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The Economics of Palliative and End of Life Care Services in Northern Ireland

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This briefing is the fourth in a series of papers on palliative and end of life care in Northern Ireland. It provides background, context and an overview of the funding landscape.

Contents

Key Points

Rising Demand and Increasing Complexity

Northern Ireland's palliative and end-of-life care (PEOLC) services are experiencing increased demand due to demographic changes and the rising prevalence of complex, chronic conditions such as dementia, cancer, and heart disease.

- Projections indicate that by 2048, the number of people requiring PEOLC could rise by over 30 per cent, with population ageing and increasing comorbidities contributing to greater demand and complexity; and
- This demographic trend is associated with increasing healthcare costs, particularly during the final year of life, when care needs are typically most intensive.

Current Funding Model: Origins and Structure

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

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

Financial Pressures and Service Sustainability

The current reliance on short-term, non-recurrent funding mechanisms contributes to financial uncertainty for PEOLC providers.

- In 2024, the UK hospice sector was estimated to face a combined deficit of £60 million;
- Financial instability can affect service planning, staff retention, innovation, and the capacity to provide integrated care - challenges that may be particularly acute in rural or socioeconomically disadvantaged areas.

Allocation of Resources and System Efficiency

Northern Ireland has the highest per capita expenditure on end-of-life care in the UK, estimated at £40,410 per person in the last year of life.

- A large share of this expenditure (over 75 per cent) is directed towards unplanned hospital care, while hospice care accounts for approximately 4 per cent;
- This distribution contrasts with evidence suggesting that community-based care can be more cost-effective and better aligned with patients' preferences; and
- While nearly 80 per cent of people express a wish to die at home or in a hospice, only 44 per cent do so, indicating a potential disconnect between system investment and outcomes.

Inequities in Access and Unmet Need

Access to PEOLC remains uneven, with estimates suggesting that one in four people in the UK may not receive the palliative care they require.

- In Northern Ireland, disparities are most apparent in rural and deprived areas, where hospital-based care is more common and community-based support may be limited; and

- Variability in service provision, including availability of 24/7 specialist palliative care, continues to be observed across Health and Social Care Trusts.

Data, Modelling, and Transparency

The absence of a region-wide commissioning framework and unified data infrastructure limits the ability to assess need and evaluate service delivery.

- There is currently no comprehensive modelling of population need or unmet need across Northern Ireland, which constrains equitable planning and resource allocation;
- Greater consistency in data collection, analysis, and sharing may support more evidence-informed decision-making and increase transparency in funding distribution; and
- The introduction of ENCOMPASS, Northern Ireland's integrated digital care record system, offers potential to enhance palliative and end-of-life care (PEOLC) provision. The system is being implemented in phases, and hospice providers currently do not have access.

Workforce, Infrastructure, and Service Integration

Sustainable PEOLC is linked to workforce capacity, infrastructure readiness, and integration across care sectors.

- Workforce development, including training in generalist and specialist palliative care, remains essential for delivering high-quality care;
- Centralised referral systems, robust administrative support, and interoperable electronic records can improve access and reduce provider burden; and
- Integrated care models, underpinned by continuous outcome monitoring and flexible contracting, may contribute to improved service coordination and responsiveness.

Economic Evaluation and Value for Investment

Economic evaluation plays a key role in understanding the impact and value of PEOLC interventions.

- Community-based palliative nursing services have demonstrated high returns on investment (e.g., over 2,100 per cent in Northern Ireland, according to Marie Curie), suggesting both economic and quality-of-life benefits;
- Although inpatient hospice care involves higher fixed costs, broader impacts, such as improved patient and family experiences, are relevant to holistic value assessments; and
- Economic evidence can inform resource decisions, while ensuring that models of care remain centred on patient needs.

Learning from Other Jurisdictions

Experience from other regions offers insight into alternative approaches to funding and organising PEOLC services:

- In the Republic of Ireland, palliative care is designated as a core health service, with full statutory funding for core operations and charitable income directed towards innovation and capital costs;
- England has introduced statutory commissioning duties for PEOLC, supported by national guidance and service specifications; and
- Wales uses needs-based planning and benchmarking to inform development and ensure regional consistency in service provision.

Children’s Palliative Care: Distinct Needs and Funding Gaps

Children’s hospice services in Northern Ireland support approximately 2,300 children each year but receive less than 10 per cent of their £20 million budget from statutory sources.

- Recent budget constraints have contributed to reductions in bed availability;
- The transition from children to adult palliative care services remains a known challenge, with implications for continuity of care; and
- Funding approaches may need to reflect the specific clinical and developmental needs of children and young people, including tailored transition arrangements.

The Role of PEOLC in the Wider Health System

PEOLC services support the wider health and social care system by facilitating timely discharge, reducing unnecessary hospital stays, and delivering care closer to home.

- Collaboration with primary care providers has enabled more individuals to achieve their preferred place of death;
- Advance care planning and the use of digital tools to record patient preferences may enhance care coordination and patient satisfaction; and
- Further development of the infrastructure supporting shared decision-making and advance care planning could strengthen the alignment of services with individual goals and values.

Key components of a Sustainable Funding Model

Achieving a sustainable and equitable funding system for PEOLC in Northern Ireland may involve several interrelated elements:

- **The use of multi-year, needs-based funding agreements** that reflect demographic projections and case-mix complexity;
- **The presence of clear service specifications and transparent payment mechanisms** informed by robust data and stakeholder engagement;
- **Leadership, governance, and accountability** structures that are coordinated across commissioning and service delivery;

- **Attention to workforce development, digital infrastructure, and integrated care pathways** that support high-quality, person-centred care; and
- **Continued partnership working and public engagement** to ensure services are aligned with patient and family priorities.

Other research briefing papers in this series:

Paper 1: Introduction to palliative and end of life care

Paper 2: Palliative and end of life care provision in Northern Ireland

Paper 3: How other countries fund and deliver palliative care

Paper 4: The economics of palliative and end of life care and sustainable funding mechanisms

Paper 5: Equity, access, coordination and integration of palliative and end of life care; Future planning and need for palliative and end of life care services

1. Introduction

Palliative and end-of-life care (PEOLC) plays an essential role within the wider health and social care system, supporting individuals with life-limiting conditions and their families. In Northern Ireland, the sustainability of PEOLC services is increasingly challenged by demographic change, rising demand, and persistent financial and structural pressures. These issues affect the capacity of services to meet needs consistently and equitably across the region.

As people approach the end of life, their interaction with healthcare services intensifies, particularly in hospital settings. Research from Marie Curie estimates that the UK spends approximately £11.7 billion annually on healthcare for individuals in their final year of life, with a substantial proportion directed toward inpatient care.[1] In Northern Ireland, public expenditure on adults in their last year of life averages £40,410 per person - higher than any other UK nation - largely associated with unplanned hospital admissions and lower levels of investment in community-based alternatives. These spending patterns raise questions about how expenditure aligns with patient outcomes, and health system performance.

Demographic shifts, including population ageing and a rising burden of chronic illnesses such as dementia, cancer, and heart disease, are expected to increase demand for PEOLC services in Northern Ireland by more than 30 per cent by 2048.[2] In parallel, healthcare costs escalate with proximity to death, and the number of comorbidities a person has is a known predictor of higher care costs.[3] Nuffield Trust, the Health Economics Unit, and Marie Curie reported that 81 per cent of healthcare spending in the final year of life is allocated to hospital care, with a significant portion directed towards emergency services. Even though nearly 80 per cent of individuals express a preference to die at home or in a hospice, only 44 per cent do so. This indicates a gap between stated preferences and actual place of death.[4] Inequities in palliative care provision in Northern Ireland, identified in the 2016 review of the PEOLC strategy, have continued to be reported, including differential access to 24/7 specialist palliative care services across Trusts.[5]

Evidence suggests that timely access to palliative care can prevent unnecessary hospitalisations, reduce costly interventions, and lead to better patient and family outcomes - including higher satisfaction, improved symptom control, and reduced distress among carers and the bereaved.[6] Furthermore, integrating palliative care earlier in the course of illness has been associated with reduced use of acute services while improving quality of life and potentially extending survival.[7]

However, the increasing complexity and heterogeneity of patient needs, combined with financial pressures on health budgets, present challenges to expanding access to high-quality, person-centred PEOLC. Currently, planned, and unplanned deficits have been reported by hospices in Northern Ireland and across the United Kingdon. In September 2024, Hospice UK estimated the that the sector was heading for a deficit in the region of £60 million for that financial year.[8] While cost does not determine eligibility for care, understanding the economic implications of service models is important for strategic planning. Economic evaluations, including return-on-investment (ROI) studies, are not designed to drive clinical decisions, but rather to inform where best to allocate limited resources to deliver value and ensure sustainability.

Structured, data-informed planning is increasingly recognised as a priority. Across the UK, initiatives in England, Scotland, and Wales have acknowledged the importance of establishing resilient funding frameworks for PEOLC.[9] The Republic of Ireland has adopted a fully state-funded model, which represents one example of an alternative approach.[10] These policy developments reflect ongoing efforts to support care models that are coordinated across settings and responsive to the needs and preferences of individuals nearing the end of life.

2. Expenditure in the Last Year of Life

2.1 Overall Spending Patterns

Marie Curie recently produced a policy briefing (February 2025) exploring public expenditure in the last year of life in the UK.[11] They estimated that in 2022 there was at least £22 billion in public expenditure for people in the last year of life in the UK. This amounts to £33,960 of public expenditure per person. Over half of this expenditure was on healthcare (almost £12 billion), 22 per cent on social care (almost £5 billion) and 25 per cent on social security (£5.5 billion).

In Northern Ireland in 2022, public expenditure on individuals aged 18 and over in their final year of life totalled approximately £688 million. This equated to £40,410 per person. The breakdown of this spending was as follows (Table 1):

- Healthcare: £349 million (51 per cent), or £20,490 per person
- Social care: £199 million (29 per cent), or £11,700 per person
- Social security: £140 million (20 per cent), or £8,210 per person

When compared with other UK nations, Northern Ireland recorded the highest combined public expenditure per person in the final year of life. This has been attributed in part to higher levels of investment in social care. For instance, social care expenditure per person in Northern Ireland was 60 per cent higher than in England and more than 1.5 times higher than in Scotland or Wales.

Key Trend: Health and Social Care spending is higher in Northern Ireland

Table 1: Estimated spend on people in their last year of life by sector (UK, 2022)

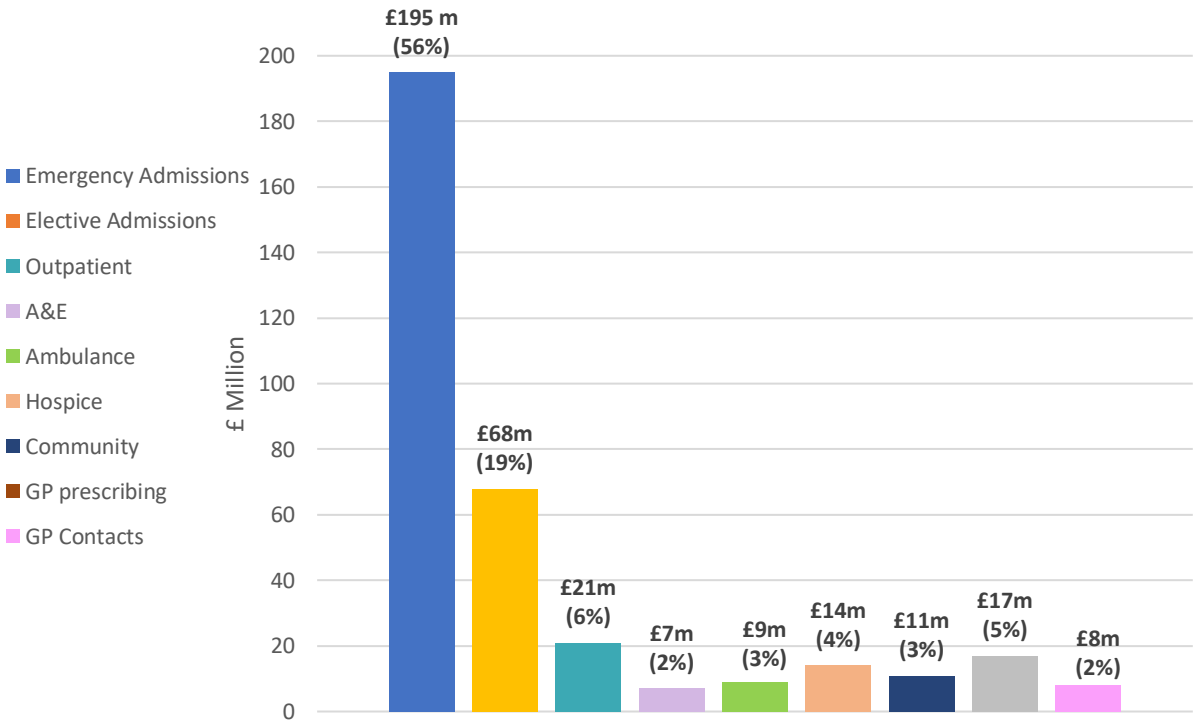
	Health Care		Social Care		Both Sectors	
	Spend/ person (£)	£ millions	Spend/ person (£)	£ millions	Spend/ person (£)	£ millions
England	17,630	9,463	7,290	3,911	24,920	13,374
Scotland	21,170	1,327	7,240	454	28,410	1,781
Wales	17,170	610	8,070	287	25,240	897
Northern Ireland	20,490	349	11,700	199	32,190	548

Most of the health expenditure was allocated to hospital care (83 per cent, £290 million), with emergency and elective inpatient admissions together accounting for 75 per cent (Figure 1). A&E attendances and emergency admissions, accounted for 2 per cent (£7 million) and 56 per cent (£195 million) respectively, so taken together, **over half of all health spending was on urgent hospital care**. In contrast, only 5 per cent of health care expenditure for people in their last year was spent on community care (£11 million) and primary care through a GP (£8 million). Statutory funding of independent hospices accounted for less at approximately 4 per cent (£14 million).

The Marie Curie policy briefing also presented several recommendations for the Northern Ireland Executive. These included the development of a long-term, sustainable regional funding model for the independent hospice sector; the creation of a new PEOLC strategy to provide up-to-date strategic direction and support, particularly in relation to workforce planning and delivery accountability; and the introduction of a dedicated palliative care strategic policy lead within the Department of Health.

Key Trend: High levels of hospital expenditure in last year of life in Northern Ireland

Figure 1: Estimated expenditure on healthcare for people in the last year of life, Northern Ireland 2022[12]



3. Funding Comparisons: UK Countries

Spending on hospital care in Northern Ireland is comparatively high, despite policy aspirations to shift care delivery to the community. Table 2 provides estimated spend on health and social care in the last year of life by UK Region in 2022.[13] While Scotland has the highest healthcare spend per person (£21,170), Northern Ireland's figure of £20,490 is higher than England (£17,630) and Wales (£17,170). Within Northern Ireland, spending on unplanned hospital care accounts for a major share of healthcare costs, totalling approximately £11,840 per person in the last year of life.

Hospice care, by contrast, receives a smaller portion of funding. Inpatient hospice care in Northern Ireland is supported at an estimated £370 per person, with an additional £440 per person spent on community and outpatient hospice services. These funding patterns reflect current allocations across care settings, which may be associated with differences in patient experience and system resource use.

Key Trend: High public expenditure in last year of life

Table 2: Estimated Spend on Health and Social Care in the last year of life, by setting and UK Region (UK, 2022)

		Spend per adult who died (£m UK)			
Setting	**Subtype**	**England**	**Scotland**	**Wales**	**Northern Ireland**
GP practice	Contacts	440	440	440	440
	Prescribing	780	950	920	1020
	Subtotal	1,220	1,390	1,360	1,460
Community	**Subtotal**	800	470	640	640
Hospice care	Inpatient	340	320	160	370
	Community and outpatient	310	300	150	440
	Subtotal	650	620	310	810
Unplanned care out of hospital	Ambulance	680	620	350	550
	NHS 24	45	60	30	-
	Subtotal	720	680	370	550
Unplanned care in hospital	ED visits	500	330	340	390
	Emergency admissions	9,360	12,220	9,260	11,450

	Subtotal	9,860	12,550	9,600	11,840
Planned care in hospital	Elective admissions	3,340	4,400	3,730	3,970
	Outpatient appointments	1,030	1,060	1,160	1,230
	Subtotal	4,370	5,460	4,900	5,200
Hospital care (planned and unplanned)	**Subtotal**	**14,230**	**18,010**	**14,500**	**17,040**
Health care	**Subtotal**	17,630	21,170	17,170	20,490
Social care	**Subtotal**	7,290	7,240	8,070	11,700
Social security	**Subtotal**	8,550	8,180	8,430	8,210
Spend per adult who died (£) Health & Social care	**Subtotal**	**24,910**	**28,410**	**25,250**	**32,200**
Total spend (£millions)	Health	9,463	1,327	610	349
	Social care	3,911	454	287	199
	Social security	4,588	512	300	140
	Subtotal	17,962	2,293	1,197	688

Slight differences in values between Table 1 and Table 2 are due to rounding.

The setting in which palliative care is provided influences its cost-effectiveness. It should be noted that the design and delivery of services is based on patient need and not assessment of cost-effectiveness. Nevertheless, information on the economic value of services may be relevant to commissioners and other stakeholders in the context of resource planning and efficiency considerations. Community-based palliative care services have been linked to reduced hospital admissions and lower healthcare costs.[14] A study examining the Marie Curie Nursing Service (MCNS) in the UK found that patients receiving community-based palliative care incurred 30 per cent lower costs in their last year of life compared to those without such support. This reduction was attributed to decreased reliance on acute hospital services.[15]

4. Hospice Reach, Value and Capacity

Northern Ireland's hospice sector forms a key component of the wider PEOLC system. The reach of hospice services in Northern Ireland is comparatively high, with hospices supporting approximately 11,000 people in 2022 - representing 64 per cent of all deaths in Northern Ireland (17,159 deaths).[16] This level of access exceeds that reported in some other parts of the UK.

Hospice services are currently operating within a context of financial pressure. There are four independent hospices in Northern Ireland providing a total of 70 inpatient beds (64 for adults and six for children), along with an additional 21 HSC Trust-managed palliative care beds. The total cost of delivering hospice services in Northern Ireland is £28.9 million annually, with statutory funding covering just £11.6 million. This results in a funding gap of £17.3 million each year.[17]

In 2023-24, 16 per cent of hospices' total service activity in Northern Ireland was delivered in an inpatient unit and 73 per cent of hospices' total activity was delivered directly to patients at their residences. This included 59,000 visits by palliative care nurses and doctors, and 29,000 visits by generalist healthcare staff to hospice patients at home. Additionally, there were 14,000 outpatient appointments, 19,000 days and nights of inpatient care and 7,200 appointments provided to patients' families, friends and carers.[18]

Economic evaluations have indicated that hospice care delivers value for money. For example, Marie Curie's economic analysis found that community-based hospice services offer a higher ROI than inpatient services, although both are necessary to meet diverse patient needs. The absence of individualised economic evaluations for each hospice in Northern Ireland may present challenges for generating consistent evidence to inform funding decisions.

4.2 Understanding ROI in PEOLC

In health and social care, ROI is a tool used to support decisions about where to allocate limited resources to achieve the greatest overall benefit. It is commonly used in areas such as drug approval and medical device assessment through frameworks like the National Institute for Health and Care Excellence (NICE) Health Technology Assessment (HTA). In recent years, similar methods have been applied to evaluate service-based interventions, including PEOLC.

ROI analyses in PEOLC aim to estimate the value generated by services relative to their cost. This value can include a wide range of outcomes, such as reduced pressure on acute hospital services, improved patient and family experience, or greater efficiency within the healthcare system. However, it is important to note that ROI findings do not equate to direct cash savings. For example, a projected return of £50 million does not mean £50 million will be available for spending elsewhere. Instead, ROI indicates where investment may lead to better use of existing resources and broader system-wide improvements.

For hospice and specialist palliative care services, the benefits identified in ROI studies often include:

- Reducing hospital admissions and freeing up bed space for other patients;
- Supporting earlier discharges and improved care coordination;
- Enhancing workforce retention by reducing burnout and improving staff wellbeing;
- Contributing to better patient outcomes and increased satisfaction with care.

This approach does not determine how services should be delivered, nor does it replace clinical judgement or patient need as the basis for care provision. Rather, ROI is one of several decision-support tools used to ensure that investment is

aligned with the principles of value for money, system sustainability, and high-quality patient care.

In the following section, evidence from Marie Curie will be presented to illustrate how ROI analysis has been applied to PEOLC services, and what implications this might have for future planning and investment decisions in Northern Ireland. All ROI estimates should be interpreted in context, as they rely on assumptions and may not fully capture qualitative outcomes or broader system impacts.

4.1 Economic Evaluation of Marie Curie Services in Northern Ireland

The total ROI, including estimated benefits to productivity and quality of life, in relation to total running costs estimated for Marie Curie services delivered in Northern Ireland, taken together is 564 per cent (Table 3).[19] This is higher than the corresponding UK-wide figure of 372 per cent.[20] Productivity refers to the amount of work time lost by patients or carers as a result of the patients' condition or death, and health-related quality of life (HRQOL) relates to the impact a medical condition and/or treatment has on a person's functioning and well-being. An ROI of 564 per cent means you earn £5.64 in profit for every £1 invested, resulting in a total return of £6.64 (your original £1 plus £5.64 profit). An ROI of -20 per cent means that the investment has lost 20 per cent of its original value. In other words, for every £1 invested, you incur a loss of £0.20, leaving you with £0.80 in total.

When focusing on statutory funding only, the total for all services is estimated to be higher at 978 per cent (Table 3). This comparison illustrates the contribution made by charitable income toward the delivery of Marie Curie services in Northern Ireland

Considering health and social care costs alone, excluding the estimated benefits to quality of life and productivity, ROI is calculated at 103 per cent. This figure varies depending on what is assumed to be the alternative statutory provision to a given

Marie Curie service. For example, if the number of hospital admissions, ICU admissions, or ED visits avoided increases, the ROI increases accordingly.

The analysis was undertaken separately for three main nursing service models in Northern Ireland (planned variable; multi visit; and rapid response) The ROI for nursing services was 213 per cent. Including the impact on social care services increased this to 285 per cent.

The analysis also assessed three hospice service models in Northern Ireland (inpatient unit planned; inpatient unit unplanned; and hospice day case). The ROI estimates for hospice services differed from those for nursing services. The ROI for hospice services was -65 per cent when considering healthcare resource use only, and -58 per cent when including health and social care resources. This result reflects, in part, the higher capital and fixed costs associated with providing inpatient hospice care. When including estimated gains in productivity and quality of life, the ROI for statutory funding only increased to 33 per cent.

Key Trend: Marie Curie palliative care services demonstrate value.

Table 3: ROI for Marie Curie services for health and social care and for all outcomes (Northern Ireland, 2019/20)

Service	ROI (healthcare resource use)	ROI (health & social care resource use)	ROI (all outcomes)	
	Statutory funding only	Statutory funding only	Statutory funding only	Total costs
Nursing MVS	202%	271%	1960%	1327%
Nursing PVS	83%	124%	1184%	682%
Nursing RRS	438%	567%	3474%	2126%
Nursing Total	**213%**	**285%**	**2020%**	**1225%**
Hospice IPU planned	-68%	-62%	32%	-19%
Hospice IPU unplanned	-68%	-61%	32%	-18%
Hospice Day Case	-15%	-15%	54%	-5%
Hospice Total	**-65%**	**-58%**	**33%**	**-18%**
Volunteer Services				848%
Totals	**66%**	**103%**	**978%**	**564%**

The report calculates the total costs of delivering Marie Curie's services in 2019/20 to be just under £9 million per year, while generating an estimated benefit value of around £59 million per year. This results in an 'incremental value' - or net benefit - of just over £50 million (Table 4).

Key Trend: Marie Curie services demonstrate £50 million in incremental value.

Table 4: Costs, value of outcomes and bet benefit of Marie Curie services (Northern Ireland, 2019/20)

Service	Costs	Value of outcomes	Incremental value
Nursing services	£4,129,876	£54,704,204	£50,574,328
Hospice services	£4,721,689	£3,871,816	-£849,874
Totals	**£8,911,711**	**£59,146,360**	**£50,234,649**

Additional considerations:

For Marie Curie's urgent care at home service, if these services had not been available:

84 per cent of patients would have been conveyed by ambulance; and

43 per cent would have phoned the Northern Ireland Ambulance Service[21]

Marie Curie also operates a fast-track service (lasting 7-10 days) that enables immediate discharge for those that are medically fit to leave hospital, bridging the gap until a domiciliary care package is in place.

A positive return on Investment has also been observed for Children's hospice services. Evaluation of children's hospice services across Scotland, conducted by YHEC in 2018/19, revealed a return on investment of 175 per cent. This translates to an equivalent value of £1.75 for every £1 spent on service delivery, when considering health, social care and broader societal outcomes.[22]

5. Current Funding Arrangements

Palliative and end-of-life care (PEOLC) services in Northern Ireland are delivered through a mixed funding model, combining statutory support with charitable income. While this approach reflects the sector's long-standing partnership between public and voluntary sectors, it has been associated with challenges for workforce stability, innovation, and long-term planning. Multi-year funding arrangements have been identified to support provider capacity for effective planning, staff retention, and service development in response to population needs.

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

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

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

5.1 Overview of Hospice Funding - Adult Services

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

Since 2004/05, adult hospice inpatient services have operated under a 50:50 funding arrangement, with the Department of Health and charitable sources each contributing half of the agreed service costs. This model was extended to community-based hospice care in 2005/06. Importantly, these agreements apply to the costs of commissioned services rather than the total running costs of each hospice, leaving hospices to bridge the gap through fundraising and other sources. Currently, four local hospices benefit from this framework, but the reliance on multiple funding streams, including Health and Social Care Trusts and the voluntary sector, can result in a complex and sometimes fragmented commissioning landscape. Annual Funding from 2019-2024 is presented in Table 5 below.

Table 5. Annual Departmental Funding for Adult Hospice Services in Northern Ireland, 2019–2025

Year	Funding (millions)	Notes
2019/20	£7.502	*Includes £867k recurrent funding from a previous review.*
2020/21	£7.916	
2021/22	£9.300	
2022/23	£9.142	*Includes non-recurrent funding for financial and inflationary pressures.*
2023/24	£9.334	*Includes non-recurrent funding for financial and inflationary pressures.*
2024/25	£9.388	*Includes non-recurrent funding for financial and inflationary pressures.*

In addition to core allocations, hospices received £16 million in 2020/21 to mitigate the impacts of COVID-19, as well as non-recurrent support for advanced communication skills training, staff recognition payments, and National Living Wage uplifts. These payments helped manage financial challenges associated with the pandemic and rising costs.[23]

SPPG maintains engagement with all four hospices through annual contract monitoring meetings and ongoing dialogue. In recent years, this has included targeted contract uplifts. For example, in 2022/23, £0.324 million in non-recurrent funding supplemented the £8.818 million core allocation; in 2023/24, a 4.9% contract uplift and an additional 0.8 per cent (£74,000) addressed inflationary pressures. For 2024/25, a further £72,000 supported the National Living Wage increase, with an interim 1.38 per cent uplift applied to contracts.

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

Two earlier reviews assessed hospice funding arrangements. The 2014 Health and Social Care Board (HSCB) review benchmarked hospice funding against 50 per cent of the average General Medical bed cost in Northern Ireland, finding most hospices adequately funded but recommending additional support for one provider. The 2019/20 HSCB review compared hospice funding with similar Health and Social Care services and, following professional advice, identified an £867,000 shortfall, which was later addressed and backdated.

While the 50:50 model has provided a basis for hospice funding, variation in service provision and access has been observed across Northern Ireland’s HSC Trusts. The

mixed model - relying on statutory, local government, and charitable contributions - can contribute to differences in service availability and integration. The absence of multi-year budgets may constrain investment in workforce development and service improvement, while limitations in data infrastructure may affect efforts to standardise quality.

Targeted initiatives have supported palliative care service development. Limited Cancer Strategy funding has enabled region-wide syringe pump guidance and training, clinician access to the Palliative Care Formulary, support for Keyworker role development, expanded out-of-hours advice, and scoping for a seven-day nursing service. These activities reflect ongoing collaboration between statutory bodies and hospices.

Looking ahead, stakeholders have identified the need for a comprehensive review of PEOLC funding.[24] With demand for community-based end-of-life care projected to rise by 30 per cent by 2040,[25] attention to funding sustainability, integration, data systems, and public understanding of palliative care has been highlighted in the regional PEOLC work plan (2023–26).

Northern Ireland's adult hospices benefit from a longstanding statutory funding framework and regular engagement with commissioners. Nonetheless, challenges remain requiring continued collaboration across statutory and voluntary sectors.

5.2 Overview of Hospice Funding – Children's Services

The Northern Ireland Children's Hospice (NICH) is currently the only provider of specialist palliative, respite, and end-of-life care for children aged 0–19 with life-limiting or life-threatening conditions. Each year, it supports approximately 2,300 children, nearly half of whom are under one year old, reflecting the complexity of paediatric palliative care needs. Services are delivered through Horizon House (inpatient care), 24/7 community teams, Hospice-at-Home nursing, and family

support. NICH collaborates with HSC Trusts to coordinate care across hospital and community settings. However, funding constraints have affected the service's ability to respond to increasing demand.

5.2.1 Funding Framework: Gaps and Pressures

Service-Level Agreements (SLAs)

The Department of Health funds NICH through SLAs, covering only part of operational costs (Table 6):

Table 6: Service provision for 2024/25

Service	Department Funding
Bed Nights (Horizon House)	~30% of costs
Hospice at Home	50% of costs
Family/Bereavement Support	41% of costs
Community Support Teams	43% of costs

Despite incremental increases, statutory funding has not kept pace with inflation and staffing costs. In 2023/24, the Department allocated £1.857 million, including £150,000 for inflation adjustments and £170,000 to retain a bed after the closure of Horizon West in Fermanagh. In response to rising operational costs, including energy and wage increases, NICH reduced bed capacity from seven beds, seven nights per week to six beds on weekdays and three on weekends. This reduction may affect regional access and availability of respite care.

5.2.2 Recent Funding Trends and Non-Recurrent Support

Annual departmental allocations are outlined in Table 7. These figures include inflationary adjustments and non-recurrent uplifts but exclude contributions from HSC Trusts and other sources.

Table 7: Annual Departmental Allocations (2021-2025)

Financial Year	Total Funding	Key Allocations
2021/22	£1.326m	Includes £68,897 for staffing
2022/23	£1.830m	Includes £64,756 for non-pay inflation
2023/24	£1.857m	includes £14,738 for non-pay inflationary pressures £170k bed retention; £150k inflation support
2024/25	£1.685m	Inflationary uplifts for non-pay costs

Excludes HSC Trust contributions and non-recurrent streams.

Horizon West Bed Funding

Following the 2017 closure of Horizon West - a facility serving families in Fermanagh - the Department allocated £170,000 annually to support a dedicated bed at Horizon House for families traveling long distances. Initially a three-year commitment, this funding was extended to March 2024 due to COVID-19-related service disruptions.

COVID-19 and Staff Recognition Support

- **Pandemic Relief**: In 2020/21, NICH received £8.23 million in non-recurrent funding to mitigate fundraising losses.
- **Staff Payments**: Recognition payments were issued in 2021/22 and 2022/23 to support workforce retention.

5.2.3 Service Impacts and Escalating Costs

Media reports state that NICH requires over £20 million annually to maintain its full range of services, while recurrent statutory funding remains significantly lower. The 2023/24 allocation of £1.857 million - an increase of £27,000 from the previous year - has coincided with a 12 per cent rise in energy costs and a 10 per cent increase in staffing-related expenditure. These cost pressures have resulted in reduced bed

capacity, which in turn can affect access to respite care and require families to travel longer distances during periods of high clinical need.

2024/25 Priorities and Service Delivery

The £1.685 million allocated for 2024/25 will contribute to the continuation of four key services:

1. **Bed Nights**: Short-break inpatient care at Horizon House.
2. **Specialist Community Team**: 24/7 crisis support for families.
3. **Palliative and Life-Limited Service (PALLS)**: Coordinating transitions between home, hospice, and hospital.
4. **Hospice at Home**: Personalised nursing care provided in the home environment.

6. Funding Pressures and Threats to Sustainability

Palliative and end-of-life care (PEOLC) services in Northern Ireland face a range of financial and structural pressures that may affect their long-term sustainability. These pressures stem from rising demand, cost escalation, and persistent limitations in the current funding and commissioning framework. This section outlines the most pressing challenges, drawing on available data and research evidence.

6.1 Rising Demand and Increasing Complexity of Care

Demographic changes are projected to place increasing pressure on PEOLC services. Between 2023 and 2048, demand for such care in Northern Ireland is expected to rise by 32 per cent, with approximately 20,433 individuals projected to require PEOLC annually, up from 15,443. This increase is driven primarily by an ageing population and a rising prevalence of chronic and progressive conditions such as dementia, heart failure, and motor neurone disease. Current funding models are not structured to reflect this projected increase in volume or complexity, raising questions about future service capacity and responsiveness.

6.2 Cost Inflation and Workforce Pressures

Financial pressures on the sector have been compounded by significant cost inflation. In 2023/24, UK hospices collectively reported an estimated sector deficit of £77 million. Payroll costs alone increased by 11 per cent, equivalent to an additional £130 million in expenditure, according to Hospice UK's financial benchmarking data. Rising energy costs, salary inflation, and general cost-of-living increases have added to the financial burden.

Workforce challenges add further pressures. Hospices compete with the Health Service for clinical staff and aim to offer equivalent pay under the Agenda for Change framework. However, achieving parity is increasingly difficult due to funding constraints. Upcoming changes in Employers National Insurance Contributions

(NICs), including a rise from 13.8 per cent to 15 per cent for employers and a lower salary threshold for liability, are expected to further impact staffing costs.

In England, the hospice sector anticipates an additional £30 million in annual costs from this change. In Northern Ireland, Marie Curie estimates that the impact of Employers NIC increases will be almost £300,000 (for clinical staff £237,253 and non-clinical staff £59,544). This figure is equivalent to 65 per cent of one Trust's budget with Marie Curie.[1]

6.3 Inflexible and Fragmented Funding Structures

The predominant funding model for PEOLC in Northern Ireland is mixed, comprising statutory contributions (covering 34–50 per cent of hospice costs) and charitable income. While this model provides multiple income streams, it introduces complexity. These include financial instability due to reliance on voluntary donations, particularly vulnerable to economic downturns and inflation, as well as administrative complexity in managing multiple funding sources. These factors can limit strategic planning and service development.

Short-term budgets and non-recurrent funding uplifts are common, with limited use of multi-year allocations. This structure can constrain providers' ability to invest in workforce development, infrastructure, or service innovation. It may also reduce flexibility in planning for future demand.

6.4 Funding Not Aligned with Population or Patient-Level Need

Current funding mechanisms are rarely linked to either local population needs or patient complexity. Many services operate under non-activity-based models (e.g., block contracts), which do not reflect care volume or intensity. This may result in

[1] Personal Communication with Mark Gill (Business Manager, Marie Curie)

variation in service provision and a misalignment between funding and need. While activity- or case-mix-based models have been discussed as potential alternatives, these would require enhanced data systems for implementation.

6.5 Fragmented Commissioning and Lack of Minimum Service Specifications

PEOLC services in Northern Ireland are commissioned through multiple channels, including Health and Social Care Trusts, the Department of Health, and charitable organisations, without a unified framework. This fragmentation may affect coordination and accountability and can complicate strategic service planning. For example, a regional overview of community specialist palliative nursing activity is currently unavailable, limiting performance tracking and resource optimisation. It should be noted that a scoping exercise is currently being conducted by the Department of Health.

There is also no defined minimum service specification linked to PEOLC funding, contributing to variation in access and delivery across regions. The absence of service benchmarks makes it more difficult to assess whether funding is aligned with intended outcomes or distributed consistently.

6.6 Data and Evidence Gaps

Robust data systems support evaluation, planning, and resource allocation. However, PEOLC data infrastructure in Northern Ireland remains limited. Gaps in regional and patient-level data availability affect the ability to track outcomes, assess equity, and apply evidence in commissioning. This may contribute to both under- and over-provision in some areas.

Marie Curie has suggested standardising data collection for PEOLC services and associated outcomes, supporting data analysis capacity, investing in infrastructure,

harmonising data across the UK, enhancing workforce skills in data use, and providing guidance for linking data to service planning.[26]

6.7 Impact of External Economic Conditions

Macroeconomic pressures – including aforementioned inflation and the broader cost-of-living context - have influenced both operational costs and the ability of hospices to raise charitable income. Increases in costs for materials and services have made fundraising activities more expensive, while reduced public disposable income has affected donation levels. These factors may reduce the financial resilience of voluntary sector contributions to PEOLC.

6.8 Legacy of the COVID-19 Pandemic

The COVID-19 pandemic underscored the vulnerabilities of the charitable funding model. Emergency government funding was required to maintain service continuity, including £8.23 million in additional support allocated to Northern Ireland's hospices. [27] While this response provided short-term relief, it also highlighted the lack of resilience in existing funding arrangements and the need for more predictable, needs-based financial planning.

7. Approaches to Support a More Sustainable Funding Model

Following the identification of key threats to the sustainability of PEOLC services in Northern Ireland, this section outlines a range of alternative approaches that have been adopted or explored in neighbouring jurisdictions. These approaches vary in their structure, funding mechanisms, and degrees of integration into national health systems. While no single model offers a universal solution, each highlights elements that may contribute to a more sustainable, transparent, and resilient PEOLC funding system. Common themes emerge include aligning funding with need, clarifying commissioning responsibilities, specifying core services, and strengthening data collection and impact measurement.

7.1 A State-Funded Model: The Republic of Ireland

In January 2024, the Republic of Ireland implemented a change to hospice funding, with four voluntary hospice providers redesignated from Section 39 to Section 38 agreements under the Health Service Executive (HSE).[28] This change introduced 100 per cent statutory funding and designated hospice staff as public employees. The estimated annual cost of extending this model to both adult and children's hospices is approximately €18.6 million.[29]

The policy seeks to promote service equity by removing the reliance on charitable fundraising, reducing administrative burdens on providers, and supporting a more integrated public health model. It also provides greater workforce planning certainty, potentially contributing to staff retention and alignment with broader health system objectives. This approach requires central coordination to sustain funding levels and manage service delivery across multiple care settings.

7.2 Statutory Commissioning Duties: England's Experience

In England, the Health and Care Act 2022 introduced a statutory duty for Integrated Care Boards (ICBs) to commission palliative and end-of-life care.[30] The intention was

to standardise service provision and address regional disparities. However, early evidence indicates variable implementation. A 2023 Freedom of Information request by Hospice UK showed per capita hospice funding across ICBs ranged from £10.33 to £0.23.[31] Similarly, a study by Together for Short Lives found children's hospice funding varied from £511 to £28 per eligible child.[32]

In addition to funding variation, differences were noted in the types of services commissioned. Respondents to a UK All-Party Parliamentary Group (APPG) inquiry cited limited specificity in statutory guidance, enabling divergent interpretations.[33] Financial constraints, workforce pressures, and unclear accountability arrangements have also been reported as implementation challenges.

The King's Fund has noted the need to strengthen commissioning capacity and capability, including the use of data, outcome measurement, and partnership collaboration.[34] The English experience suggests that statutory duties may require accompanying measures - such as clearer service specifications, improved oversight, and longer-term contracting - to support consistent delivery.

7.3 Activity-Based and Case-Mix Funding: The Currency Model

Some systems use activity-based or case-mix-adjusted models (such as the "currency model") to allocate funding based on care complexity and intensity. These models aim to reflect patient-level needs more accurately than block grants or historical allocations and account for factors like multidisciplinary care, nursing time, and travel.

Potential benefits include enhanced transparency and closer alignment between funding and service delivery. However, effective implementation depends on data quality, documentation standards, and digital infrastructure. Predictors of care complexity are also needed to avoid under-funding.

In the absence of minimum service specifications or detailed costings, these models can be difficult to operationalise. Nonetheless, case-mix adjustment is considered to have potential, especially when combined with outcome-based contract monitoring.

7.4 Outcome-Linked Financing: Social Impact Bonds

Some jurisdictions have piloted outcome-based funding models such as social impact bonds (SIBs), where investment returns are linked to achievement of service outcomes. These models may support innovation and shared accountability.

However, they can be complex to administer and may be less suited to areas where outcomes are difficult to quantify, including end-of-life care. Administrative costs and concerns about potential diversion from core delivery have also been reported. Outcome-linked contracts may be more appropriate when used selectively to support specific service transformation efforts within broader frameworks.

7.5 Emerging Models and Principles from Wales

Wales has taken a structured approach to planning and funding specialist palliative care services. Guidance recommends population-based needs assessment, clear service specifications, and comparative costing of care settings (e.g., hospice, hospital, home) to inform commissioning.

Other key elements include service mapping, electronic integration, cross-sector collaboration, multi-year funding models, and outcome monitoring. While data infrastructure challenges remain, this model demonstrates how planning frameworks and defined service expectations can support more consistent delivery.

7.6 Considerations for Future Development of a Sustainable PEOLC Model

Developing a more sustainable and equitable PEOLC model in Northern Ireland may involve a combination of structural, financial, and operational approaches. While no single model applies universally, UK and international examples suggest that targeted system improvements can support longer-term stability.

Recurring features of more sustainable models include:

- **Population-based needs assessment** to support resource planning and service development.
- **Clear commissioning responsibilities** across sectors to improve coordination and reduce fragmentation.
- **Defined service specifications and minimum standards** to promote consistency and performance evaluation.
- **Multi-year funding arrangements** to enhance financial predictability, support workforce planning, and enable innovation.
- **Transparent costing methodologies** to account for diverse care inputs and workforce patterns.
- **Investment in digital infrastructure** to improve data collection, outcome monitoring, and commissioning efficiency.
- **Workforce development and planning**, including recruitment, parity in pay, and training for generalist and specialist roles.
- **Public engagement** to increase awareness and facilitate access to PEOLC services.

Addressing system inefficiencies, such as duplication across IT systems and fragmented rota, may support indirect savings. Broader impacts of instability in

PEOLC services, including pressures on acute care, transport, and unpaid carers, also merit consideration in strategic planning.

While the preferred model will depend on Northern Ireland's specific context, examples from other jurisdictions suggest that coordinated, transparent, and needs-based frameworks are feasible.

7.7 Vision Underpinned by Robust Research

A robust evidence base has been widely regarded as important for shaping effective palliative and end-of-life care strategies, as highlighted by Dierberger and colleagues in their national study of healthcare use and costs at the end of life.[35] In Scotland, for example, policy frameworks have explicitly referenced research-driven approaches to understand unmet need, variations in access, and patient outcomes. These approaches draw on systematic literature reviews and analyses of hospital resource use and mortality trends.[36] Designing patient-focused services requires not only a detailed understanding of how and where people currently receive care - including the type, intensity, and variability of services - but also insight into patient and family preferences. This comprehensive approach can be supported by data on demand, service costs, and the value delivered, whether measured through cost-effectiveness or ROI.

Similar research-informed strategies are evident in other UK nations and in Ireland. Wales has established a national implementation group and funding formula informed by evidence, intended to support equitable access and resource allocation. England routinely publishes statistics on patterns of care at the end of life.[37,38] In both Northern Ireland and the Republic of Ireland, cross-border investments have supported the development of research networks designed to strengthen the evidence base and inform policy. However, evidence gaps have been identified, including in areas such as out-of-hours care and patient-reported perspectives.[39,40]

Despite these developments, methodological challenges remain. Economic evaluations in palliative care are often complex due to the multifaceted nature of

interventions, diverse patient populations, and the relatively low cost of some essential services, which may result in their exclusion from traditional cost-effectiveness frameworks.[41] In addition, qualitative research, capturing the lived experiences, preferences, and values of patients and families, can provide important contextual understanding that complements quantitative findings and supports a broader perspective on what constitutes value and quality in end-of-life care.[42]

While research in this field is methodologically complex, it plays a key role in supporting service design and investment decisions. High-quality studies, both quantitative and qualitative, may help ensure that resources are directed effectively, that services are aligned with patient preferences, and that health systems are able to respond to evolving needs in a sustainable and equitable manner.

8. Conclusion

Palliative and end-of-life care services in Northern Ireland operate within a context of increasing demand, financial uncertainty, and structural complexity. Demographic trends, including population ageing and the rising prevalence of complex conditions, are projected to place additional pressure on services. Current funding and commissioning arrangements may affect the capacity for long-term planning, coordination, and equitable delivery.

Discussions among policymakers, commissioners, and providers could examine how future models of PEOLC might more effectively reflect population needs, support financial and service sustainability, and facilitate integration across care settings. Approaches incorporating needs-based planning, multi-year funding mechanisms, transparent commissioning structures, and strengthened data infrastructure have been applied in other jurisdictions to support the development of more stable funding systems. In Northern Ireland, a strategic direction, developed collaboratively by policymakers, commissioners, providers, and the voluntary sector, may support efforts to deliver coordinated, person-centred, and high-quality care at the end of life.

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