**FROM THE MINISTER OF HEALTH**

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Dear Philip

**CORS 0198/2026 & 0282/2026 - HEALTH COMMITTEE REPORT ON ACCESS TO PALLIATIVE CARE SERVICES – RESPONSE TO RECOMMENDATIONS**

Thank you for the Committee's report on Access to Palliative Care Services in Northern Ireland, which was published on 2 December. As I have previously stated, I welcome the extensive work undertaken by the Committee during its inquiry and the Committee's report and recommendations.

Please find enclosed my Department's response to the report recommendations, which I trust Members will find helpful.

Officials have been invited to attend the Committee on 7 May to discuss the formal response to the Committee's report, and written briefing has been requested. The response to the report recommendations constitutes the written briefing for that session. Officials attending on 7 May will be:

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| Jim Wilkinson | Deputy Secretary, Healthcare Policy Group |
| Gearóid Cassidy | Director of Primary Care |
| Roger Kennedy | Programme Director Community Care Directorate (DOH Strategic Planning and Performance Group). |
| Ryan Wilson | Director of Secondary Care |

Officials will be happy to provide further information to the Committee and respond to any questions during the oral briefing session.

Yours sincerely

**Mike Nesbitt MLA**
**Minister of Health**

**Annex A**

# DEPARTMENT OF HEALTH RESPONSE TO RECOMMENDATIONS OF THE HEALTH COMMITTEE REPORT ON ACCESS TO PALLIATIVE CARE SERVICES

The Department of Health (DoH) welcomes the Committee's report on *Access to Palliative Care Services in Northern Ireland,* published on 2 December 2025, and the opportunity it provides to highlight the importance of palliative care and the difference it can make.

The Department acknowledges the work of the Health Committee in undertaking its inquiry and the breadth of evidence which has informed the findings and conclusions of the report and its recommendations. The Department particularly recognises the personal insight provided by people with lived experience of palliative care services, which has been reflected in the report.

As our population continues to live longer[1] and with more complex health conditions, the need for proactive and co-ordinated palliative and end of life care support is expected to increase by a projected 30-40% by 2040.

There has been significant improvement in palliative and end of life care in Northern Ireland over recent years. The Palliative Care in Partnership (PCiP) Programme, co-led by the Department's Strategic Planning and Performance Group (SPPG) and the Public Health Agency (PHA), has been the driving force behind this. These improvements have contributed to better experiences and care for people living with palliative care needs and those important to them.

However, the Department also recognises that challenges remain including:

- earlier identification of people likely to be nearing the end of life
- reducing unplanned admission rates for people at end of life,
- the need for better co-ordination between services, and
- the need to improve data to inform service planning and delivery.

Within the context of such challenges, and an increasing demand and need for palliative care, we must continue to focus on how palliative care can be improved for people living with a life limiting condition and those important to them. The Health Committee's report will help inform how we do this.

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[1] The proportion of the NI population aged 65 and over increased by 38.2 per cent from mid-1999 to mid-2024. The population aged 85 and over increased by 24.6 per cent in the decade since mid-2014, a rate over five times higher than the population as a whole. *Source: NISRA 2024 mid-year population estimates for Northern Ireland (September 2025)*

The scope and breadth of this inquiry, and the number and range of recommendations in the report, are reflective of the priority and focus that the Committee has given to palliative care.

The Committee's report includes a number of recommendations that call for increased investment. These recommendations are uncosted, however, they are likely to require additional funding. In the context of the wider budgetary position and the proposed Draft Budget 2026-29, which will result in a significant shortfall between the funding needed to maintain services at existing levels and the proposed funding allocation, the Department will make every effort to deliver the recommendations but may need extra time to redirect existing resources rather than have the ability to access new resource.

The Department's response to the individual recommendations is set out in the following pages. A range of work is already underway which will fulfil some of the Committee's recommendations. In addition, actions being taken, or that the Department commits to undertake, will impact on several recommendations.

## Health and Social Care Reset Plan - Neighbourhood Model for Health and Wellbeing

The Department recognises the importance of access to quality palliative and end of life care across all care settings and irrespective of a person's condition or where they live. We also recognise that for many people living with a life limiting illness, their preference is that, wherever possible, care is provided at home.

Importantly, the Health and Social Care Reset Plan[2], published on 9 July 2025, provides the strategic context and direction for the Department's consideration of, and response to, many of the issues highlighted in the Committee's report, in particular, the commitment to develop a new Neighbourhood model for primary, community and social care which will deliver greater levels of care for citizens in their communities.

The Department has been working at pace to deliver on this commitment. A Policy Framework - *A Vision For Neighbourhood Health And Wellbeing In Northern Ireland*, including a high-level operating and funding model was published on 31 March 2026 – Neighbourhood Model of Health and Wellbeing in Northern Ireland - Policy Framework - March 2026 - FINAL PDF.PDF

The Neighbourhood Model of Health and Wellbeing Policy Framework sets out the vision and design principles for the Neighbourhood approach. It is the first step in a long-term reform programme that will reshape how services are planned, how resources are allocated, and how professionals work together with voluntary and community sector partners and the public. This will include palliative care services.

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[2] Health and Social Care Reset plan | Department of Health

The introduction of the Neighbourhood model represents a significant change in the way care is delivered in communities and is a key enabler for the Department's objective to shift the focus of health and social care provision from secondary care to primary and community care. The focus will be on enabling people to stay well for longer, and when care or support are needed, they should, wherever possible, be provided in the community setting. Improved palliative care services will be one of the key priority areas for our new Neighbourhood approach.

A Neighbourhood model that delivers more care in primary and community settings will be key to significantly improving how palliative and end of life care is delivered, helping more people with palliative care needs to be cared for in the community while at the same time reducing regional disparities. This includes supporting people to remain at home at end of life without inappropriate admission to hospital and facilitating earlier discharge from hospital so that people are able to die at home with the support in place that they, and those important to them, need.

A key focus of the Neighbourhood Model will also be the redesign of the health and social care system so that more advanced, specialised and proactive care is delivered closer to people's homes, reducing reliance on hospital-based services or the need to move into nursing or residential care. This will mean planning and redesigning clinical pathways so routine and scheduled care increasingly happens in community and primary care settings, with higher acuity care retained in hospitals. It also means strengthening anticipatory and proactive care so high-risk groups receive early, tailored support locally, keeping people independent and well in their communities. For example, a care pathway where people with serious illness or at end of life are identified early and supported by multi-disciplinary teams to manage symptoms, plan and receive co-ordinated care in the place they call home, with access to specialist care when needed.

To support this new way of working, from 2026/27 there will be a refocusing of care from hospital to community with commensurate redirection of funding, with an aim to move 2% each year from hospital based spend to community spend, delivered through the new neighbourhood model and the Integrated Neighbourhood Teams (INTs).

A mixed funding approach will support the model, using existing resources, invest-to-save opportunities and external funding partnerships. This ensures long-term change can get started, grow steadily and sustainably.

As part of the Neighbourhood model, the Department is working with Macmillan to develop a new approach to proactive care to address frailty and provide end of life care with the tailored support needed. Macmillan have committed to investing up to £10 million over the coming three to five years in this service from their Neighbourhood Transformation Fund.

The Department's response to the Committee's recommendations reflects the significant change in the strategic context of health and social care envisaged under the auspices of the Neighbourhood Model of Health and Wellbeing, as set out in the Policy Framework.

The Department believes the Neighbourhood approach, including the potential for the redirection of funding from hospital to community care and new funding opportunities as noted above, will be a key enabler for re-shaping how palliative and end of life care services are planned, commissioned and delivered into the future. This will be fundamental to addressing and responding to many of the challenges and barriers identified in the Committee's report and reflected in its 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 Palliative and End of Life Care.**

The Department partially accepts Recommendation 1.

The Department accepts the Committee's recommendation for a new palliative and end of life care strategy for adults (see Recommendation 27) and also accepts the recommendation for a regional Clinical Lead for Palliative Care (Recommendation 20). These developments will have a fundamental, direct and immediate impact on palliative and end of life care in Northern Ireland and on ensuring more accessible and equitable services to meet population need.

As part of the development of the new palliative care strategy, the Department will give consideration to the need to introduce legislation mandating the commissioning of Palliative and End of Life Care.

The Department's draft Strategic and Operational Planning Guidance for 2026/27, (draft pending agreement of a Budget) has been issued to Chief Executives of Trusts and ALBs and sets out the Department's strategic priorities and service delivery expectations to support HSC organisations develop their operational plans primarily for 2026/27 within the strategic framework of the HSC Reset Plan and implementation of the Neighbourhood model. The Planning Guidance includes palliative care as one of the key areas for service improvement.

Under existing legislation, the Department of Health already has a statutory duty to commission palliative and end of life care. The statutory provisions contained in Section 2 of the Health and Social Care (Reform) Act (Northern Ireland) 2009, place a duty on the Department to promote an integrated system of health and social care designed to secure improvement in the physical and mental health and social well-being of people in Northern Ireland.

This also includes the duty to secure the commissioning and development of programmes and initiatives conducive to the improvement of the health and social well-being and the reduction of health inequalities. Section 3 of the 2009 Act provides that the Department may provide or secure the provision of such health and social care as it considers appropriate to the discharge of its duty.

Whilst not specifying services to be commissioned, the wide breadth of the Health and Social Care (Reform) Act (Northern Ireland) 2009 ensures the scope of commissioning is inclusive of all health and social care services, including palliative care.

The Health and Social Care Act (Northern Ireland) 2022 dissolved the Health and Social Care Board (HSCB) and established the Strategic Planning and Performance Group (SPPG) within the Department of Health. SPPG, in collaboration with the Public Health Agency (PHA), leads on assessing population health needs and planning integrated care services.

The Department recognises the importance of access to quality palliative and end of life care across all care settings. We also recognise that for many people living with a life limiting illness, their preference is that care is provided at home. The implementation of the new Neighbourhood model of care provides the strategic context for improving palliative and end of life care in Northern Ireland and will be integral to addressing many of the issues highlighted by the Committee's inquiry.

## 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 pressures of the palliative care sector.**

The Department accepts Recommendation 2.

The Department acknowledges that there is variation in how and to what extent palliative care services are available across Northern Ireland and that commissioning and delivery of palliative and end of life care should be equitable and reflect identified need.

The landscape of palliative care in Northern Ireland has changed significantly over recent years reflecting demographic changes and service developments. The majority of palliative and end of life care is generalist palliative care, delivered by GPs supported by District Nurses, or within the independent care home sector, with specialist palliative care available to support those with more complex needs or unresolved symptoms.

Given the range and diversity of palliative care services that are in place, the Department had already accepted that we did not have a clear or comprehensive oversight of palliative care activity, nor an up to date palliative care population needs assessment to allow us to fully understand the performance of existing services for people likely to be in their last year of life.

To address this the Department is undertaking a Baseline Scoping of Adult Palliative Care. The overall goal of this Scoping Exercise is to identify whether services are, or are not, meeting the palliative and end of life care needs of our population. The outcome of the Scoping Exercise will provide the basis for ensuring that palliative and end of life care is planned, commissioned and delivered in response to identified population need.

The baseline Scoping Exercise has three Key Aims:

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| Key Aim 1: | To baseline palliative care services (both generalist and specialist) which are available to people likely to be in their last year of life across key providers and to understand the service activity, staffing, funding, contracting arrangements and performance; |
| Key Aim 2: | To understand the palliative and end of life care needs of the NI population including a focus on people facing inequalities; |
| Key Aim 3: | To understand the experience and quality of palliative and end of life care currently being delivered across care settings and establish key areas for service improvement. |

The outworking of Key Aim 1 will provide a population level picture of existing service provision, activity and performance and will be the basis for future work required to:

(i) ensure the maximisation of existing resources and that these are aligned to population need and demand; and

(ii) provide a gap analysis to inform the development of a regional Service Specification for Palliative and End of Life Care which would support standardisation of service provision, consistent performance metrics and equity of access to services.

Data validation is progressing in relation to Key Aim 1 and it is anticipated that a report on this will be completed in June 2026.

Key Aims 2 & 3 are designed to have a specific focus on the provision of equitable palliative and end of life care (PEOLC), including a focus on people facing inequalities, and to better understand the current experience of specific populations and the future demands and challenges which the Department, as commissioner of services, will need to plan for in respect of:

- People with malignant & non-malignant conditions
- People from areas of deprivation
- Older people living alone
- Rural vs urban populations
- People with learning disabilities
- Homeless people
- People in prisons
- Ethnic minority groups
- LGBTQ+ community

All three aims of the Baseline Scoping Exercise are important. Taken together, they will provide an extensive overview of service activity, population need, the quality of palliative care based on patient and carer experience, and whether there are gaps in service delivery impacting on outcomes for patients and those important to them.

The future commissioning of palliative and end of life care services will also be set within the strategic framework of the new Neighbourhood Model of Health and Wellbeing to ensure that services are provided closer to home, where it is known people prefer to be cared for.

The implementation of the Neighbourhood model, with an initial focus on older people, will impact on both how and where palliative and end of life care is commissioned and delivered. The outcome of the Baseline Scoping Exercise will provide an evidence-led baseline against which future service delivery can be planned, commissioned and monitored in line with the principles of the Neighbourhood Model to enable more accessible palliative and end of life care provided in the community and designed to meet identified local population need.

### Recommendation 3

**The Department move to 100% funding for all hospice services, with an initial 50% of actual cost of care for 2026-27, and a sliding scale increase over 5 years, based on cost of delivery of all hospice services, and inflation accounted for as appropriate. 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 uplift applied to full contract value; and**
- **c. Service Specific KPIs & volume-based remuneration.**

The Department partially accepts Recommendation 3.

The Department is committed to sustainable funding to support palliative and end of life care. This Recommendation has been considered within the context of the proposed Draft Budget 2026-29 for the Department, which will result in a significant shortfall between the funding needed to maintain services at existing levels and the proposed funding allocation. Given the limited additional funding provided as a general allocation, for 2026/27 at least, funding will have to be generated internally through savings and efficiencies to cover inescapable commitments. Based on current financial planning assumptions this will require cash releasing savings in the region of between 10% to 12% to be generated in the coming financial year.

While the proposed funding position improves in the following two years of the draft budget, further savings will still be required to cover inescapable pressures. Consequently, it will be extremely difficult to generate additional funding internally to move to a position where this recommendation could be implemented as this would likely involve reductions in other services.

Any move to 100% funding for specialist palliative and end of life care services delivered by hospices would require a fully costed business case to justify the Value for Money of such a change which, given the difficult financial position outlined above, would be challenging. The business case would need to be informed by a wider fully costed future service delivery model for palliative and end of life services that would consider where and how specialist palliative care is provided within the strategic context of the Neighbourhood model of care and moving more services into the community with commensurate redirection of funding of up to 2% each year from hospital based spend to community spend, as well as the findings and outcomes of the Baseline Scoping Exercise.

The Department maintains the position that using a benchmark, rather than actual costs incurred, is the most appropriate basis for funding services as this approach encourages the achievement of value for money in service delivery. In addition, the Department is of the view that the Agenda for Change uplift should only be applied to those elements of the contract that are relevant, as opposed to full contract value, i.e. a proportionate element to support the cost of payment of those staff who are in receipt of pay, which hospices may have made a local business decision to align to the Agenda for Change payscales.

The Department has recently completed a benchmark review of current funding levels against the 50:50 funding arrangements for adult hospice services. As part of this process, SPPG officials held a series of meetings with the adult hospices to discuss the current contract values and the elements of the commissioned services to ensure a shared understanding of the current contract values for each element of service provision. The benchmark review identified a shortfall of £0.6million across the four hospices. Payments to adjust funding levels were made to hospices in February.

Whilst the Department is only able to accept this recommendation partially, it is recognised the last benchmark review was in 2019/20. The Department commits to undertake a benchmark review against the 50:50 funding arrangement on a biennial (alternate year) basis. This will ensure that the level of funding is kept under more regular review than has previously been the case and allow for action to address any funding shortfall identified to be taken more quickly than has previously been the case. The next review will take place in 2027/28

As noted at Recommendation 2 above, the outworking of Key Aim 1 of the Baseline Scoping Exercise will inform the development of a regional Service Specification for Palliative and End of Life Care which would support standardisation of service provision, consistent performance metrics and equity of access to services within the context of the Neighbourhood approach.

Service specific performance indicators are set out in SPPG and HSC Trust contracts with hospice providers. Working with the hospice providers, SPPG introduced online patient reporting Dashboards in 2024/25 and for Community Specialist Palliative Care Services in 2025/26. These Dashboards provide monthly online reporting by each hospice provider and form the basis of ongoing SPPG monitoring of existing contracts. Outcomes from the baseline scoping review, may shape new Key Performance Indicators that would be agreed by all key partners. The current Dashboard for KPIs covers in-patient bed provision, with the Community Dashboard currently being developed.

## Recommendation 4

**Immediate increased investment in a regional Out of Hours Palliative and End of Life Care workforce, generalist and specialist, particularly in rural areas, to ensure equitable access to services for all patients in a timely manner, seven days a week and 24 hours a day.**

The Department accepts Recommendation 4.

The Department accepts the need to improve and invest in out of hours (OOH) palliative care services, including the out of hours workforce. Whilst the recommendation calls for immediate increased investment for a 24/7 service, this must be considered within the context of the proposed Draft Budget 2026-29 for the Department, which will mean there is significant shortfall between the funding needed to maintain services at existing levels and the proposed funding allocation. As noted above, the Department may need to redirect existing resources rather than have the ability to access new resource.

Whilst there are examples of OOH services working effectively in some Trust areas, there continues to be variation and the Department recognises the need to improve out of hours services generally, including increased access to 24/7 District Nursing services.

Under existing processes, patients who are identified as being likely to be in their last year of life should be allocated a Palliative Care Keyworker (typically the District Nurse) who is responsible for planning and co-ordinating their palliative and end of life care – this includes anticipating and planning for care needs in out of hours periods.

In Trusts where 24/7 District Nursing is available, Belfast HSC Trust and South Eastern HSC Trust, local arrangements should be in place to ensure patients, and those important to them, know how to contact their Palliative Care Keyworker in the out of hours period. In other Trusts where 24/7 District Nursing is not available, local processes should ensure patients and those important to them know who else to contact in the out of hours period.
All Trusts have arrangements to access Marie Curie Rapid Response service in the out of hours periods.

The Palliative Care in Partnership Programme plans to review the role and function of the Regional Palliative Care Keyworker in 2026/27. This will include strengthening existing guidance on the role in respect of planning and communicating to patients (and those important to them) the arrangements in place to support them in the out of hours periods, and how to access these.

The outcomes of Key Aim 1 of the Baseline Scoping Exercise for adult palliative and end of life care will highlight gaps in service provision, including where some levelling up of staff provision may be required in the out of hours periods. This will help inform how out of hours palliative care services can best be configured and staffed to meet demand.

The Department will explore how digital technology might support integrated care through remote monitoring and the delivery of out of hours services, particularly within the community as part of a Neighbourhood approach to care. The Department will be informed by initiatives being undertaken at Trust locality level, for example, FREEBIS for palliative heart failure patients in the South Eastern Trust and work being taken forward in the Southern Trust as part of a pilot of rural access.

The Department recognises how important it is for clinicians to have access to specialist palliative care advice. Following regional investment in 2023/24, all HSC Trusts now have arrangements in place for the provision of medic to medic out of hours specialist palliative care advice. Hospital doctors and Out of Hours GPs can contact this service for specialist advice, for example in managing deterioration or development of more complex symptoms. The Department acknowledges the need to improve communication and arrangements for direct access to this advice at local level and undertakes to review the process for this.

The current Palliative Care in Partnership (PCiP) work plan includes an action to scope and cost options for a 7-day (9 to 5) model for Specialist Palliative Care Nursing. This work is ongoing and due to report in the coming months. Any agreed option to move to a 7-day model will require investment and will need to be considered within the context of the current budget position.

The Northern Ireland Ambulance Service (NIAS) Out of Hours Palliative and End of Life Care Referral Pathway is operational in all HSC Trusts. The NIAS Urgent Care Team has reviewed the current Palliative Care pathway and is working with HSC Trusts to improve its effectiveness and reduce variations in out of hours provision and different Trust operating models.

The Pathfinder pilot with Foyle Hospice in the Western HSC Trust area, which enables qualified non-medical prescribers working in hospices to be able to prescribe for people in the community, has improved access to prescription only medicines for individuals with specialist palliative care needs and reduced pressure across the primary care and out of hours systems. Work is ongoing to progress roll out across Northern Ireland in order to support the timely access to medication for palliative care patients in the community.

**Health Committee Recommendation 5**

**Immediate investment in pharmacy services within Palliative and End of Life Care services, rural proofed, to include:**

a. **an Electronic Prescription Service to allow prescribers to send prescriptions electronically to a community pharmacy;**
b. **clear pathways on how to access palliative medicines outside normal working hours, ensuring equitable access (in collaboration with the 24/7 Palliative and End of Life Care single central point of access);**
c. **better collaboration between pharmaceutical wholesalers, primary care and palliative care, to ensure that wholesalers are aware of the critical nature of palliative medicines and that they must be available promptly for primary care patients;**
d. **a funded agreement in primary care to provide urgent access to palliative medicines from wholesalers implemented, to address particular challenges accessing controlled drugs in community outside normal working hours;**
e. **the use of 'Just in Case' boxes rolled out regionally and innovative initiatives involving GP Out of Hours service that can address urgent access to palliative medicines explored;**
f. **increased roll-out of nurses as independent prescribers who can issue prescriptions;**
g. **increased specialist palliative care pharmacists in each Trust, hospice, community to provide support for families, including the role of the pharmacy technician in palliative care;**
h. **pharmaceutical wholesalers to keep sufficient stocks of certain Palliative and End of Life Care medicines;**
i. **nursing homes keep stocks of non-controlled palliative medicines, not just named patient supplies;**
j. **include Palliative and End of Life Care in core training for undergraduate, Foundation Year, postgraduate pharmacists; and**
k. **provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in.**

<u>The Department partially accepts Recommendation 5.</u>

The Department accepts Recommendation 5(a), 5(c), 5(d), 5(e), 5(f), 5 (g), 5(h), 5(j), 5(k).
The Department partially accepts Recommendation 5(b).
The Department does not accept Recommendation 5(i).

<u>The Department accepts Recommendation 5(a)</u>

The prescription of a medicine is the most common intervention in the HSC system. In 2024/25, 45.7 million prescription items were dispensed in primary care, an increase of 0.7% on 2023/24. The total number of items dispensed has risen by 14.1% since 2014/15. The prescribing, dispensing, payment, administration and monitoring of this process is currently dependent upon the exchange of information on a paper prescription form signed by a prescriber.

The Department is currently leading on an ePharmacy Programme, which is a key strategic priority enabler for the transformation of HSC primary care services. A central component of this programme is the Electronic Transfer of Prescriptions (ETP) Project, which will introduce a fully electronic system to replace the current paper-based prescription process. This system will enable the secure transmission of prescriptions from prescribers to community pharmacies, and onward to the Business Services Organisation (BSO) for processing and payment. ETP will support an enhanced patient experience, a reduced administrative burden on key stakeholders, and the provision of a more effective and efficient service. It will enable enhanced and more secure information flows between patients and other users, and support research which can drive better patient outcomes.

The ETP Project has been included within the Department's 10-year capital investment plan. The project is currently at Outline Business Case (OBC) stage. The Business Case has been completed and submitted to the Department for review and approval. The OBC sets out the strategic, economic, and financial justification for the project.

ETP delivery is dependent on the successful implementation of both the Prescription, Processing and Validation (PPV) project and the Drug Masterfile (DM) project. These initiatives will replace obsolete systems that are unable to receive electronic prescriptions for processing, validation, and costing. Both enabling projects are scheduled for completion within a three-year period from business case approval. Approval of the Business Case is anticipated before the end of the summer 2026.

The project is under active consideration for funding by the NICS Public Sector Transformation Board. Implementation will commence upon approval of the Business Case, with detailed delivery planning undertaken through the ePharmacy Programme. Implementation will involve deploying the solution identified as the preferred option within the Business Case, followed by a controlled, phased roll out across all prescribers and dispensers. It is currently estimated that full regional roll out of Electronic Transfer of Prescriptions (ETP) to all prescribers and dispensers will commence immediately and be completed on an accelerated timeframe to complete no later than 30 June 2030.

The Department partially accepts Recommendation 5(b)

There is a lack of awareness in relation to mechanisms to access palliative medicines outside normal working hours across Northern Ireland. There are also differences in relation to access across different Trust areas.

Work has commenced to increase awareness about the services currently available to access palliative medicines outside normal working hours and to identify geographical areas where the Community Pharmacy Palliative Care Network provision could be improved. Promotional materials are currently being procured to promote the recently enhanced Community Pharmacy Palliative Care Network to key stakeholders, such as District Nursing, GPs, Out of Hours services and nursing homes. These will be distributed during Quarter 1 of the 2026/27 financial year.

A Palliative Care webinar is due to be delivered to Community Pharmacists on 21 April 2026 and will cover pathways on access to palliative medicines outside normal working hours.

### The Department accepts Recommendation 5(c)

The Department will collaborate with the main pharmaceutical wholesalers to seek agreement to stock the entirety of the palliative care list, including agreement of sufficient stock holdings of the less commonly used lines. Funding may need be secured to require wholesalers to retain the stock and reimburse products that go out-of-date. Collaboration with pharmaceutical wholesalers has commenced with timescale for implementation by 31 March 2027.

### The Department accepts Recommendation 5(d)

There is currently a funded provision where the wholesalers, AAH and Alliance, provide urgent access to palliative medicines, including controlled drugs in the community outside normal working hours. Community pharmacies pay wholesalers a call out fee which is then reimbursed. Information on this arrangement is available on the BSO website for pharmacy contractors and is re-issued on a regular basis, most recently in early February 2026. MPS-3469-How-to-obtain-clinically-urgent-medicines-out-of-hours.pdf

However, wholesalers will not always have the requested medicine as there is no requirement in place for wholesalers to keep an agreed stock list of named palliative medicines – further information on this is at 5(i) below.

### The Department accepts Recommendation 5(e)

The roll out of Just in Case boxes is being undertaken by HSC Trusts and is well underway. Three out of five Trusts have fully implemented Just in Case boxes in the community with the other two Trusts working towards implementation. Work is being taken forward with the GP Out of Hours service during 2026/27 to explore innovative initiatives that include consideration of the possibility of supplying a regionally agreed list of non-controlled drugs directly from the Out of Hours centre for use in patients' homes. Scoping could also take place around OOH centres obtaining the necessary controlled drugs licence to enable them to stock controlled drugs, in addition to any support that may be needed to achieve this.

The Department accepts Recommendation 5(f)

There is a growing number of qualified non-medical Specialist Palliative Care Nurse (SPCN) prescribers working in community settings.

The Palliative Care in Partnership Programme has piloted a new process for qualified non-medical prescribers working in hospices to be able to prescribe for people in the community. This Pathfinder pilot, with Foyle Hospice in the Western HSC Trust area, has improved access to prescription only medicines for individuals with specialist palliative care needs and reduced pressure across the primary care and out of hours systems. Work is ongoing to progress roll out across Northern Ireland in order to support the timely access to medication for palliative care patients in the community.

The Integrated Prescribing Team in the Department's Strategic Planning and Performance Group are in the process of implementing arrangements that will enable all hospice-employed SPCN prescribers to issue HS21 prescriptions to patients living in their own homes or a care home. This will ensure the needs of palliative patients are adequately met and will maximise capacity as far as possible within existing resource. This is in line with the strategic direction of the Neighbourhood model, supporting people with palliative care needs in the community.

The Department accepts Recommendation 5(g)

Employment of specialist palliative care pharmacists is undertaken by HSC Trusts and hospices.

There is currently a lack of consistency in palliative care pharmacy input across hospital and community services and in hospices. The Department accepts there is a need to explore this to ensure equitable service availability across Northern Ireland.

Potential roles for community-based specialist palliative care pharmacists include outreach pharmacy service to help with medicines management in the home and improved links to community pharmacies and practice pharmacists. The 2020 Pharmacy addendum of the NI Specialist Palliative Care Workforce Planning Report (2017-2024) estimates the number of whole time equivalent (WTE) pharmacist positions required to meet population need in 2024 to be between 13.1 and 19.65 WTE. Following recurrent investment into the service, there are currently around 12.5 WTE palliative care pharmacy posts across Northern Ireland. This includes a regional Palliative Care Consultant Pharmacist post and represents a significant increase from the baseline position of 2.3 WTE in 2017. Recurrent allocations made to Trusts in 2023/24 for new palliative pharmacy posts stipulated the need for the roles to enable palliative pharmacy support across all care settings, including into local hospices.

The role of the pharmacy technician could be explored to free up specialist pharmacist time and improve savings on medicines in Trusts and hospices. Decisions in relation to staffing in hospices are a matter for the hospice's management and Board.
In April 2025, the Marie Curie Daffodil Standards for palliative and end of life care were launched across community pharmacies. The Daffodil Standards for pharmacies provide a framework for community pharmacies to build on the high standard of care they already provide to palliative care patients and their families. The Standards are a joint initiative between the Royal Pharmaceutical Society and Marie Curie, supported by Department of Health, Pharmacy Forum NI, and Community Pharmacy NI. At end March 2026, 135 community pharmacies in Northern Ireland had signed up to this initiative.

## The Department accepts Recommendation 5(h)

The acceptance of this recommendation is conditional on agreement from pharmaceutical wholesalers, as well as the availability of funding and business case approval to pay wholesalers to keep sufficient stocks of agreed palliative and end of life care medicines. The Department will explore this, and if approved, will aim to move to implementation by the end of March 2027.

## The Department does not accept Recommendation 5(i)

In April and May 2020, Urgent Pandemic Packs were offered to nursing homes in Northern Ireland in response to the COVID-19 pandemic to facilitate access to urgent medicines, including those medicines used in palliative care. The packs were available to use by staff involved in the care of patients requiring clinically urgent treatment for both COVID and non-COVID conditions.

In October 2023, as part of a wider evaluation conducted by the Department's Strategic Planning and Performance Group, a survey of key stakeholders was undertaken to seek feedback on the usage of the pandemic packs. Of nursing homes surveyed, 57% indicated there was no longer a need for the pack. A number of reasons were given, including that good working relationships were in place between GPs, pharmacists and nursing homes ensuring that medicines were delivered in a timely manner; the packs were no longer or rarely used; and the packs increased governance requirements and associated workload.

Furthermore, 84% of nursing homes surveyed required replacement stock with over half (55%) indicating that it was because the stock went out of date. Antibiotics and paracetamol were reported as the most frequently used medicines from the pack.

In September 2024, in response to the survey and wider evaluation, Urgent Pandemic Packs were withdrawn from nursing homes in Northern Ireland.

Continual review by GP practices of their patient population who may need end of life care and undertaking anticipatory prescribing in advance would negate the need to hold stock at an individual home level.

The Department accepts Recommendation 5(j)
The four-year Master of Pharmacy (MPharm) programme provides the knowledge, practical skills, and professional development required to enter the pharmacy profession.

In Northern Ireland, the MPharm course is offered by both Queen's University Belfast and Ulster University. The Chief Pharmaceutical Officer (CPO) has written to the Head of School at both universities with a request that they support this element of Recommendation 5 by including palliative and end of life care in core training for pharmacy undergraduates in Northern Ireland.

Under Article 44 of the Health and Personal Social Services (Northern Ireland) Order 1972, the Department of Health has authority to provide training for pharmacists providing or intending to provide their services in the Health and Social Care arena in NI. Within this legislative framework, the Department commissions the Northern Ireland Centre for Pharmacy Learning & Development (NICPLD) to act as the statutory education body for pharmacy in NI and to develop and deliver a range of workforce development programmes and continuing professional development opportunities.

NICPLD's programme of education and training is commissioned annually by the CPO, who is advised by the Northern Ireland Committee for Pharmaceutical Education and Training. As well as education and professional development opportunities for pharmacists and pharmacy technicians in Northern Ireland, NICPLD manage the development and delivery of experiential learning for MPharm students and the Foundation Training Year (FTY) for trainee pharmacists. NICPLD do this through the development, delivery and quality management of education programmes, including those requiring accreditation with the pharmacy regulators, and through the provision of professional development courses and resources. The overall aim is to enable the pharmacy team to optimise their role in providing clinical care and in improving the health and well-being of people in Northern Ireland.

The CPO has formally written to NICPLD to request that palliative and end of life care is included within the NICPLD commission for 2026/2027 and will therefore be included in training for Foundation Year and postgraduate pharmacists.

The Department accepts Recommendation 5(k)

The CPO has formally written to NICPLD to request that palliative and end of life care is included within the NICPLD commission for 2026/2027 and will therefore be included in training for registered pharmacists and pharmacy technicians, irrespective of which healthcare setting they work in.

In addition, the CPO has formally written to the training providers, SERC (South-Eastern Regional College), SWRC (South Western Regional College), UCA-NI (Ulster Chemists' Association), Belfast Metropolitan College, National Pharmacy Association and Buttercups, with a request that they support this recommendation by including palliative and end of life care in training for pharmacy counter staff.

**Recommendation 6**

**The Department expedite a scoping exercise on Specialist Palliative Care Multidisciplinary Team requirement, to meet agreed quality care indicators with the sector, and provide equitable access to Specialist Palliative Care for children and adult patients. To include all Emergency Departments, hospital and hospice In-Patient Units, and care in the community including care homes and nursing homes, for clarity on total service provision and training needs in Specialist Palliative Care, including Out of Hours.**

The Department accepts Recommendation 6.

The Department has understood this recommendation to relate to expediting the work of the Baseline Scoping Exercise for adult palliative care.

As noted at Recommendation 2 above, the Department continues to progress a Baseline Scoping Exercise for adult palliative care services (children's palliative care is not within the remit of the Scoping Exercise).

This is a significant and challenging project looking across the whole system – acute, community, primary, hospice, care homes and home care, with the added complexity of extracting comparable data at a time where HSC Trusts have been at various stages of encompass optimisation.

Under Key Aim 1, information has been requested from all provider organisations in relation to current baseline services, activity, staffing and contracting and performance information. Data validation is progressing as part of this process, with work also continuing on data extraction in relation to Primary Care, District Nursing and care home palliative and end of life care activity. The intention is that a report on Key Aim 1 will be completed in June.

In terms of Key Aim 2 (population-based needs assessment), there has been some delay in progressing this Key Aim, however, the Department continues to engage with the Public Health Agency to secure the capacity for this, including the potential for alternative options to facilitate this if necessary; for example, via a university or third party.

In relation to the qualitative assessment of palliative and end of life care experience under Key Aim 3, new sources of information are available to support this, including the results of the National Audit of Care at the End of Life (NACEL) Round 5 for 2024/25, which includes 450 Bereavement Surveys, completed by bereaved relatives, carers and those important to the person who died in hospital during the audit period regarding experience of last days of life. Further information is also available from analysis of 112 palliative care stories from Care Opinion (2020-2025), a platform which enables service users, carers and families to share their experiences of health and social care across Northern Ireland.

The Department is engaging with Marie Curie in Northern Ireland on participation in a UK-wide national survey of bereaved people. The survey will help to better understand the experience of end of life care for a loved one to see where supports and services are good and identity those areas where improvements are needed. The NI Bereavement Network have indicated their support for this survey. Options for how best to disseminate the survey in NI and timescale for this are being considered and ethics approvals are underway.

**Recommendation 7**

**Paediatric palliative care services prioritised and invested in to provide:**

- a. **adequate funding of Specialist Palliative Care beds for children:**
- b. **a dedicated paediatric palliative care consultant in the NI Children's Hospice;**
- c. **an increase in medical leads Programmed Activity (PA) per week;**
- d. **additional support for 'non-cancer' conditions in children;**
- e. **stabilised and predictable funding for community-based palliative services for young people and increased investment in community-based Out of Hours cover for Paediatric End of Life Care;**
- f. **adequate provision of supported Out of Home Respite; and**
- g. **a strategic approach to building capacity and resources to meet growing demand in Paediatric Palliative Care.**

The Department accepts Recommendation 7.

The Department accepts in principle the need for increased investment in paediatric palliative and end of life care to adequately meet population needs.

This aligns with the commitments of the existing "*Strategy for Children's Palliative and End of Life Care 2016 – 2026*", however full implementation remains subject to available funding and competing priorities across the Health and Social Care system. The strategy has 23 objectives aimed at providing high-quality, safe, sustainable and appropriate palliative and end of life care to ensure the best possible outcome for the child and their family. Limited transformation funding in 2019 has enabled partial implementation, specifically: the appointment of a Regional Paediatric Palliative Care Consultant; appointment of a Paediatric Palliative Care clinical lead in each Trust (1 programmed activity per week); and appointment of a Paediatric and Life Limited Nurse within the NI Children's Hospice (NICH) - this nurse works across the Royal Belfast Hospital for Sick Children (RBHSC) and NICH.

A Regional Paediatric Palliative Care Network was also established in 2019 - this is the main vehicle for implementing the strategy and sharing best practice through regional collaboration across the statutory, community and voluntary sectors. The Network is well supported by Trust paediatric palliative care leads, Allied Health and pharmacy leads, as well as Macmillan and the NICH. The Network has developed antenatal care pathways, rapid discharge plans, an ECHO learning platform in conjunction with NICH and established links with Republic of Ireland colleagues.

7(a) and 7(f) are accepted, both subject to additional funding and timing will be dependent on the release of resource and/or new money, for example from the 2% shift of funding as part of the Neighbourhood approach. Capacity constraints across the system, including specialist palliative care (SPC) beds are recognised, and fluctuating demand for paediatric palliative care is managed regionally through the Network. SPC beds are provided at RBHSC as the regional tertiary centre. Children can also be cared for in local District General Hospital (DGH) paediatric units when suitable to their requirements, however, these are non-specialist beds and District General Hospital capacity can be impacted by winter pressures.

7 (b): accepted. Funding is in place for a Regional Paediatric Palliative Care Consultant which is appropriately based in RBHSC as the regional tertiary centre, however this post is currently vacant with recruitment expected in 2026, and discussions are ongoing to consider how best this could be linked with the NICH.

7 (c), (d), (e) and (g): accepted, subject to additional funding. A model of care that would offer solutions to these recommendations is currently being developed by the Network in conjunction with relevant partners, to be finalised when the Paediatric Palliative Care Consultant is in post. However, there are significant recurrent cost implications with this model and no additional funding identified at this stage.

Consideration is being given to the future strategic direction reflecting progress to date against the current strategy, the inquiry recommendations and available resources.

**Recommendation 8**

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

The Department accepts Recommendation 8.

The Department is committed to regional implementation of the Advance Care Planning policy and the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) framework. Reflecting the importance placed on this, Advance Care Planning was confirmed as one of the workstreams in the Department's winter preparedness plans, under the Big Discussion programme of work.

The Department is continuing to work with the Public Health Agency (PHA) to consider how an implementation programme can be sustainably structured and resourced, taking account of the current financial context within which the Department and the HSC is operating.

A detailed project implementation plan, including a draft timeline, will be developed when the programme structures are established and can be shared with the Committee when finalised. The implementation plan will include a focus on robust communications to ensure stakeholders are kept appropriately informed and engaged.

While full implementation, and the pace of implementation, is subject to the confirmed resourcing position, delivery is already underway in several key areas with an initial focus on supporting system readiness through assessing the initial training requirements across the HSC and through the development and completion of Level 1 and Level 2 training modules on Advance Care Planning. The Level 1 e-learning awareness training is currently available to the public and all care providers, with the Level 2 training aimed at supporting all registered Health and Social Care professionals and lead members of community and voluntary organisations who will support and be involved in Advance Care Planning conversations as part of their job role. The roll out of the Level 2 training commenced in mid-November 2025 and is currently scheduled to continue through 2026.

A letter of support was issued jointly from the Chief Medical Officer and Chief Nursing Officer to Trusts to encourage uptake of the training, recognising its fundamental importance to the successful implementation of the Advance Care Planning policy. PHA continue to monitor and support roll out of Level 1 and Level 2 training and to consider further opportunities for increasing training capacity.

PHA are also working with colleagues from the HSCNI Clinical Education Centre and Resuscitation Council UK to finalise the Level 3 training package, which will have a specific focus for professionals who will complete a ReSPECT plan. The ReSPECT plan will record, consider and respect a person's wishes and beliefs and outline clinical recommendations about what is realistic and appropriate treatment around emergency care and treatment.

Early progress has been made on other key strands of work including preparedness for the implementation of the ReSPECT process and the roll out of the ReSPECT pathway on encompass. A palliative and advance care planning group, the Palliative Care Pathway Council, has been established under the encompass project. The group is co-chaired by the PHA and Palliative Medicine Consultants from Belfast HSC Trust and South Eastern HSC Trust and has identified the encompass system build as a priority to be progressed over the coming months. In parallel, working together with stakeholders, the Palliative Care Pathway Council will consider and advance a number of other operational elements of the ReSPECT pathway across the HSC system in anticipation of go-live.

## Recommendation 9

**A 24/7 Palliative and End of Life Care 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.**

The Department accepts Recommendation 9.

Co-ordination and Quality Improvement In Palliative Care Services is one of the four agreed priorities for the Palliative Care in Partnership Programme workplan for 2023-26.

The Department recognises the benefits of a single 24/7 palliative and end of life care point of access to support the co-ordination of care through information sharing, communication and streamlining transitions between hospital, community and hospice services.

The PCiP has previously undertaken work to explore how similar services based on a central point of access have been implemented in other areas of the UK.

The Department will scope the potential for such a service to be developed, including the potential to also include a 24/7 telephone/online support service for patients and carers and other health care professionals delivering care, particularly in the out of hours periods.
In doing so, the Department will consider learning from the recently established Belfast Community Palliative Care Hub, which provides a co-ordinated single point of in hours referral for patients who have specialist palliative and end of life care needs which cannot be managed by their core healthcare team and require support from specialist palliative care professionals.

The Belfast Community Palliative Care hub model has streamlined a number of previous referral mechanisms ensuring that GPs and other healthcare professionals referring patients have one point of contact for specialist palliative care referrals and enabling the hub professionals to triage the referrals and allocate the collective resources in the most appropriate way to respond to patient needs and demand.

The Hub's community-based model aligns with the Neighbourhood approach by integrating existing local specialist services and better co-ordinating delivery of care for people in their own homes and local community.

The establishment of a 24/7 single point of access in line with this recommendation would require additional funding, with a business case required to support this. The development of an evidence-based business case for such a service would be informed by the findings of the adult palliative care Baseline Scoping Exercise. Activity and referral data from existing out of hours services, including the Marie Curie Rapid Response and the OOH SPC advice services available in all Trusts, is currently being reviewed as part of the Baseline Scoping Key Aim 1 in order to support future planning considerations.

The Department will seek to commence the scoping exercise for a potential single point of access service, informed by the outcomes of Key Aim 1, within the next 6 months.

As noted at Recommendation 4, all HSC Trusts now have arrangements in place for the provision of medic to medic out of hours specialist palliative care advice. Hospital doctors and Out of Hours GPs can contact this service for specialist advice, for example in managing deterioration or development of more complex symptoms. The Department acknowledges the need to improve communication and arrangements for direct access to this advice at local level and undertakes to review the process for this.

The Northern Ireland Ambulance Service (NIAS) Out of Hours Palliative and End of Life Care Referral Pathway is operational in all HSC Trusts. The NIAS Urgent Care Team has reviewed the current Palliative Care pathway and is working with HSC Trusts to improve its effectiveness and reduce variations in out of hours provision and different Trust operating models.

## Recommendation 10

**A system established to oversee continuity and coordination of Palliative and End of Life Care patients moving between all palliative care settings, that prevents patients falling through gaps in care and gives a clear referral framework and support system for patients, families, and healthcare providers.**

The Department accepts Recommendation 10.

Co-ordination and Quality Improvement In Palliative Care Services is one of the four agreed priorities underpinning the Palliative Care in Partnership Programme 2023-26.

In line with the PCiP Programme priorities, co-ordination of care is a continual focus for each of the five Palliative Care Locality Boards which operate at Trust locality level within the PCiP structure. The Palliative Care in Partnership Programme provides a mechanism and platform, through the Palliative Care Locality Boards, to improve co-ordination of care between local palliative and end of life care service providers. The development of the Belfast Community Palliative Care Hub referenced at Recommendation 9 above is an example of this.

A number of 'hub' type arrangements are already in place in other areas. For example, the Southern HSC Trust have their own Community Specialist Palliative Care (SPC) multi-disciplinary team which centrally co-ordinates referrals received and allocates appropriate resources to respond. The South Eastern HSC Trust operates a SPC multi-disciplinary team hub, whilst the Western HSC Trust offer a community specialist palliative care multi-disciplinary team which works alongside the Foyle Hospice who provide community SPC nursing services across the Trust.

As noted at Recommendation 9 above, the Department will scope the potential for a 24/7 single point of contact service to support the co-ordination of care through information sharing, communication and streamlining transitions between hospital, community and hospice services.

Additionally, work being progressed under Advance Care Planning (see Recommendation 8) and the roll out of encompass (see Recommendation 11) will support the better continuity and co-ordination of care across sectoral and care setting boundaries.

Full realisation of this recommendation will be dependent on:

- Improvement in local operational processes, workforce capacity and training and data sharing (as highlighted in other Recommendations 4, 5, 9, 12 and 18)
- Improved data sharing between providers including hospices, GPs and care homes

- Development of detailed service specifications to support standardisation of service provision, improved equity of care and consistent performance metrics, as well as a future investment.

At a strategic level, the implementation of the Neighbourhood model of care, with its focus on care closer to home in the community, will be a key driver to achieving this recommendation.

**Recommendation 11**

**Full read and write access of the Encompass IT system given to all generalist and specialist Palliative and End of Life Care services and every palliative care patient's journey is planned and recorded through the Encompass system, to include support for the patient's emotional and spiritual wellbeing.**

The Department partially accepts Recommendation 11.

The Department recognises and supports the intent of ensuring that all generalist and specialist palliative and end of life care providers have appropriate access to a single, shared digital care record through the encompass system. This aligns with the strategic ambition for integrated, person-centred digital information across the HSC and with the wider digital transformation agenda.

For the reasons outlined below, the Department is unable to fully accept this recommendation at present, however, it is accepted in principle subject to feasibility, affordability and the establishment of appropriate governance.

Full read/write access to encompass for all external partners cannot be committed to at this time. Extending access to independent and voluntary sector providers – and potentially primary care beyond current arrangements - requires significant work across multiple domains; including licensing, identity management and technical configuration; information governance, consent and data sharing assurance; cyber security assessment; onboarding, training and support; and ongoing service management.

These activities are not currently funded, are outside the scope of the approved encompass business case, and would require additional resource, contractual arrangements and programme prioritisation.

There are complexities at the primary-secondary care interface, particularly around documentation, Advance Care Planning records, and ReSPECT workflows. Work to strengthen these interfaces is at an early stage and will require dedicated investment and technical development, including potential future integration between interfaces and systems.

The Department will utilise the work of the External Access Advisory Group as the mechanism to scope, prioritise and risk-assess any expansion of access to independent and voluntary sector palliative care services for example to ensure appropriate staff permissions to ensure patient safety and the integrity of information updates.

Digital Health and Care NI (DHCNI) will work with the External Access Advisory Group and the encompass programme to:

- determine which external providers require access and at what level

- assess technical, Information Governance safety and contractual requirements
- identify expected resourcing, licensing and technical support implications
- explore interim options, including MyCare-based patient-mediated access where appropriate
- create a deliverable, phased roadmap that aligns with available funding and capacity.

Through encompass governance structures, DHCNI will continue to support the configuration of palliative care workflows, including:

- alignment with ReSPECT implementation (build on this is already underway)
- consideration of cross-sector data flows as part of pathway design
- engagement through the newly established Palliative Care Pathway Council which is considering palliative care and advance care planning.

Work to develop the framework for external organisations accessing HSC clinical information is ongoing. A first iteration of access principles is expected during 2026, subject to governance approval and funding.

Detailed timelines for onboarding independent and voluntary sector palliative care providers will depend on the outcome of scoping, prioritisation and budgetary decisions.

Work continues between DHCNI and the Hospice Alliance NI to consider full Epic access for hospices, this is currently at Discovery phase.

**Recommendation 12**

**Hospital Emergency Departments have designated palliative care professionals and systems in place that will ensure rapid assessment, imaging, or direct admission for Palliative and End of Life Care patients in crisis, and will ensure safe and supported discharges for palliative patients from acute care settings into the community.**

The Department accepts Recommendation 12.

The Department is aware of the valuable work of initiatives to support people with palliative care needs who arrive into Emergency Departments. This includes the Palliative Care at the Front Door Project in place in Antrim Area Hospital in the Northern Trust to support earlier involvement of palliative care 'at the front door' of hospital arrival. In the Southern Trust area, a project is in place which identifies patients known to the Community Specialist Palliative Care MDT Team or who have a Palliative Care Keyworker, if they attend an ED.

In the strategic context of the Neighbourhood model, the focus will be on having increased access to palliative care in the community, which will be key to reducing avoidable admissions and the significant and unnecessary pressures placed on hospital services, including EDs and NIAS. In this context, having designated palliative care professionals and systems in place in Emergency Departments would be one element of a Neighbourhood model which supports better identification of palliative care patients, and increases the provision of palliative care services in the community.

The Big Discussion programme of work focussed on the growing needs of an ageing population with complex health conditions and led to seven improvement projects covering topics such as frailty identification, keeping people well at home, avoiding admission to hospital for end-of-life care, frail elderly falls pathway and Advance Care Planning. As noted above, the initial focus of the Neighbourhood model will be on older people, and this will include palliative care.

Work is already being progressed that will help minimise avoidable ED attendance and hospital admission for people receiving end of life care so that their preferences are respected and patients are not admitted to hospital unnecessarily for the last days or hours of life when their preference is to be at home. 'Just in case' boxes for anticipatory care medicines, the consolidation of the Community Pharmacy Palliative Care Network and the development of the Belfast Community Palliative Care Hub are examples of initiatives that are supporting this so that patients are less likely to have to go to a hospital Emergency Department.

The Department is also exploring the potential of developing rapid discharge/hospital turnaround models similar to Marie Curie REACT service which provides 72hr support service in the patient's own home following discharge.

Some independent sector care homes have undertaken Quality Improvement actions to enhance palliative care communication and symptom management by improving the confidence of their staff, which has resulted in reducing avoidable hospital admissions and facilitating early hospital discharge when admission is unavoidable.

Importantly, early identification of people who are likely to be in the final year of life allows for the appropriate care and support to be put in place to help pre-empt and avoid escalations that might otherwise result in attendance at EDs or admission to hospital. This also includes improving the recognition of the dying phase of inpatients with longer stays and supporting them to be discharged 'home' or somewhere more appropriate for the last days of their life. Early identification and timely intervention of those who would benefit from a palliative care approach is one of the four priorities that make up the Palliative Care in Partnership work plan 2023-26.

## Recommendation 13

**A framework established that fully supports young people as they transition from children's Palliative and End of Life Care services to adult services, and stabilised and predictable funding for community-based palliative services for young people.**

The Department accepts Recommendation 13.

The Department, as well as paediatric palliative care leads, care providers and the Regional Paediatric Palliative Care Network, recognises the importance of supporting young people as they transition to adult services. Like all paediatric services, the challenge is ensuring that the correct adult services are identified and have the capacity to care for the young person who is transitioning.

Regarding community-based palliative care services, it is recognised that children's community nurses are essential partners in the care of children and young people. Additional investment would be required to enhance capacity in this area; however, this is not possible to identify currently.

In 2024/25, the Palliative Care in Partnership Programme and Paediatric Palliative Care Network worked in partnership to explore existing pathways and challenges facing young people transitioning out of paediatric palliative care services. Analysis of the data available highlighted the relevantly small number of young people each year who would be eligible for direct transition from paediatric palliative care services to the adult palliative care pathway (c.7 patients per year).

In these cases, Paediatric palliative care clinicians have indicated if a young person is nearing age of transition and has been identified as 'likely to be within their last year of life' then the young person is often maintained within the paediatric service until the time of death in order to minimise disruption to the young person and those important to them.

Both the Palliative Care in Partnership Programme and the Paediatric Palliative Care Network are committed to working together to find workable, practical solutions moving forward to support transition from paediatric to adult services. This includes considering ways through which to seek the views and better understand the experience of young people and those important to them who may be eligible for transition directly to adult palliative care services and working with both paediatric and adult palliative care service providers to better understand the experience and challenges from a clinical/ service perspective.

As noted at Recommendation 7, a draft model of care is being developed that outlines potential solutions for the management and care of children with palliative care conditions, which includes a sustainable means to manage children in the community. While this will set out the case for enhancing the service it will not fully address wider issues in transitional care which depends on capacity within adult health and social care services to support young adults with complex needs who reach an age where they are required to transition from paediatric palliative services.

**Recommendation 14**

**Remove barriers to Palliative and End of Life Care 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.**

The Department accepts Recommendation 14.

Education and training in palliative and end of life care is one of the four priorities of the Palliative Care in Partnership Programme. Under this priority, the PCiP is developing a Regional Palliative and End of Life Care (PEOLC) Education and Learning Framework for use by providers across all care settings to ensure their staff have the required skills and competencies to care for people approaching the end of life. The Framework Document is due to be finalised later this year.

The Framework recognises the need to improve palliative and end of life care training and learning across the wider HSC and the independent workforce. Accordingly, its development has been a collaborative process of partners from across all care settings, including care homes and home (domiciliary) care providers.

The draft Framework has been developed for staff operating across the system at Tier 1 and Tier 2[3] to include pre-registration and post graduate education pathways, as well as the information and training needs of informal caregivers. The draft Framework covers 5 key domains of palliative and end of life care, namely:

1. Fundamentals of palliative care: enhancing quality of life
2. Communication skills
3. Holistic assessment, care planning and symptom management
4. Optimising comfort, maintaining dignity and wellbeing
5. Care in the last weeks/ days of life and after death.

The Framework's intention is to provide a comprehensive guide to support HSC and independent care providers to identify the domains of palliative and end of life care

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[3] Tier 1 – infrequently provide palliative and end of life care as part of role
Tier 2 – frequently provider palliative and end of life care as part of role
Tier 3 – provide specialist palliative and end of life care

required for staff working at Tier 1 and Tier 2 in order to promote competence and confidence in staff caring for people approaching the end of their life across all care settings.

The draft Framework clearly defines how the responsibility for ensuring staff are appropriately skilled to carry out their duties lies with individual employing organisations, however, the regional Steering Group, which is overseeing the development of the Framework, have recognised the common areas of learning and are in the process of identifying modules of the Framework which would be suitable for a standardised regional e-learning or digital solution.

Any potential standardised training opportunities/solutions identified through the development of the regional Framework would require additional investment to deliver.

As noted above, part of the Baseline Scoping Exercise of adult palliative care services is the development of a population-based palliative and end of life care needs assessment that will include a focus on addressing inequalities in accessing palliative care. The needs assessment will include consideration of the needs of:

- People with malignant & non-malignant conditions
- People from areas of deprivation
- Older people living alone
- Rural vs urban populations
- People with learning disabilities
- Homeless people
- People in prisons
- Ethnic minority groups
- LGBTQ+ community

By identifying population needs and assessing how existing services meet or fail to meet these needs, barriers to accessing good palliative care can be identified and addressed.

People aged 85 and over

The introduction of the Neighbourhood model and the focus on shifting care and services into the community, closer to people's homes will support the delivery of palliative and end of life care for older people.

The first year of the Neighbourhood model will see Integrated Neighbourhood Teams beginning to meet across Northern Ireland to focus initially on the needs of older citizens, helping to keep more people in their neighbourhood out of hospital or nursing/residential care.

HSC Trusts will also work with the wider system to begin to implement changes to refocus care from hospital to community, starting with older people and a focus on anticipatory and proactive care and clinical pathways that seek to enable more care to be provided through the INTs, reducing the need for hospital attendances.

As part of the implementation of the Neighbourhood model, Macmillan's Neighbourhood Transformation Fund has committed to investing up to £10 million, over the coming three to five years, to work in partnership with the Department to address frailty and provide end of life care with the tailored support needed.

It is recognised that for many older people, home will be a residential or nursing home. The Care Standards for Nursing Homes and Residential Care Home Minimum Standards (the Standards) set out the requirements for registration and inspection of providers by the Regulation and Quality Improvement Authority (RQIA) to ensure both a consistency of approach and that residents, families or those important to them, and providers have a clear understanding of the standards they expect to receive and provide.

The Reforming Adult Social Care and Support 10 year Strategic Plan, published on 23 March 2026[4], sets out a strategic commitment to introduce a package of measures aimed at improving the quality of care in care homes, including actions to enhance the regulatory framework and associated standards.

The Department is currently leading a review of both sets of Care Homes Standards. This will include a review of Nursing Home Standard 32 – Palliative and End of Life Care. This will take account of, amongst other initiatives, the pertinent recommendations set under the Enhancing Clinical Care Framework (ECCF).

The ECCF was led by the Chief Nursing Officer (CNO), working in partnership with the Independent Care Home Sector. The aim of ECCF is to ensure that people who live in care homes are supported to lead the best life possible and that their right to access timely, integrated, equitable healthcare provision is observed.

The Framework describes what "good" looks like when someone in a care home accesses multi-disciplinary clinical care and support, in line with their needs and wishes, to support their health and wellbeing. The Framework is relevant and equitable for adults living in both residential and nursing homes and across the full range of categories registered by the Regulation and Quality Improvement Authority.

A Working Group is taking forward the review of the Standards on a collaborative basis. The Working Group consists of social care stakeholders, including some of those involved in the development of the ECCF. The purpose of the exercise is to review and update the Standards (and relevant supporting documentation) to ensure they reflect the most recent developments, guidance, policy and procedures.

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[4] Adult Social Care Reform Strategic Plan - 2026 - v7.pdf

A benchmarking exercise was commissioned by the Department, through the HSC Leadership Centre, to identify gaps between the Standards and recommended good practice and produce a gap analysis report based on the findings.

The Working Group have agreed Terms of Reference, developed and agreed a workplan which sets out key deliverables, and are in the process of amending the Nursing Home Standards to reflect the gaps identified in the analysis report. The review is scheduled for completion in December 2026.

### People with Serious Mental Illness

The Mental Health Strategy 2021–31 prioritises timely access to appropriate mental health services, particularly through its focus on "providing the right support at the right time" (Theme 2). The Strategy also underpins the development of a Regional Mental Health Service designed to deliver equitable, consistent, and locally accessible care, ensuring individuals with serious mental illness receive the support they need when they need it. This includes palliative and end of life care.

### People with Learning Disabilities

The Department's current draft Learning Disability Service Model (LDSM) proposes a new approach to supporting adults with a learning disability through health and social care services with access to tailored support in a timely manner. The draft LDSM includes a number of ambitions, including that people with learning disabilities will be prepared and supported throughout important changes in their lives and will have equal access to general healthcare and well-being services, with a focus on the implementation of reasonable adjustments and access to relevant support.

A draft 3-year Service Delivery Plan, which focuses on how the LDSM can be translated into action and how success will be measured, has also been developed. Both the Learning Disability Service Model and the Service Delivery Plan have been subject to a public consultation. Work is ongoing to finalise these by Spring 2026, subject to Ministerial approval.

Implementation of the Learning Disability Service Model will require alignment between existing palliative and end of life care pathways and the LDSM ambitions to ensure equitable access and appropriate reasonable adjustments for people with learning disabilities.

### People with Autism

The Department's Autism Strategy 2023-2028 includes a commitment that individuals and families will have access to early intervention and support which can meet emotional health and wellbeing needs through improved regional pathways of care.

A Project Lead for adult autism services has been appointed to better understand the population, pathways, presenting need and to further develop supports and services across the region.

Work is underway regionally with HSC Trusts to review and update the existing Adult Autism Care Pathway to ensure it remains relevant, evidence-informed and aligned with needs of the people it supports. This builds upon recommendations identified following the 2023 review of adult autism services and will involve extensive stakeholder engagement over the coming months. The aim of this work is to standardise adult autism service provision across Northern Ireland.

Training is key to ensure that appropriate adjustments are made for each autistic person. Health and social care staff have access to a range of autism training modules and work has recently been developed by the Department in partnership with the Middletown Centre for Autism as an internationally recognised Autism Centre of Excellence. The new modules are now available on Learn HSCNI which cover Autistic Differences, Providing Supportive Environments and Promoting a Neuro-affirming Culture.

Marginalised Groups

As part of the Palliative Care in Partnership's public health approach to palliative care priority, the Public Health Agency has provided funding (circa £50k) to the All Ireland Institute of Hospice and Palliative Care to support scoping work it has undertaken to identify the palliative care needs of marginalised groups, such as people with disabilities, the homeless population, and individuals in prison. This builds on their previous work with the Rainbow Project in holding Death Cafés with the LGBTQIA+ community to get a better understanding of their palliative and end of life care needs and barriers impacting on this.

The annual grant to the Institute always has an element of exploring or supporting palliative and end of life care within underserved communities, such as the Death in Pride events run in partnership with the Rainbow Project.

This year, the focus has been people with learning disabilities and the AIIHPC is supporting a pilot of 'No Barriers Here'© in Northern Ireland. This is an arts-based workshop designed to support more inclusive conversations about palliative care and Advance Care Planning, particularly with communities who may experience barriers to accessing services. This includes people with learning disabilities, people experiencing homelessness, dementia, migrant communities and other marginalised groups.

## Recommendation 15

**Remove barriers to Palliative and End of Life Care services for Northern Ireland's neurodivergent population through greater investment in research and innovation.**

<u>The Department accepts Recommendation 15.</u>

The Department recognises that the growing prevalence of autism in our society places responsibility on Government departments and public bodies to be equipped and informed in the understanding of autism, the development of policies and in the delivery of services.

Whilst the recommendation aligns with commitments in the Autism Strategy 2023-2028, the strategy is being delivered under unprecedented budgetary challenges, and it would therefore be difficult to commit to greater investment in research and innovation at this time.

However, recent research has been carried out under the Autism Strategy 2023 -2028. The HSC Leadership Centre, in 2024, was commissioned to take forward work to provide proposals for the development of a Regional Autism Information Service which will provide signposting to services and support. This involved extensive stakeholder engagement to determine the most important and effective sources of information and support to be included in the service.

As approximately 3 in 10 autistic people have a co-occurring diagnosis of learning disability, which can present with exceptional levels of need, a review has recently been completed by the HSC Leadership Centre to better understand the needs of people with learning disabilities and a co-existing diagnosis of autism. This work aims to ensure health and social care services are sufficiently adjusted and enhanced to support people with autism.

More broadly, the establishment of a new Academic, Health and Economic Partnership in 2026/27, alongside enhancements of local oversight for innovation for HSC Trusts, will target inward commercial investments for research, continuous improvement and innovation programmes.

**Recommendation 16**

**Stabilised and predictable funding for community-based palliative services for older people, to ensure that regardless of the type of home they live in, they 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 Palliative and End of Life Care services:**
b. **a Specialist Palliative Care workforce sufficient to meet the needs of care homes, following completion of the scoping exercise;**
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 Palliative and End of Life Care; and**
e. **consideration given to reforming the distinctions between care homes and nursing homes.**

The Department partially accepts Recommendation 16.

The Department accepts Recommendation 16(a),16(b),16(c) and 16(d)
The Department does not accept recommendation 16(e)

The Department accepts Recommendations 16(a) and (b)

The Department's adult palliative care Baseline Scoping Exercise is seeking to understand the current generalist and specialist palliative and end of life care services and support in place for patients and those important to them across care settings including at home, in a care home, in a hospice and in hospitals.

Key Aim 2 of the Baseline Scoping Exercise involves a palliative care population-based need assessment, with a particular focus on inequalities. This will include consideration of the palliative care needs of older people and older people living alone. Key Aim 3 of the exercise aims to better understand the experience of patients being cared for at end of life and those important to them, including people who are receiving care in their own homes and care homes. The outcomes of these Key Aims will inform the services that need to be delivered and the skills, training and competences that are required to support delivery.

As noted at Recommendation 14 above, a Regional Palliative and End of Life Care Education and Learning Framework is currently being developed as one of the priorities of the Palliative Care in Partnership Programme. This is due to be completed later this year.

The development of the draft Framework has been a collaborative process involving partners from across all care settings, including care homes and home (domiciliary) care providers. The draft Framework is applicable for staff operating across the system, including in care homes and covers 5 key domains of PEOLC care:

1. Fundamentals of Palliative Care: enhancing quality of life
2. Communication skills
3. Holistic assessment, care planning & symptom management
4. Optimising comfort, maintaining dignity & wellbeing
5. Care in the last weeks/ days of life and & after death.

Whilst it is the responsibility of individual employers to ensure their staff have the necessary skills and competencies to undertake the duties of their role, the Framework is intended to provide a comprehensive guide to support HSC and independent care providers to identify the domains of palliative and end of life care required for staff working at Tier 1 and Tier 2 (see Recommendation 14 for definitions). Any potential standardised training opportunities/solutions identified through the development of the regional Framework would require investment to deliver.

Education and training in nursing homes was part of the Big Discussions process which informed winter planning for 2025/26. Trust palliative care education facilitators and Care Home Support teams provide education for care home staff and support teams.

The Department accepts Recommendation 16(c)

The assessment of the care home tariff increase is an annual process in relation to inflationary uplifts to the existing tariff only. It does not deal with any review of the baseline tariff, nor any impact future reforms of adult social care may have on the tariff.

In establishing the uplift to be applied to the tariff in any particular year, statutory changes such as increases in the National Living Wage, employer National Insurance rate changes, increases for other agreed pay awards (if applicable), together with other inflationary uplifts are taken into consideration.

The tariff relates to the standard weekly payment related to categories of nursing or residential care, representing a standard rate that will be paid towards care home fees. Homes are at liberty to set their own price in line with normal commercial practice, and the tariff is used as the basis for calculating any additional top-up or supplementary fees which care homes charge above this rate for additional services.

Work continues under the Social Care Collaborative Reform Board (SCCRB) with commissioners and care providers working in partnership to develop and introduce a framework based on an agreed true cost of care, which includes an agreement of a sustainable return for providers. This will recognise and take account of workforce recommendations around pay and terms and will include the cost considerations of the chosen model of care, the staffing needed to deliver on that model, the desired terms and conditions for the workforce involved and the regulation of profits and overheads.

The Department accepts Recommendation 16(d)

The Department recognises the need to minimise delays in discharge for people moving from hospital to a care home setting. The Trusted Assessor approach was introduced to reduce the number of delayed discharges, reflecting the evidence which demonstrates that one of the top five primary delays in timely transitions from hospitals to care homes is the period of time waiting for a care home pre-admission assessment and then awaiting a decision for acceptance from care homes.

There is evidence of variance across HSC Trusts in relation to how the model has been implemented. Whilst it is acknowledged that there is established deviance from the original vision, nevertheless, there has been significant progress in the co-ordination and management of how individuals transition from hospital to care homes and importantly in regard to the relationship between Trusts and the care home sector. Whilst variance is justified in some instances, it is recognised that there is a need to harmonise and redefine the model.

The Department continues to establish regional guidance, duties and responsibilities around the Trusted Assessor role to ensure consistency across Trusts. The revised role's core function is to facilitate the safe, effective and timely discharges of individuals from acute and non-acute hospitals when transitioning to a care home setting on a temporary or permanent basis (inclusive of intermediate care beds). The primary purpose of the role is to act as a conduit between the Health and Social Care Trust and the care home provider in order to minimise delays experienced due to communication challenges, professional relationships, inappropriate placement recommendations and care home pre-admission assessments and decision making. This includes palliative and end of life care.

Nursing liaison roles in each HSC Trust are in place to facilitate discharge to independent sector care homes/nursing homes.

As noted at Recommendation 12 above, some independent sector care homes have undertaken Quality Improvement actions to enhance palliative care communication and symptom management by improving the confidence of their staff, which has resulted in reducing avoidable hospital admissions and facilitating early hospital discharge when admission is unavoidable. This demonstrates the benefits of training and support for staff in care homes.

As noted at Recommendation 14, Palliative Care in Partnership is developing a Regional Palliative and End of Life Care (PEOLC) Education and Learning Framework for use by providers across all care settings to ensure their staff have the required skills and competencies to care for people approaching the end of life. The Framework recognises the need to improve palliative and end of life care training and learning across the wider HSC and the independent workforce, this includes staff working in care homes. The Framework Document, which has been developed in collaboration with key stakeholders including cares home and home (domiciliary) care providers, is due to be finalised later this year.

The introduction of a Neighbourhood Model of Health and Wellbeing will mean a significant change in the way care is delivered in communities and is a key enabler for Department's objective to shift the focus of health and social care provision from secondary care to primary and community care. Keeping people out of hospital, and caring for and treating people closer to home, is not only more cost effective but is key to improving outcomes and quality of life by improving patient choice, and ensuring patients are treated in the right place at the right time.

An early priority for the Neighbourhood model will be older people's services, where it is expected that improvements in co-ordination should have a rapid, visible impact.

A Neighbourhood approach will support how palliative and end of life care is delivered, helping more people with palliative care needs to be cared for in the community. This includes supporting people to remain at home at end of life without inappropriate admission to hospital and also facilitating earlier discharge from hospital so that people are able to die at home with the support in place that they, and those important to them, need.

On 23 March 2026, the Department published the *Reforming Adult Social Care and Support 10 year Strategic Plan* and the first 3-year Delivery Plan[5], which have been developed in collaboration with delivery partners, including those in the voluntary and independent sectors. The vision is for a person-centred, rights-based, adult social care and support system, co-produced with people who receive care and support and unpaid carers, that delivers a whole systems collaborative approach to the design and delivery of adult social care and support with a focus on the centrality of home, local community based services provision and harnessing the power of communities.

The Department does not accept recommendation 16(e)

Both residential and nursing homes are defined by legislation including registration with the Regulation and Quality Improvement Authority, standards of care and service and through the regional rate. There are no current plans to review existing legislation.

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[5] Adult Social Care Reform Strategic Plan - 2026 - v7.pdf
Reforming Adult Care and Support - 3 Year Delivery Plan - 2026 - v3.pdf

## Recommendation 17

**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.**

The Department accepts Recommendation 17.

The Department is committed to providing the best possible end of life care experience for patients and their families and carers, including exploring with patients what matters to them and providing care that responds to this.

The Department's position has been that the NICE Guidelines NG31: Care of Dying Adults in the Last Days of Life, which have been considered and endorsed for use by the Department, provide the required detailed guidance on delivering care to individuals in their final days of life and should be used and implemented to support the delivery of high-quality care. The development of a specific 'prompts/aide-memoire' template may not be the optimum approach, as care cannot always be prescriptive but should be focussed on the individual and that their needs should provide the 'prompts' for delivering their care.

However, in response to the Committee's Recommendation 17, on 9 March 2026, officials met with one of the clinicians leading the current pilot initiative in the Southern Trust to develop an individualised end of life care template for potential regional use. In addition, officials joined Committee members on a visit to Craigavon Area Hospital on 12 March to observe a demonstration of the template in use. This provided a further opportunity to hear from palliative care and frontline nursing and medical staff about their experience using the template.

The Department is committed to giving further consideration to this recommendation and to working with HSC colleagues to understand more about the utility, added value, and outcomes for patient, families and staff from use of the template in practice. This will include consideration of findings from a planned evaluation and learning from the pilot exercise being undertaken in Craigavon Area Hospital. Any decision to implement the template across the region will require further discussion and consideration.

**Recommendation 18**

**Health and Social Care staff supported to ensure referrals for patients to PEOLC services in a timely and appropriate manner, 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.**

<u>The Department accepts Recommendation 18.</u>

One of the key priorities of the Palliative Care in Partnership Programme's 2023-26 work plan is early identification and timely intervention for those who could benefit from a palliative care approach, regardless of their condition.

The Department recognises the importance of palliative and end of life care education and training for Health and Social Care staff. This includes training to support timely identification of those with palliative care needs in order to facilitate timely referral.

A number of regionally endorsed tools are already in place and being used to support the identification of people with palliative and end of life care needs. These include the Supportive and Palliative Care Indicators Tools (SPICT), the Gold Standards Framework and the Surprise Question (whether a clinician would be surprised if the person died within the next 12 months)

As noted at <u>Recommendations 14 and 16</u>, a Regional Palliative and End of Life Care Education and Learning Framework is being developed by the Palliative Care in Partnership Programme. The draft framework comprises a number of domains, including the Fundamentals of Palliative Care, which will support training in relation to identification of people with palliative care needs and the use of regionally endorsed tools to support this.

It is the responsibility of employing organisations to ensure their staff have the necessary skills and competencies to undertake the duties of their role. However, the Framework's intention is to provide a comprehensive guide to support HSC and independent care providers to identify the domains of palliative and end of life care required for staff working at Tier 1 and Tier 2

Effective communication is fundamental to providing quality palliative care. In recognition of this, the draft Regional Palliative and End of Life Care Education and Learning Framework also includes a Communication Skills domain, with three levels of training - foundation, intermediate and advanced.

Under the Cancer Strategy for Northern Ireland, all health care professionals who are expected to carry out sensitive communication must complete an Advanced Communication Skills training programme. The Palliative Care in Partnership programme has also supported the roll out of an Advanced Communication Skills Project ensuring the needs of the specialist palliative care workforce are considered as part of this. A regional approach to Advanced Communication Skills Training is now established and all Trusts are delivering this training, supported by a growing number of trained facilitators,

The content of the Education and Learning Framework will seek to support standardisation of terminology where possible, however, the development of a new palliative care strategy (see Recommendation 27) would provide an opportunity to standardise terminology in relation to palliative care.

As noted at Recommendation 5 above, the Chief Pharmaceutical Officer (CPO) has written to the Head of School at both Queen's University and Ulster University with a request that they include palliative and end of life care in core training for pharmacy undergraduates in Northern Ireland.

The Department commissions the Northern Ireland Centre for Pharmacy Learning and Development (NICPLD) to act as the statutory education body for pharmacy in Northern Ireland and to develop and deliver a range of workforce development programmes and continuing professional development opportunities.

The CPO has formally written to NICPLD to request that palliative and end of life care is included within the NICPLD commission for 2026/2027 and will therefore be included in training for Foundation Year and postgraduate pharmacists, registered pharmacists and pharmacy technicians, irrespective of which healthcare setting they work in.

In addition, the CPO has formally written to the training providers, SERC (South-Eastern Regional College), SWRC (South Western Regional College), UCA-NI (Ulster Chemists' Association), Belfast Metropolitan College, National Pharmacy Association and Buttercups, with a request that they include palliative and end of life care in training for pharmacy counter staff.

## Recommendation 19

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

The Department accepts Recommendation 19.

Public awareness and understanding of palliative and end of life care are key elements of a public health approach to palliative care. It is recognised that a dedicated programme of communication activity, using a range of channels and methods to engage key audiences, would support population level messaging in relation to palliative and end of life care.

Due to funding pressures, there is currently a pause on campaign advertising. However, there are actions being taken through the Public Health Agency that support public messaging in relation to palliative and end of life care.

The Public Health Agency provides annual grant funding to the All Ireland Institute of Hospice and Palliative Care (AIIHPC), with deliverables agreed at the start of each financial year to align with priorities identified in the Palliative Care in Partnership work plan and overseen collaboratively by the PHA, the Department (through the Strategic Planning and Performance Group) and the AIIHPC.

Key areas of work supported through this funding to the AIIHPC include:

(i) raising public awareness of palliative and end of life care through the annual Palliative Care Week campaign, led by the AIIHPC and supported and endorsed by the Department. Resources to support Palliative Care Week are accessible through the AIIHPC website and are widely available to professionals and the public, including personal experience videos which share the stories of people affected by palliative care.

(ii) The AIIHPC Palliative Hub which provides publicly accessible information on hospice and palliative care for individuals, families, and carers. The Hub's Learning Platform hosts a range of online learning resources and introductory education, with some content tailored to specific audiences but generally open to all.

(iii) Voices4Care - AIIHPC manages and recruits the Voices4Care group in Northern Ireland, ensuring that the views of people with life-limiting illness, carers, and the wider community inform palliative care development. The Voices4Care NI membership provide the service user and carer input to the Palliative Care in Partnership Programme

(iv) Supporting Marginalised Communities - this year's focus includes scoping the palliative care needs of marginalised groups, such as people with disabilities, the homeless population, and individuals in prison. This builds on the previous engagement with the LGBTQIA+ community to get a better understanding of their palliative and end of life care needs and barriers impacting on this.

In addition, the PHA Nurse Consultant for Palliative and End of Life Care is working with Compassionate Communities NI and the Open University to explore research and funding opportunities to further raise public awareness of palliative and end of life care through the Take 5 to Age Well campaign.

**Recommendation 20**

**The Department appoint an independent Palliative Care Clinical Lead for Northern Ireland who would report directly to the Minister of Health and be able to affect Palliative and End of Life Care 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 Chief Executive Officers) and be an ambassador for the palliative care sector of Northern Ireland. An interim regional clinical lead be installed with immediate effect.**

<u>The Department accepts Recommendation 20.</u>

The Department accepts the recommendation to appoint a regional Palliative Care Clinical Lead for Northern Ireland to support the further development and improvement of palliative care.

The Department will engage with relevant stakeholders in the development of a job description for the Palliative Care Clinical Lead role. In terms of the remit, role description and governance arrangements, the Department will be informed by similar roles in the UK and Ireland and clinical lead roles already in place in the Health and Social Care system in Northern Ireland.

The Department will develop a business case to ensure the availability of funding for this post. The aim will be to have business case approval and to have commenced the appointment process within the next 6-9 months. The timescale for appointment of a Clinical Lead for Palliative Care will be dependent on the availability of funding and the time taken for the completion of the appointment process.

In the interim, the Clinical Engagement Group within the infrastructure of the Palliative Care in Partnership structures will continue to provide clinical expertise in relation to adult palliative care in Northern Ireland. Immediate consideration will be given as to how the role of the CEG can be further enhanced in the interim. This will include engagement with the Chief Medical Officer and the PHA Director of Public Health to seek their professional advice on this aspect given their respective responsibilities for providing professional policy and commissioning advice to the Department and SPPG.

**Recommendation 21**

**The Minister of Health and the Northern Ireland Executive:**

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.**

<u>The Department partially accepts Recommendation 21.</u>

The Department accepts Recommendation 21(a)
The Department accepts Recommendation 21(b), however as this recommendation extends beyond the scope of the Department of Health, we will work with the Department for Infrastructure to address this
The Department accepts Recommendation 21(c)
Recommendation 21(d) falls outside the scope of the Department of Health.
<u>The Department accepts Recommendation 21(a)</u>

The Department recognises the challenges that exist for some communities, including in rural areas. Within the resources available, the Department remains committed to working with Executive colleagues to support patients, families and carers in rural areas to access the health care they need. The Department will continue to meet its responsibilities to incorporate the voice of those living in rural areas in its strategic planning and expects HSC Trusts to do the same.
The Rural Needs Act (NI) 2016 places a statutory duty on Northern Ireland departments and Trusts to have due regard to rural needs when developing, adopting, implementing or revising policies, strategies and plans, and when designing and delivering public services.

The Department of Health's Policy Guidance Circular on Change or Withdrawal of Services sets out the roles and responsibilities of HSC bodies when considering temporary or permanent service changes. This guidance is reviewed and updated as required. As part of the next review, the Department will commit to strengthening consideration of rural and equality impacts and public involvement at an early stage.

The Department will also continue the ongoing work, commissioned by the Chief Nursing Officer, to develop a more strategic and consistent approach to public engagement across the HSC. The overarching aim is to ensure that lived experience, including that of rural communities, continues to be embedded in policy development, service design and delivery and to support better use of service user and patient experience over time.

This includes ongoing consideration of governance and accountability arrangements for public engagement, recognising that responsibilities are currently dispersed across several HSC organisations. This work, which is informed by the Strategic Approach to Public Engagement Oversight Group and involves engagement with a wide range of stakeholders including HSC Trusts, the Patient and Client Council, PHA and RQIA, is expected to conclude by March 2027

Importantly, as outlined previously and as set out in the Neighbourhood Model of Health and Wellbeing Policy Framework, the shift left of services into the community that underpins the Neighbourhood approach, including the use of technology, will improve access to palliative and end of life care in or close to people's homes and help address the rural premium identified in the Committee's report. The Neighbourhood model places local communities at the heart of how services are planned and delivered.

The Department accepts Recommendation 21(b), and will work with the Department for Infrastructure to address this

Transport is ultimately the responsibility of the Department for Infrastructure (DfI), and there are limitations to the action the Department of Health can take in relation to this recommendation. The Department is committed to working with DfI and the Department of Agriculture, Environment and Rural Affairs (DAERA) on issues around transport, including in rural areas, through a cross departmental group. The Working Group has focussed on how to maximise the benefits of the current services provided by community transport using existing resources and how to maximise the future potential of community transport.

In addition, while the existing Transport Strategy for Health and Social Care Services in Northern Ireland remains broadly in line with current national guidance, as it was last updated in 2007 the Department has committed to reviewing the existing Transport Strategy for Health and Social Care services in Northern Ireland, subject to available resource. Eligibility for access to non-emergency transport services is based on medical need as determined by a medical practitioner. As a general principle, patients should be expected to make their own way to hospital, either using their own transport, or that of friends and relatives, or by using a number of schemes that exist to help people who have transport difficulties.

The Department accepts Recommendation 21(c)

The Department has regular engagement with the All Ireland Institute of Hospice and Palliative Care (AIIHPC) and its Chief Executive is a member of the Palliative Care in Partnership (PCiP) Programme Board.

The Institute's Voices4Care Group includes people living with palliative care needs, carers or former carers of people with palliative care needs, and members of the public who are interested in palliative care. The PCiP's service user and carer engagement group is made up of Northern Ireland based members of the Voices4Care group. Through participation in the PCiP programme, local Voices4Care members support the design and development of palliative care in Northern Ireland.

Palliative Care Week, which is led by the AIIHPC, is a co-ordinated campaign across the island of Ireland to raise awareness of what palliative care is, the difference it can make for patients, families and carers and how to access services. The Minister and the Department support and endorse the annual Palliative Care Week campaigns. In September 2025 for example, Minister spoke at an event in Parliament Buildings on palliative care in rural areas and provided a video message of support for the AIIHPC website promotional material.

The All Ireland Institute of Hospice and Palliative Care has recently set up a community of practice for palliative care pharmacists on the island of Ireland, with an introductory meeting held in February 2026. It is planned that meetings will occur every three months to share good practice. The community pf practice is co-chaired by the regional lead pharmacist for palliative care in Northern and a counterpart from ROI. This is one of a number of AIIHPC professional Communities of Practice which Northern Ireland professionals participate in.

The Paediatric Palliative Care Network is working to build stronger links with colleagues in the south of Ireland. This will include the area of joint care pathways and also peer discussion and learning on the most complex cases. In due course, a formalised all Ireland Paediatric Palliative Care Network may be created.

<u>Recommendation 21(d) falls outside the scope of the Department of Health</u>

The pay and terms and conditions for staff employed by voluntary and community sector organisations are the responsibility of the employing organisation and are not within the remit of the Department of Health. The V&C sector is an important part of the development of the Neighbourhood model of Care; the Department anticipates that their involvement in the model will help boost the sustainability of V&C providers and therefore enhance their capacity to ensure staff are appropriately remunerated.

**Recommendation 22**

**The Minister of Health and the Northern Ireland Executive:**

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.**

<u>The Department partially accepts Recommendation 22</u>

The Department accepts Recommendations 22(a), 22(e), 22(f) and 22(g)
Recommendation 22(b) 22(c) and 22(d) – the Department has or is taking action to address these parts of the recommendation and whilst responsibility extends beyond the scope of the Department of Health, we will work with other Departments to support these.

<u>The Department accepts Recommendation 22(a)</u>

One of the four key priorities of the regional Palliative Care in Partnership Programme workplan for 2023-26 is to promote a public health approach to palliative care. A public health approach recognises the need for society and community to play an active role in supporting people with life limiting conditions to live well with flexible, holistic and person-centred care based on positive and collaborative partnership. It also involves increasing awareness, understanding and discussion around palliative care and encouraging people to think about and plan for their future physical, emotional, social, financial and spiritual needs.

The Department supports the Compassionate Communities NI initiative and since 2022 has fully funded the project, which originated in the Western Trust locality and is currently hosted through Foyle Hospice

Examples of the work of Compassionate Communities NI include delivering Compassionate Conversations and Plan Ahead workshops, engagement with local Council Age-Friendly Officers, a series of art-based projects and social media campaigns to promote death literacy and an ongoing partnership with Libraries NI to roll out Death Positive libraries across Northern Ireland.

The Department reviewed its funding for Compassionate Communities in 2025, as a result of which funding (c £97k annually) was renewed and maintained for a further 3 years to 2028.

<u>Recommendation 22(b) extends beyond the scope of the Department of Health</u>

The Department of Health does not have responsibility for the school curriculum in Northern Ireland and this recommendation therefore falls outside the remit of the Department.

The Department of Education, as the department with lead responsibility for the school curriculum, is best placed to make an assessment on this recommendation. The Department will work with the Department of Education to support this.

However, in terms of bereavement support more widely, the Department of Health hosts the Northern Ireland Bereavement Network (NIBN), which includes representation from a range of public sector organisations, including those in Health and Social Care, the Education Authority as well as voluntary and community organisations.

In 2024, the NIBN launched the 'Bereaved NI' website, Bereaved NI which signposts users to an extensive range of support services, including a number that are specific to children and young people, for example Barnardo's Child Bereavement Service; the Cancer Fund for Children; and Winston's Wish. During the third quarter of 2025 over 4,000 people accessed the Bereaved NI website.

The NIBN and its member organisations could make an important contribution to any work to streamline death, dying and bereavement education in school and special education school curricula. The Department would be supportive of the NIBN's involvement in this work.

<u>Recommendation 22(c) extends beyond the scope of the Department of Health</u>

Recommendation 22(c) is wide-ranging and will therefore require a cross-departmental approach.

The Department of Health recognises the impact that poverty has on health outcomes and on health inequalities. The Department supports the delivery of a range of actions, policies, strategies and programmes to prevent and address this issue.

Making Life Better (MLB) is the overarching strategic framework for public health through which the Executive committed to creating the conditions for individuals, families and communities to take greater control over their lives and be enabled and supported to lead healthy lives and address health inequalities. The next stage of MLB is currently with the Executive for agreement and takes into consideration recent developments, including the new Neighbourhood model of care, whilst also considering the need for the most effective and efficient use of existing resources.

The Anti-Poverty Practice Framework for social work in Northern Ireland was launched in June 2018 and has been widely embedded into practice. It aims to help social workers recognise and respond to the impact of poverty on the people they support.

The Public Health Agency works collaboratively with several partners to deliver interventions to improve health and address some of the associated health inequalities related to living in poverty. This includes cold weather and energy efficiency interventions to improve the health and wellbeing outcomes of identified vulnerable target groups. Examples include a regional Keep Warm Pack Scheme developed to provide immediate, short-term support to help those most vulnerable or at risk of fuel poverty to stay warmer at home during cold weather. The scheme is co-ordinated by the PHA in collaboration with a range of local government, HSC Trusts and community and voluntary partners.

The PHA also support or commission a number of locally responsive fuel poverty interventions for those most vulnerable or at risk of fuel poverty during colder weather.

The Department of Health has also been represented on the Department for Communities cross-departmental working group to support the development of the Anti-Poverty Strategy.

The Department of Health also worked with colleagues from the Department for Communities throughout the development of the Warm Healthy Homes Strategy.

<u>Recommendation 22(d) extends beyond the scope of the Department of Health</u>

Whilst the Department of Health cannot ensure this element of the recommendation, we will work to support it happening.

The Department of Health recognises the crucial role unpaid carers and young carers play, and the substantial amount of care they provide. Unpaid care often places significant burdens and demands on individual carers, including financial pressures and hardships, emotional demands, challenges in maintaining their own health and wellbeing, and on their ability to take part in paid employment, education or social, leisure and recreational activities.

The Department chairs a Cross Departmental Senior Official Group for Unpaid Carers which provides a forum to share policy perspectives on the provisions for unpaid carers across departments.

The recently published Reforming Adult Social Care and Support 10 year Strategic Plan sets out several strategic commitments to support unpaid carers, including: putting in place legislative and strategic frameworks that put unpaid carers rights on an even footing, reviewing the 2006 Carers Strategy to inform the future strategic approach to unpaid carers; and improving the information, advice and guidance available to carers to enable easier access to support.

The HSC continues to support unpaid carers through the provision of carer assessments and carer support services and by continuing to improve the identification of carers and signposting carers to sources of support and advice.

Responsibility for criteria for payment of Carer's Allowance and the implementation of statutory carer's leave is for other departments and Ministers.

<u>The Department accepts Recommendations 22 (e) and (f)</u>

The Department recognises the importance of palliative care for the homeless and prison populations. Workstreams are in place for these population groups and the Department will consider the recommendations made by the Committee within these workstreams.

Both the homeless and prison populations often have complex health needs and require additional healthcare across physical health, mental health and addiction services. The Department provides healthcare in prison through the South Eastern Health and Social Care Trust and to the homeless population primarily via the Inclusion Health Services in each Health and Social Care Trust area. The need for additional support for palliative care will be considered along with and prioritised against the wider healthcare requirements of these populations.

The Palliative Care in Partnership Programme is working with the All Ireland Institute of Hospice and Palliative Care to identify existing work, gaps and opportunities for people with palliative and end of life needs experiencing homelessness. This work is ongoing.

The Department is currently reviewing and revising its Partnership Agreement with the Northern Ireland Prison Service (NIPS) relating to the provision of healthcare in prison. Part of this work will be the development of a work plan to deliver against agreed outcomes and priorities. The Committee's recommendation will be considered as part of this process.

As noted at Recommendation 2 above, the Baseline Scoping Exercise Key Aim 2 population needs assessment will have a specific focus on the provision of equitable palliative and end of life care, including a focus on people facing inequalities, to better understand the current experience of specific populations and the future demands and challenges which the Department, as commissioner of services, will need to plan for. Both the homeless population and people in prison will be considered as part of this work.

The Department accepts Recommendations 22(g)

Access to palliative and end of life care is important for everyone and the Department is committed to ensuring that those facing a language or cultural barrier are supported to access palliative care services.

In recognition that awareness and understanding of palliative care, and how to access services, may vary across different cultural groups, the draft Regional Palliative and End of Life Care Education and Learning Framework includes learning objectives on diversity and different cultures in the provision of palliative care (including diversity of staff providing care) as part of the Fundamentals of Palliative Care domain.

The HSC Bereavement Booklet "When someone dies: Information, guidance and support for family and friends" is available in a range of languages. The booklet, and a link to Cruse Bereavement Support – Help for those who don't speak English - are available on the Northern Ireland Bereavement Network and can be accessed at Translated Bereavement Support - Bereaved NI

Arrangements are in place to support people who may have difficulty accessing health and social care services through language, cultural or other barriers. The Business Services Organisation (BSO) Interpreting Service is commissioned by the Department to provide foreign language interpreting support to Health and Social Care (HSC) providers in Northern Ireland, including GP Practices. The main aim of the service is to improve access to HSC Services for patients who do not speak English proficiently. This is demand-led and requests vary according to the needs of patients/service users.

In addition to the HSC Regional Interpreting Service, the Big Word (telephone foreign language interpreting) is also available. The service, which is commissioned by the Department, supports communication with patients who do not speak English proficiently through a fully trained interpreter, over the phone.

Further information about interpretation services is available at [BSO Interpreting Service - Business Services Organisation (BSO) Website]

Individuals who are d/Deaf, d/Deafblind or hard of hearing can utilise the Regional Communication Support Service (RCSS), which is commissioned by the Department of Health and provided by Sign Language Interactions. The service introduced on 1 April 2023, provides British Sign Language (BSL) and Irish Sign Language (ISL) interpreting in person, via video, lip speaking and electronic note taking [Regional Communication Support Service - DOH/HSCNI Strategic Planning and Performance Group (SPPG)]. The RCSS Service Lead in the Department's Strategic Planning and Performance Group recently presented to members of the Palliative Care in Partnership's Clinical Engagement Group to promote this service.

A best practice guide, '*Making all Contacts Count*', was disseminated to all GP practices in October 2025. This guidance provides recommendations of best practice to support equitable access to GP services for vulnerable groups, such as the elderly, people with disabilities, ethnic minorities, homeless populations and those facing a language or cultural barrier to accessing GP services.

**Recommendation 23**

**The Department of Health include in the Transformation Agenda:**

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;**
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;**
d. **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;**
e. **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**
f. **investment in palliative care services as 'preventative' policy in terms through a sustainable multi-disciplinary team workforce and prehabilitation services.**

The Department accepts Recommendation 23.

The Department accepts Recommendation 23 (a) and (b)

The NI Ambulance Service (NIAS) Palliative Care referral pathway allows the opportunity for paramedics who are notified of a patient's palliative status, and do not believe transfer to an Emergency Department would be in the best interests of the patient, to directly refer to district nursing/ palliative care teams for support. Within some Trust areas, this referral pathway may also enable clinicians to refer to Marie Curie Rapid Response services, where available.

The Northern Ireland Ambulance Service Urgent Care Team is continuously reviewing the current Palliative Care pathway as part of its commitment to patient-centred, ongoing quality improvement, working closely with HSC Trusts to enhance effectiveness, reduce unwarranted variation in out of hours provision, and align differing Trust operating models.

NIAS is also actively involved in the planning of Advance Care Planning training and the implementation of the ReSPECT document – see Recommendation 8.

The integration of district nursing and palliative care pathways supports a co-ordinated, patient-centred approach, enabling NIAS staff to access appropriate community services and essential patient information promptly. Strengthened information sharing arrangements improve decision-making, reduce unnecessary hospital conveyance, and help maintain patient comfort, dignity, and choice. The revised referral pathway is more streamlined and accessible, supporting clinicians to make timely, appropriate referrals for palliative patients and reinforcing NIAS's commitment to continuous quality improvement and consistent, compassionate care across the system.

The Department accepts Recommendation 23(c).

The Department acknowledges the critical role of District Nursing in supporting people with palliative and end of life care needs and those important to them, particularly through their Key Worker role. District Nurses will also have a vital role to play as the Neighbourhood model of care is implemented across Northern Ireland supporting the 'shift left' approach to the delivery of more services in the primary and community sector and to reduce inappropriate attendance at EDs.

The Department agrees that there is a need to increase investment in District Nursing services, however funding pressures will impact on the timing and extent to which funding levels can be increased.

The Department accepts Recommendation 23(d).

As noted previously, a Regional Palliative and End of Life Care Education and Learning Framework is currently being developed by the Palliative Care in Partnership programme. The draft Framework recognises the need to improve palliative and end of life care training and learning across the wider HSC and independent workforce and its development has been a collaborative process involving partners from across all care settings, including care homes and home (domiciliary) care providers.

The draft Framework covers staff operating across the system at Tier 1 and Tier 2 and covers 5 key domains of palliative and end of life care:

1. Fundamentals of Palliative Care: enhancing quality of life
2. Communication skills
3. Holistic assessment, care planning & symptom management
4. Optimising comfort, maintaining dignity & wellbeing
5. Care in the last weeks/ days of life and & after death.

Any potential standardised training opportunities/solutions identified through the development of the Regional PEOLC Education and Learning Framework would require additional investment to deliver.

As noted previously, it is the responsibility of individual employers to ensure their staff have the necessary skills and competencies to undertake the duties of their role.

The Department accepts Recommendations 23(e) and (f)

The Department recognises that being able to access palliative and end of life care and support when needed is important for everyone, no matter where they live or whether their care is being provided at home or in any other setting.

The introduction of the Neighbourhood care model will mean a significant change in the way care is delivered in communities and is a key enabler for the Department's objective to shift the focus of health and social care provision from secondary care to primary and community care. This includes supporting people to remain at home at end of life without inappropriate admission to hospital and facilitating earlier discharge from hospital so that people are able to die at home with the support in place that they, and those important to them, need.

The new Neighbourhood Model of Health and Wellbeing will be built around 17 Integrated Neighbourhood Teams. These will act as provider alliances which will bring together professional teams and organisations, representing health, social care and voluntary and community sector services in their respective areas, including palliative care providers. As part of the Neighbourhood approach, the health and social care system will be redesigned so that more advanced, specialised and proactive care is in community and primary care settings, with higher acuity care retained in hospitals. It also means strengthening anticipatory and proactive care so high-risk groups receive early, tailored support locally, keeping people independent and well in their communities.

To support the new Neighbourhood model, from 2026/27 there will be a refocusing of care from hospital to community with commensurate redirection of funding - with an aim to move 2% each year from hospital based spend to community spend, delivered through the new neighbourhood model and the INTs.

The commitment of funding from Macmillan's Neighbourhood Transformation Fund of up to £10 million over the coming three to five years will be instrumental in delivering the aims of addressing frailty and providing end of life care with the tailored support needed.

**Recommendation 24**

**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.**

The Department accepts Recommendation 24.

The Department accepts the recommendation that a branch be established with specific policy responsibility for palliative care. In the first instance the remit will be adult palliative care. This will also align to the initial focus of the new Neighbourhood model on older people.

The future role, remit and structure of the branch will be considered within the context of the Neighbourhood model and the structures and resources that are being put in place within the Department to support this, as well as the Department's governance arrangements and requirements.

As part of restructuring to support the Neighbourhood model, the Department's Strategic Planning and Performance Group has already established a Neighbourhood Care Directorate, whose remit includes palliative and end of life care.

## Recommendation 25

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

<u>The Department accepts Recommendation 25.</u>

The Department is committed to continuing to engage with hospices, and other stakeholders, to develop and improve palliative and end of life care.

Each of the independent hospices in Northern Ireland, as well as Hospice UK, are members of the Palliative Care in Partnership (PCiP) Programme, which is co-chaired by the Department's Strategic Planning and Performance Group and the Public Health Agency. The PCiP is the regional driver for the development of palliative and end of life care services and its members and member organisations, including hospices, have been actively engaged through the PCiP structures in agreeing and implementing the PCiP priorities and work plan for 2023-26.

Hospices are playing an intrinsic role in the Baseline Scoping Exercise for adult palliative care services – the Hospice Alliance NI is represented on the Project Board responsible for overseeing the work to deliver the 3 Key Aims of the project. The outcomes of the Baseline Scoping Exercise will inform the future strategic direction for palliative care and the planning and commissioning of palliative care services.

Again, at a strategic level, in 2025/26, representatives from the hospice sector were part of the Big Discussion, a whole systems series of events to explore the learning from Winter 2024 as preparation for Winter 2025/26. Coming out of this, seven workstreams were identified for progression, with a particular focus on the needs of frail older patients, including reducing unnecessary admission to hospital for end of life care. Hospice representatives have been included in the work of a number of these workstreams.

The commitment under the HSC Reset Plan to introduce a Neighbourhood model of care with more health and social care services provided in the community will have implications for how palliative and end of life care services are planned and delivered. As part of the Design phase of the Neighbourhood model, hospices were among attendees at an engagement event held specifically for the voluntary, community and social enterprise sector.

As part of engagement to support the design and build phases of the Neighbourhood model, Department officials have actively engaged with colleagues in the hospice sector to learn how similar community-focussed approaches to palliative care have been implemented elsewhere. The Department will continue to engage with hospices as the Neighbourhood model is implemented and these conversations will help inform how palliative and end of life care is taken forward within this wider strategic context.

**Recommendation 26**

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

The Department is unable to accept Recommendation 26.

It is unclear from the report as to the nature of the support being recommended and whether this is operational or financial.

In terms of capital funding, the Department does not currently have a capital grant scheme or any other mechanism available to provide financial support to health and social care related voluntary and community sector infrastructure, with the focus being on statutory providers.

The Health Service continues to face significant financial pressures. Although the Finance Minister's proposed capital funding allocations, totalling £1.8 billion over the four-year Budget period 2026/27 to 2029/30, will allow the Department to meet its inescapable pressures, it is significantly lower than the £3.0 billion the Department bid for in the Budget Exercise in order to progress partially committed and new investment projects across the Northern Ireland.

It is therefore anticipated that no capital funding will be available to allow new or emerging projects such as the Evora Hospice to be supported within the four-year Budget period due to funding constraints. The financial position in respect of revenue funding is even more constrained.

However, the Department recognises that by empowering charities to deliver earlier, more localised support in the community, it is possible to help people stay well for longer and reduce avoidable pressure on hospital services. The Department will work with Evora Hospice, and other hospices, to support the building of competence in relation to identifying funding opportunities that may be available to the Voluntary and Community sector.

**Recommendation 27**

**A new Palliative and End of Life Care 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.**

The Department accepts Recommendation 27.

The Department has already indicated its commitment to the development of a new palliative care strategy for adults.

In line with the approach outlined at Recommendation 25, the Department will work collaboratively with the palliative care sector and other stakeholders as part of a co-production approach to the development of a new palliative care strategy.

The development of a new strategy for adult palliative care will be aligned to the strategic direction set out in the Department's HSC Reset Plan, and in particular the commitment to a new Neighbourhood model for primary, community and social care, which will deliver greater levels of care in the community.

A new strategy will also be informed by the outcomes of the Department's Baseline Scoping Exercise for adult palliative care services. This exercise will provide a more complete source of data, including the assessment of projected need, with a focus on people facing inequalities, and identification of where there are gaps in service. This will provide a foundation for the development of a new evidence-based strategy that will more effectively respond to population needs.

The new strategy will also be informed by the findings and recommendations of the Health Committee's report.

A new palliative care strategy will be included in the Department's three year business plan. This recognises that the development of the strategy will need to be informed by outcomes of the Baseline Scoping Exercise and that it will also need to reflect the strategic direction of the Neighbourhood care model as this is further developed and rolled out over the coming months.

The Department recognises that the wide-ranging aspects of palliative and end of life care are not restricted to Health. The Northern Ireland Executive's Programme for Government 2024-27, published in March 2025, includes a commitment to work across the Executive to identify opportunities to improve support to those coping with death, dying and bereavement. The development of a new palliative care strategy will therefore require a cross-Departmental approach.

**HEALTH COMMITTEE REPORT – ACCESS TO PALLIATIVE CARE SERVICES**

**RECOMMENDATIONS SUMMARY**

The Committee's wide-ranging report on Access to Palliative Care services makes a total of 27 recommendations.

This response outlines that the Department has accepted 19 recommendations in full, with 7 partial acceptances and only one recommendation not being accepted.

Of those recommendations which are partially accepted, the Department has generally accepted the principle underlying the recommendation but may have been unable to agree to all parts of the recommendation. In all instances, the Department has sought to engage constructively with the breadth of these recommendations.

A summary of the Department's response to each is provided below for ease of reference.

| **RECOMMENDATION** | |
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| **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 Palliative & End of Life Care. | **Partially Accepted** |
| **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 pressures of the palliative care sector. | **Accepted** |
| **Recommendation 3** | |
| The Department move to 100% funding for all hospice services, with an initial 50% of actual cost of care for 2026-27, and a sliding scale increase over 5 years, based on cost of delivery of all hospice services, and inflation accounted for as appropriate. The Department must liaise with each Hospice and begin to standardise contract templates across all Trusts, to include:<br>a. Multi-year contracts;<br>b. Agenda for Change uplift applied to full contract value; and<br>c. Service Specific KPIs & volume-based remuneration. | **Partially Accepted** |
| **Recommendation 4** | |
| Immediate increased investment in a regional Out of Hours Palliative and End of Life Care workforce, generalist and specialist, particularly in rural areas, to ensure equitable access to services for all patients in a timely manner, seven days a week and 24 hours a day. | **Accepted** |

| **Recommendation 5** | |
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| Immediate investment in pharmacy services within Palliative and End of Life Care services, rural proofed, to include:<br>a. an Electronic Prescription Service to allow prescribers to send prescriptions electronically to a community pharmacy;<br>b. clear pathways on how to access palliative medicines outside normal working hours, ensuring equitable access (in collaboration with the 24/7 Palliative and End of Life Care single central point of access);<br>c. better collaboration between pharmaceutical wholesalers, primary care and palliative care, to ensure that wholesalers are aware of the critical nature of palliative medicines and that they must be available promptly for primary care patients;<br>d. a funded agreement in primary care to provide urgent access to palliative medicines from wholesalers implemented, to address particular challenges accessing controlled drugs in community outside normal working hours;<br>e. the use of 'Just in Case' boxes rolled out regionally and innovative initiatives involving GP Out of Hours service that can address urgent access to palliative medicines explored;<br>f. increased roll-out of nurses as independent prescribers who can issue prescriptions;<br>g. increased specialist palliative care pharmacists in each Trust, hospice, community to provide support for families, including the role of the pharmacy technician in palliative care;<br>h. pharmaceutical wholesalers to keep sufficient stocks of certain Palliative and End of Life Care medicines;<br>i. nursing homes keep stocks of non-controlled palliative medicines, not just named patient supplies;<br>j. include Palliative and End of Life Care in core training for undergraduate, Foundation Year, postgraduate pharmacists; and<br>k. provide regular and varied training opportunities for registered pharmacists, pharmacy technicians, and counter staff, irrespective of which healthcare setting they work in. | **Partially Accepted**<br>All elements accepted except for Recommendation 5(b) partially accepted Recommendation 5(i) not accepted |
| **Recommendation 6** | |
| The Department expedite a scoping exercise on Specialist Palliative Care Multidisciplinary Team requirement, to meet agreed quality care indicators with the sector, and provide equitable access to Specialist Palliative Care for children and adult patients. To include all Emergency Departments, hospital and hospice In-Patient Units, and care in the community including care homes and nursing homes, for clarity on total service provision and training needs in Specialist Palliative Care, including Out of Hours. | **Accepted** |
| **Recommendation 7** | |
| Paediatric palliative care services prioritised and invested in to provide:<br>a. adequate funding of Specialist Palliative Care beds for children: | **Accepted** |

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| b. a dedicated paediatric palliative care consultant in the NI Children's Hospice;<br>c. an increase in medical leads Programmed Activity (PA) per week;<br>d. additional support for 'non-cancer' conditions in children;<br>e. stabilised and predictable funding for community-based palliative services for young people and increased investment in community-based Out of Hours cover for Paediatric End of Life Care;<br>f. adequate provision of supported Out of Home Respite; and<br>g. a strategic approach to building capacity and resources to meet growing demand in Paediatric Palliative Care. | |
| **Recommendation 8** | |
| Regional implementation of the Advance Care Planning (ACP) and the ReSPECT framework as a matter of urgency. The Department provide the Palliative and End of Life Care sector with a detailed timeline, including its inclusion in encompass. | **Accepted** |
| **Recommendation 9** | |
| a. a 24/7 telephone and online helpline for patients and their families and carers;<br>b. emergency out-of-hours palliative care expertise services;<br>c. provide advice and assistance on referral pathways to HSC staff; and<br>d. provide advice and assistance on referral pathways for pre- and post-bereavement services. | **Accepted** |
| **Recommendation 10** | |
| A system established to oversee continuity and coordination of Palliative and End of Life Care patients moving between all palliative care settings, that prevents patients falling through gaps in care and gives a clear referral framework and support system for patients, families, & healthcare providers. | **Accepted** |
| **Recommendation 11** | |
| Full read and write access of the encompass IT system given to all generalist and specialist Palliative and End of Life Care services and every palliative care patient's journey is planned and recorded through the encompass system, to include support for the patient's emotional and spiritual wellbeing. | **Partially Accepted** |
| **Recommendation 12** | |
| Hospital Emergency Departments have designated palliative care professionals and systems in place that will ensure rapid assessment, imaging, or direct admission for Palliative and End of Life Care patients | **Accepted** |

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| in crisis, & will ensure safe and supported discharges for palliative patients from acute care settings into the community. | |
| **Recommendation 13** | |
| A framework established that fully supports young people as they transition from children's Palliative and End of Life Care services to adult services, and stabilised & predictable funding for community-based palliative services for young people. | **Accepted** |
| **Recommendation 14** | |
| a. people over the age of 85 are adequately supported to access palliative care;<br>b. individuals with serious mental illness gain access in a timely manner and receive tailored support as they access services;<br>c. people with learning disabilities or complex needs gain access in a timely manner and receive tailored support as they access services; and<br>d. barriers faced by marginalised groups in accessing palliative care are addressed. | **Accepted** |
| **Recommendation 15** | |
| Remove barriers to Palliative and End of Life Care services for Northern Ireland's neurodivergent population through greater investment in research and innovation. | **Accepted** |
| **Recommendation 16** | |
| Stabilised and predictable funding for community-based palliative services for older people, to ensure that regardless of the type of home they live in, they receive dignified and effective End of Life Care, to include:<br>a. recognition of increased patient acuity and the enhanced skills, training, and competencies required to deliver Palliative and End of Life Care services:<br>b. a Specialist Palliative Care workforce sufficient to meet the needs of care homes, following completion of the scoping exercise;<br>c. the regional rate paid to care homes reflect the time and resources needed to deliver these services effectively;<br>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 Palliative and End of Life Care; and<br>e. consideration given to reforming the distinctions between care homes and nursing homes | **Partially Accepted**<br>Recommendations 16 (a), (b), (c) and (d) accepted. Recommendation 16 (e) not accepted |
| **Recommendation 17** | |
| 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. | **Accepted** |

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| **Recommendation 18** | |
| Health and Social Care staff supported to ensure referrals for patients to PEOLC services in a timely and appropriate manner, to include:<br>a. appropriate palliative care training of all HSC staff to ensure early identification and timely referral to palliative care;<br>b. appropriate palliative care training to prevent terminal diagnosis being given in inappropriate environments such as EDs;<br>c. standardisation of palliative care language and appropriate training of all HSC staff and palliative care staff to remove confusion;<br>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; &<br>e. a consultant training scheme. | **Accepted** |
| **Recommendation 19** | |
| The Public Health Agency resourced sufficiently to successfully plan and implement public health messaging initiatives required for public understanding of palliative and end of life care services. | **Accepted** |
| **Recommendation 20** | |
| The Department appoint an independent Palliative Care Clinical Lead for Northern Ireland who would report directly to the Minister of Health and be able to affect Palliative and End of Life Care 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 Chief Executive Officers) and be an ambassador for the palliative care sector of Northern Ireland. An interim regional clinical lead be installed with immediate effect. | **Accepted** |
| **Recommendation 21** | |
| The Minister of Health and the Northern Ireland Executive:<br>a. address the 'Rural Premium' incurred by rural patients and their families;<br>b. integrate transport services as a care pathway critical to rural communities;<br>c. examine cross-border co-operation opportunities for communities to access palliative care more easily; and<br>d. charity staff supporting rural palliative services sufficiently paid and resourced. | **Partially Accepted**<br>Recommendations 21 (a), (b) and (c) accepted. Recommendation 21(d) is outside the scope of the Department |
| **Recommendation 22** | |
| The Minister of Health and the Northern Ireland Executive: | **Partially Accepted** |

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| 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;<br>b. streamline death, dying and bereavement education in school curriculums, including programmes tailored to special education schools;<br>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;<br>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;<br>e. increase support for front-line staff in homeless shelters dealing with challenging issues to meet the needs of individuals in their care;<br>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<br>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. | Recommendations 22 (a), (e), (f) and (g) accepted.<br>Recommendations 22 (b), (c), (d) extend beyond the scope of the Department but the Department will support these |
| **Recommendation 23** | |
| The Department of Health include in the Transformation Agenda:<br>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;<br>b. remove the need for ambulance teams to contact the patient's GP to request a referral is made;<br>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;<br>d. 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;<br>e. 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; &<br>f. investment in palliative care services as 'preventative' policy in terms through a sustainable multi-disciplinary team workforce and prehabilitation services. | **Accepted** |

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| **Recommendation 24** | |
| 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. | **Accepted** |
| **Recommendation 25** | |
| Hospices be included in strategic planning at central departmental level which will impact services & hospice finances. | **Accepted** |
| **Recommendation 26** | |
| The Department work closely with Evora Hospice Care to provide support to the hospice's move to a new site to ensure the success of the project and best outcomes for patients. | **Not Accepted** |
| **Recommendation 27** | |
| A new Palliative and End of Life Care Strategy be introduced to equip the specialist & generalist sectors to meet current and future needs with clear measurable goals & targets, & sector agreed implementation timescales. The Strategy must address:<br>a. planning of level of services needed over next 20 years;<br>b. collation of robust data to inform data-led policy;<br>c. recognition of the unique challenges faced by unpaid carers;<br>d. standardise regional services for equitable access whilst ensuring diverse local community needs are met;<br>e. rural proofing;<br>f. bereavement services; and<br>g. recognise cross Departmental work needed to remove access barriers. | **Accepted** |