a call for improvements in transport infrastructure to address critical gaps, particularly in underserved rural areas. Creating more direct routes and simplifying travel links between regions would alleviate the burden of long and convoluted journeys. Infrastructure improvements would not only reduce

travel complexity but also ensure that individuals in rural communities have equitable access to healthcare services, including palliative and end-of-life care.

Funding

413. Hospice UK states, at a region-wide level there is a need for greater transparency and meaningful engagement on funding for hospices to ensure that they are an equitable partner when decisions are being made that have a direct impact. For example, discussions on pay and terms and conditions of NHS staff (such as Agenda for Change) should include hospices as this has implications for them needing to find additional funds to match such settlements. Hospices would prefer to see an improved relationship built on partnership working, and a recognition of their willingness to support the wider health and social care system at a time of great pressure for all.

414. There needs to be a strategic review of what is needed by people across the region, and the funding must then support service delivery to meet those needs, whether that is more bed spaces or additional community services or greater delivery of hospice at home. Enhancing the contribution of hospices would enhance the services delivered to the people of Northern Ireland and help support statutory services as they work to address wider health and care pressures

415. The BHSCT states, the Living Matters/Dying Matters strategy (2010) had no funding stream and therefore it was not fully implemented. A new 10-year strategy with realistic aims, objectives and funding, would provide clear direction, coordination and accountability for delivery of services.

416. The SHSCT states it would like to see a firm commitment to produce a palliative care strategy/policy, with committed funding, accountability and implementation plan for the next 3 years. The funding of hospices is robustly reviewed to ensure these services do not fail or diminish.

Workforce Planning

417. The NI Hospice advises there is currently no regional workforce plan to facilitate recruitment, training and career progression and this may be contributing to current workforce shortages.

418. Marie Curie states, the delivery of high-quality palliative and end of life care requires multidisciplinary input, not just from specialist palliative care professionals but from a wide range of generalists as well, including GPs, district nurses, Allied Health Professionals, social care workers and more. All of these professions play crucial roles in a patient's journey with terminal illness, identifying their palliative care needs and referring them for support; managing distressing symptoms and meeting their personal care needs in the community; providing emotional support and advice on important issues ranging from access to equipment to financial support; and a lot more.

419. Workforce pressures in the health and social care system in Northern Ireland therefore have the potential to impact significantly on people living with a terminal

diagnosis and their loved ones. These shortages could mean a dying patient does not receive the care they need, when they need it, and in their preferred place.

420. Life and Time states, a new Strategy should address deficits in MDT service provision and promote the public health agenda. A review of current commissioning is needed, to provide a responsive solution to the new and expanded problems that the sector faces. There is a need for a robust palliative care workforce plan. The impact of grief and bereavement is felt through generations and impacts on the general wellbeing of society. The new strategy must address care during pregnancy through to care of the elderly.

421. The WHSCT calls for workforce planning for the next 20 years.

422. A lack of investment is leading to workforce burnout and turnover. This issue, noted **by** NI Hospice, threatens the sustainability of services and the well-being of healthcare workers. The growing demand for palliative care, coupled with the pressures on the workforce, risks exacerbating these problems unless immediate action is taken to bolster support, including investment in training and improved working conditions.

423. Marie Curie notes, delivery of specialist palliative care requires clinical oversight from specialist consultants, which are in short supply. Specialist Palliative Care doctors are critical not only for patient safety and quality care, but also for the operational efficiency of specialist inpatient units. A lack of consultant oversight for the patient ratio can impact bed occupancy rates, meaning patients can’t be admitted and hospices are unable to meet their commissioned quotas.

424. A comprehensive workforce plan should be drafted and implemented to ensure a fully funded, appropriately trained and adequately resourced multi-disciplinary workforce is in place to support the palliative patient population in Northern Ireland. This should be a key recommendation in a new PEOLC strategy for Northern Ireland and be underpinned by population needs assessment. Workforce challenges are seen as a major barrier to the delivery of quality palliative care.

425. Marie Curie stresses the importance of a multidisciplinary approach, which includes not only specialist palliative care but also complementary therapy, psychology, spiritual care, and social services. This integrated model requires significant workforce investment to function effectively.

426. RCN NI states there is an urgent need for a comprehensive strategy and emphasises workforce capacity as the greatest challenge for its members, urging for increased investment to expand palliative and specialist palliative care nursing services, which are essential for providing 24/7 care. RCN NI also call for better training and career development pathways to reduce staff turnover and prevent burnout. Supports stakeholder involvement in strategy development and recommends a review of current services to identify gaps and excellence.

Regional Approach

427. The Evora Hospice highlights that the regional approach was to be developed towards Individualised EOL Care Plans. A DoH statement showed it was not to be progressed at present. This is unacceptable and permits different working practices.

428. Macmillan points out that the regional model has proven effective in other areas, such as breast cancer services, and could provide better-quality palliative care with the right interventions, funding, and governance.

429. Marie Curie suggests that many examples of good practice exist across the region that could be scaled up to improve patient experiences and increase service efficiencies. However, services must be tailored to local delivery structures.

Concerns Raised

430. RCGP expressed concerns about the loss of local responsiveness, particularly in areas with significant rural-urban divides. There is fear that regional services might not address the unique needs of local populations.

431. The Evora Hospice also emphasises the importance of ensuring that regional services remain flexible and adaptable to local preferences, particularly the desire for people to receive care at home or close to home.

432. The WHSCT raises issues around the centralisation of services, particularly for rural populations who may face challenges accessing services. They stress the need for a regional service that does not disadvantage those in rural areas and highlights the importance of equitable access for all. WHSCT highlights the importance of being able to meet the local population's needs, especially for vulnerable patient groups. They point out that the current fragmented approach does not serve the population well.

433. Foyle Hospice and Hospice UK emphasise the importance of involving communities in developing solutions and ensuring that regional service delivery is accountable while allowing for local innovation and flexibility. The NI Hospice supports a regional strategy but insists that it must maintain the flexibility to adapt to local conditions. A "one-size-fits-all" approach is not feasible, particularly given the small, specialized workforce in palliative care.

434. NIAS states, while a regional service would be beneficial, this may be difficult to achieve across Trust boundaries due to legacy arrangements of staffing / employment and management. Instead NIAS would see benefit in having a regional set of standards and operating procedures which all Trusts should deliver.

435. As a regional service, it is the frequent experience of NIAS that the five acute Trusts frequently differ in levels of service provided and access arrangements. NIAS believes that a regional strategy could offer the opportunity to define clearly a level of best practice arrangements which all Trusts should deliver, improving equity of care and access for patients across Northern Ireland.

436. As the only Trust providing a truly regional service, **NIAS** would welcome the opportunity to join partner agencies in any review of palliative care services so that its unique perspective can be offered.

Recommendation 25: A new PEOLC Strategy be introduced to equip the specialist and generalist sectors to meet current and future needs with clear measurable goals and targets, and sector agreed implementation timescales. The Strategy must address:

- **a. planning of level of services needed over next 20 years;**
- **b. collation of robust data to inform data-led policy;**
- **c. recognition of the unique challenges faced by unpaid carers;**
- **d. standardise regional services for equitable access whilst ensuring diverse local community needs are met;**
- **e. rural proofing;**
- **f. bereavement services; and**
- **g. recognise cross Departmental work needed to remove access barriers.**

Families / Caregivers

Access to Services

437. The AHPCC points out that while some families report adequate support, many others experience a lack of access to services, which has adverse effects on their well-being. The absence of early intervention often results in the need for more complex, resource-intensive interventions later, further stressing the already strained system.

438. The BHSCT also highlights that patients and families struggle to access services due to existing barriers and a lack of resources, with services struggling to meet the growing demand.

439. Foyle Hospice similarly notes the variability of support based on geographic location and the level of palliative care provision available and highlights the confusion families face when navigating the palliative care system, particularly when they are not fully informed about available options.

440. Both BHSCT and Trust Bereavement Services identify challenges in accessing practical help and timely services. Lack of awareness among healthcare professionals regarding available services can delay crucial interventions, impacting the overall quality of care provided.

441. Carers NI calls for better communication and access to palliative care, particularly for unpaid carers from minority ethnic backgrounds (BME). Issues such as linguistic barriers and culturally inappropriate services prevent many from accessing the care and support they need.

442. Macmillan Cancer Support emphasises the confusion and complexity of the system, stating that many carers and families do not know where to turn for help,

leading them to emergency services as a last resort. This fragmented care system highlights the need for clearer guidance and more accessible support options for families and carers.

Holistic Care

443. Organisations like Foyle Hospice pride themselves on offering holistic care, focusing on the patient and their family, not just the medical symptoms. This holistic approach includes support for families and carers who have been involved in the patient's care, ensuring that the emotional and practical needs of all involved are addressed.

Psychological Support

444. Both Marie Curie and Evora Hospice emphasise the increased demand for psychological services as families and carers struggle to cope with the emotional and mental burden of caring for a loved one at the end of life. Marie Curie notes that while they offer emotional and practical support, their capacity to reach everyone in need is limited, and specialised psychological support is only available to those receiving care in hospices.

445. The Evora Hospice also acknowledges that while there is a recognised need for more psychological, social, and financial support, the availability and consistency of these services depend heavily on the location of the family or patient, leading to disparities in care.

Respite Care

446. Marie Curie points out that respite could be provided through care packages or voluntary befriending services, but these options are not guaranteed due to high demand and limited supply.

447. Carers NI has also highlighted the need for respite breaks, as evidenced in the RQIA's review of palliative and end-of-life care strategy, which stresses the importance of respite for carers to prevent burnout.

448. However, Marie Curie highlights the issue of prioritisation, where only patients with the greatest need or living alone may receive respite, leaving many others without this crucial support.

Employers

449. Carers NI and Marie Curie stress the need for supportive employers who understand the significant challenges faced by carers and, further, advocate for statutory carers' leave, allowing carers more flexibility to balance work with their caregiving responsibilities. This would help alleviate the financial insecurity that often arises when carers are forced to reduce their working hours or give up their job entirely.

Financial Strain

450. Carers NI calls for a review of the financial support provided to carers after the death of their loved one. Currently, carers are entitled to Carer's Allowance, but

this stops just eight weeks after a person dies, which compounds the financial strain during an already difficult time.

451. Marie Curie emphasises that many carers miss out on essential practical, emotional, and welfare support due to the difficulty in identifying themselves as carers. Without clear identification and proper assessments, carers are frequently overlooked, which further exacerbates the financial and emotional burden they carry.

452. Carers NI also highlights the gendered nature of caregiving, with women disproportionately shouldering the burden. Research indicates that nearly 60% of unpaid carers in Northern Ireland are women, with many having to reduce their working hours or leave employment altogether to care for a loved one.

Care Planning

453. Carers NI highlights the need for greater information, better communication, and earlier conversations about palliative care, advance care planning, and Do Not Attempt Resuscitation (DNACPR) orders. These discussions should be publicly available to help families make informed decisions about care.

454. Carers NI advocates for greater discussions around future care planning, dying, death, and bereavement. They argue that these conversations should extend beyond families and communities into broader societal frameworks, including health, social care, and local authority services such as housing, community planning, and employment. They stress the need for employers to be included in these discussions, as juggling paid work and caring responsibilities, particularly during end-of-life care, is a significant challenge for carers.

455. Furthermore, Marie Curie stresses the need for continuous reviews of care plans for those in the last year of life to ensure they meet the evolving needs of the patient and their carer’s. The RQIA’s review of palliative care emphasises the importance of planning for transitions, particularly for families with young people facing life-limiting conditions. It calls for dedicated resources and support, including hospice and short-break provisions, to support families through these challenging transitions.

Best Practice

PEOLC Hubs

456. RCN NI reports that palliative care HUBs, such as those in the Southeastern Trust, are critical in delivering care to patients with palliative and end-of-life care needs. These HUBs focus on specialized non-malignant conditions like respiratory and heart failure, providing essential services to a broad patient population.

457. The BHSCT is developing a Community Palliative Care Hub in collaboration with the Northern Ireland Hospice and Marie Curie. This initiative aims to improve coordination of community-based palliative care services and facilitate easier access for patients to self-refer. The collaboration of multidisciplinary teams at

hubs such as these has been shown to improve outcomes and patient satisfaction.

Partnerships for Effective Care

458. In the BHSCT, specialist nurses work in partnership with district nurses and other specialists to deliver palliative care to housebound patients, showing the effectiveness of collaborative models in providing high-quality care in the home setting.

Antenatal Palliative Care Pathway

459. An antenatal palliative care pathway within the BHSCT supports families who receive a palliative diagnosis at the 20-week pregnancy scan and ensures early and more frequent referrals for palliative care. This initiative aligns with the objectives of the current paediatric palliative and end-of-life care strategy, demonstrating a proactive approach in addressing palliative needs early in the pregnancy.

Collaborative Roles and Services

460. A key example of effective collaboration is the creation of the Palliative and Life-Limited Nurse role, which is employed by the Northern Ireland Children's Hospice but based at the Royal Belfast Hospital for Sick Children. This role has enhanced advance care planning, facilitated discussions about location of care, and provided crucial support for difficult conversations between healthcare professionals and families. This role complements the work of palliative consultants and has had significant positive impacts on patient and family outcomes.

461. NIAS can directly refer patients with palliative care needs in a number of Trust areas to local services which can offer a timely response. This is particularly important in the end-of-life setting where comfort, dignity, and symptom control should be the focus with the aim of improving quality of life in this phase while avoiding unnecessary hospital attendance and admission. Other UK ambulance services have developed the role of the specialist paramedic for palliative care which brings a prehospital perspective to patient care, and - crucially in Northern Ireland - could offer a genuine regional approach.

Single Point of Access

462. Marie Curie highlights a new model of service delivery is underway aimed at coordinating care for palliative care patients through palliative care referrals being made to one service with a single point of access. Similarly, the Integrated Mersey Palliative Care Team (IMPaCT), a partnership between multiple healthcare providers, serves as a successful model of integrated care, ensuring better collaboration and coordinated services for patients and their families.

Out of Hours Support

463. The WHSCT has developed comprehensive Out of Hours (OOH) and In-Hours pathway guidance to improve access to timely support for staff. This

includes the implementation of a dedicated number for community staff to contact out-of-hours GPs, enhancing the support available to those working in palliative care.

464. Furthermore, the Evora Hospice offers an Out-of-Hours Nursing Service, available 365 days a year, which ensures that patients can pass away at home, aligning with their preferred place of death (PPOD). The service's success, though positive, is at risk due to a lack of recurrent funding.

Supporting Patients to Stay at Home

465. The BHSCT highlights the invaluable service provided by the Marie Curie Night Sitters, which allows patients to stay in their homes while receiving compassionate support. NI Hospice reports that 1,695 patients were supported by Specialist Community Nursing Teams to die in the comfort of their own homes, which resulted in significant cost savings for the healthcare system. Similarly, the Just in Case Boxes piloted by BHSCT and WHSCT have been instrumental in ensuring that the necessary medications for end-of-life care are readily available at home.

466. Marie Curie has pointed out several examples of best practices, such as the REACT Bradford model, which provides 24/7 support to palliative patients at home. This model is being expanded in Northern Ireland to ensure that patients can avoid unnecessary hospital admissions and transitions to hospice settings. Additionally, Hospice UK highlighted the challenges faced by young adults transitioning from paediatric to adult palliative care, underscoring the need for enhanced care coordination and capacity in non-specialist settings.

Seven Day Specialist Palliative Care

467. Foyle Hospice has implemented a seven-day community specialist palliative care service in the Northern and Southern sectors of the WHSCT. This service has been particularly successful in preventing unnecessary hospital admissions over weekends, thereby reducing strain on emergency services and allowing patients to remain at home. Additionally, Foyle Hospice has employed a Specialty Doctor to assist the community team with more complex cases, further enhancing the service's effectiveness.

Hospice and Advanced Care Planning

468. The Evora Hospice has enhanced its advance care planning and anticipatory care efforts by collaborating with local care homes to facilitate crucial discussions about end-of-life care.

Nurse Led Beds

469. Marie Curie is working to introduce nurse-led beds within their Inpatient Unit, improving care access for patients.

Volunteer and Bereavement Support

470. Marie Curie's Volunteer Companion Service provides crucial emotional and practical support to patients and their families, both in the hospital and at home.

Additionally, several bereavement support services, such as the Healing Hearts service at Foyle Hospice and the Horizons Project by Northern Ireland Hospice, offer vital pre- and post-bereavement support to individuals coping with the loss of loved ones.

Specialised Training and Education

471. The Evora Hospice has developed the PEARL (Palliative Education and Resource Library), an interactive resource that supports healthcare professionals in delivering quality palliative care. Moreover, the WHSCT has implemented an Integrated Care Fellowship Consultant Training Program, which equips consultants to work in both community geriatrics and palliative care, safeguarding a future workforce capable of leading integrated palliative care services.

Pharmacy

472. There has also been development of community pharmacy's relationship with the Trust specialist palliative care pharmacists. The palliative care pharmacists have developed a Community Pharmacy Palliative Care Newsletter which aims to keep the palliative care network pharmacies up-to-date with any relevant information. The newsletter provides information on potential drug shortages, learning from incidents and developments in palliative care. The specialist palliative care pharmacists also recently launched the Marie Curie Daffodil Standards, and have been liaising with the pharmacists that have signed up to the standards.

Academia

473. A QUB Lecturer in Palliative and End of Life Care, School of Nursing & Midwifery, shared important recommendations for the NI Health Care system from an NIHR funded study looking at the international literature on how to integrate palliative care into heart failure management. QUB noted *improving integration between health services* and *a whole system approach to palliative care* as areas for pathways for all chronic and long-term conditions such as Heart Failure, Parkinson, Stroke, Alzheimer's. At a NI population level, the number of people living with multiple and chronic conditions is growing rapidly as we live longer. Recommendations from its Integrating Palliative Care and Heart Failure work include:

- palliative care education, education and training for health and social care staff must include palliative care for heart failure and other chronic life-limiting illnesses;
- campaign for increased public awareness, a public health approach is needed to help dispel myths and misunderstanding around palliative care;
- winning hearts and Minds, champion the value and benefits of integrating palliative care into heart failure management with service providers, service users and commissioners;
- integrate palliative care and heart failure teams, services should be sufficiently reconfigured to provide integrated palliative care and heart failure management, heart failure health and social care professionals are more

likely to have time to assess and address their patients' palliative care needs if services are provided in this way; and

- palliative care for heart failure guidelines, existing guidelines must be visible and in an accessible format for health and social care professionals, so they become embedded in routine clinical practice.

474. Further, the lecturer advised the Committee of a Marie Curie funded regional mapping exercise currently being undertaken looking at palliative care provision for those with heart failure. The aim of this study is to map the supportive, palliative, and end-of-life care services available for people with advanced heart failure in Northern Ireland, and to determine how palliative care access for people with advanced heart failure is implemented across the country. The study is being supported by a steering group involving stakeholders from heart and palliative care services, specialist charities and those with lived experience. The final report is due to be published in 2025/early2026

Conclusions and Recommendations

Recommendation 1

Northern Ireland introduce legislation mandating the commissioning and funding for palliative and end of life care. If the Committee finds the Department of Health unwilling to commit to bringing legislation forward, the Committee will consider a Committee Bill on PEOLC.

Recommendation 2

The Department review commissioning of palliative care services to ascertain capacity to meet a statutory duty of commissioning of equitable palliative care services in Northern Ireland, and to provide responsive solutions to new and expanded problems of the palliative care sector.

Recommendation 3

The Department move to 100% funding for hospices, with an initial 50% for 2026-27, and a sliding scale increase over 5 years and based on cost of services. The Department must liaise with each Hospice and begin to standardise contract templates across all Trusts, to include:

a. Multi-year contracts;
b. Agenda for Change (AfC) uplift applied to full contract value; and
c. Service Specific KPIs & volume-based remuneration.

Recommendation 4

Immediate increased investment in a regional Out of Hours PEOLC workforces, generalist and specialist, particularly in rural areas, to ensure equitable access to services for all patients in a timely manner.

Recommendation 5

Immediate investment in pharmacy services within PEOLC services, to include:

h. an Electronic Prescription Service;
i. clear pathways on how to access palliative medicines outside normal working hours (in collaboration with the 24/7 PEOLC single central point of access);
j. regional roll-out of proven sector-led best practices such as 'Just in Case' boxes, and nurse prescribing;
k. specialist palliative care pharmacy roles introduced in all Trusts in Northern Ireland;
l. pharmaceutical wholesalers to keep sufficient stocks of certain PEOLC medicines;
m. include PEOLC in core training for undergraduate, Foundation Year, postgraduate pharmacists; and
n. provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in.

Recommendation 6

The Department carry out a scoping exercise specifically for the Specialist Palliative Care sector. That is, SPC in Emergency Departments, SPC in-patient units in hospitals and hospices, SPC in the community, paediatric SPC and MDTs. This exercise must give an understanding of total service provision needed in the SPC sector, including out of hours, and be kept separate from any work on scoping generalist PEOLC. To support a future increased investment in SPC workforce needs, to remove waiting lists for SPC services and support training.

Recommendation 7

Paediatric palliative care services prioritised and invested in to provide:

c. adequate funding of SPC beds for children:
d. a dedicated paediatric palliative care consultant in the NI Children's Hospice;
f. an increase in medical leads Programmed Activity (PA) per week;
g. additional support for 'non-cancer' conditions in children;
h. increased investment in community-based, Out-of-Hours cover for paediatric end-of-life care;
i. adequate provision of supported out-of-home respite; and
j. a strategic approach to building capacity and resources to meet growing demand in paediatric palliative care.

Recommendation 8

Regional implementation of the Advanced Care Planning (ACP) and the ReSPECT framework as a matter of urgency. The Department provide the PEOLC sector with a detailed timeline, including its inclusion in Encompass.

Recommendation 9

A 24/7 PEOLC single central point of access established to co-ordinate:

e. a 24/7 telephone and online helpline for patients and their families and carers;
f. emergency out-of-hours palliative care expertise services;
g. provide advice and assistance on referral pathways to HSC staff; and
h. provide advice and assistance on referral pathways for pre- and post-bereavement services.

Recommendation 10

Hospital Emergency Departments to have Specialist Palliative Care teams and systems in place to ensure PEOLC patients have rapid access to ED processes such as assessments, imaging and admission and that patients needing palliative care are identified before being discharged from EDs and relevant palliative care packages arranged.

Recommendation 11

A fixed regional pathway framework and map of services established to support equity of access to services by continuity and coordination for patients at intersection points of services within and across all HSC interfaces. Ensure that every PEOLC patient's journey is planned and recorded and includes pathways to assess and manage emotional and spiritual wellbeing. Encompass must be integrated into the framework.

Recommendation 12

A programme established that fully supports young people as they transition from children's PEOLC services to adult services.

Recommendation 13

Remove barriers to PEOLC services for vulnerable and protected characteristic groups through investment in training and resources that will help ensure:

e. people over the age of 85 are adequately supported to access palliative care;
f. individuals with serious mental illness gain access in a timely manner and receive tailored support as they access services;
g. people with learning disabilities or complex needs gain access in a timely manner and receive tailored support as they access services; and
h. barriers faced by marginalised groups in accessing palliative care are addressed.

Recommendation 14

Remove barriers to PEOLC services for Northern Ireland's autistic population through greater investment in research and innovation.

Recommendation 15

Stabilised and predictable funding for community-based palliative services to ensure that older people, regardless of the type of care home they live in, can receive dignified and effective end-of-life care, to include:

f. recognition of increased patient acuity and the enhanced skills, training, and competencies required to deliver PEOLC services:
g. levels matching recommendations from the Specialist Palliative Care Workforce Planning Report Northern Ireland 2017-2024 implemented, to help resolve the difficulties faced by care homes;
h. the regional rate paid to care homes reflect the time and resources needed to deliver these services effectively;
i. appropriate training and additional support, to ensure care homes play a crucial role in facilitating quicker discharges from hospitals and preventing unnecessary hospital admissions for patients receiving PEOLC; and
j. consideration given to reforming the distinctions between residential care homes and nursing homes.

Recommendation 16

The ‘Regional Individualised Last Days Care’ planning template embedded in all Trust hospital wards, as a matter of urgency. The Department to meet with the clinicians leading this initiative, in the immediate term..

Recommendation 17

HSC staff supported to help prevent late PEOLC referrals, to include:

f. appropriate palliative care training of all HSC staff to ensure early identification and timely referral to palliative care;
g. appropriate palliative care training to prevent terminal diagnosis being given in inappropriate environments such as EDs;
h. standardisation of palliative care language and appropriate training of all HSC staff and palliative care staff to remove confusion;
i. include palliative care in core training for undergraduate, Foundation Year, postgraduate pharmacists and provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in; and
j. a consultant training scheme.

Recommendation 18

Full read and write access of the Encompass IT system is given to all generalist and specialist PEOLC services.

Recommendation 19

The Public Health Agency (PHA) resourced sufficiently to successfully plan and implement public health messaging initiatives required for public understanding of palliative and end of life care services.

Recommendation 20

Hospices be included in strategic planning at central departmental level which will impact services and hospice finances.

Recommendation 21

The Department work closely with Evora Hospice to provide support to the hospice's move to a new site to ensure the success of the project and best outcomes for patients.

Recommendation 22

The Department appoint a National Palliative Care Clinical Lead for Northern Ireland who would report directly to the Minister of Health and be able to affect PEOLC policy, and commissioning of services. The Clinical Lead cochair the Palliative Care in Partnership Programme (alongside the Strategic Planning and Performance Group and Public Health Agency CEOs) and be an ambassador for the palliative care sector of Northern Ireland. An interim regional clinical lead be installed with immediate effect.

Recommendation 23

The Health Minster commit to working with other Executive Ministers on rural proofing equitable access to palliative care services in Northern Ireland:

e. address the 'Rural Premium' incurred by rural patients and their families;
f. integrate transport services as a care pathway critical to rural communities;
g. examine cross-border co-operation opportunities for communities to access palliative care more easily; and
h. charity staff supporting rural palliative services sufficiently paid and resourced.

Recommendation 24

The Health Minster commit to working with other Executive Ministers on programme for government initiatives to help remove barriers to PEOLC, for Northern Ireland to:

h. embrace the Compassionate Communities model that encourages communities to support their members through end-of-life experiences, dying, death, and bereavement, and support death literacy programmes in the public arena and public bodies such as Libraries NI;
i. streamline death, dying and bereavement education in school curriculums, including programmes tailored to special education schools;
j. remove financial hardship and poverty as a significant barrier for many individuals to access palliative care, particularly vulnerable groups, and those with protected characteristics;
k. ensure financial support for unpaid carers and families of individuals receiving palliative and end of life care, including reviewing the timescale of Carer's Allowance ending after a person dies, implementing statutory Carers' Leave for employers to allow carers more flexibility to balance work with their caregiving responsibilities;
l. increase support for front-line staff in homeless shelters dealing with challenging issues to meet the needs of individuals in their care;
m. increase support for front-line staff in prisons dealing with challenging issues to meet the needs of individuals in their care needing palliative care; and
n. streamline programmes to assist patients and their families and carers where there is a language or culture barrier for access to palliative and end of life services including bereavement services.

Recommendation 25

The Department review PEOLC within Transformation and Hospital reconfiguration agendas and invest to save initiatives. To include consideration of:

e. all Trusts aligning with the NIAS initiative that patients are directed to, or liaise with, palliative care services and resolve issues at home rather at an already busy Emergency Department that may not be best suited to meet their needs;
f. remove the need for ambulance teams to contact the patient's GP to request a referral is made;
c. increased investment in District Nurses to ensure community general palliative and end of life services adequately funded, to improve patient care at home on a more consistent basis and reduce preventable ED visits and hospital admissions;
g. increased investment in training and supporting domiciliary care workers to help individuals stay at home, a preference for many at end of life, and assist discharge of palliative care patients from hospital wards;
h. investment in specialist palliative care community teams to improve patient end of life choice and timely discharge of palliative care patients from hospices and hospital wards; and
d. investment in palliative care services as 'preventative' policy in terms through a sustainable multi-disciplinary team workforce and prehabilitation services.

Recommendation 26

The Department establish a branch with specific responsibility for the adult, young adult and paediatric specialist palliative care sector as an acute service within palliative and end of life care services. The branch must work closely with specialist palliative care professionals to prioritise and have oversight and governance of quality-of-care indicators for specialist palliative care in hospitals, hospices, care homes, Emergency Departments and patients' homes. The branch to also be an important partner for collaboration on department policy of generalist palliative care services in primary care, including a 'shift-left' agenda and be responsible for the collation of robust data to inform palliative care services, projected population needs and ensure data-led policy and decision-making.

Recommendation 27

A new PEOLC Strategy be introduced to equip the specialist and generalist sectors to meet current and future needs with clear measurable goals and targets, and sector agreed implementation timescales. The Strategy must address:

h. planning of level of services needed over next 20 years;
i. collation of robust data to inform data-led policy;
j. recognition of the unique challenges faced by unpaid carers;
k. standardise regional services for equitable access whilst ensuring diverse local community needs are met;
l. rural proofing;
m. bereavement services; and
n. recognise cross Departmental work needed to remove access barriers.

Acknowledgements

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This Report can be made available in a range of formats including large print, Braille etc. For more information, please contact:

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