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Current Provision of Palliative and End of Life Care Services in Northern Ireland

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This briefing is the second of a series of papers on palliative and end of life care in Northern Ireland. It provides information on the current provisions, quality and experience of care and public perceptions and barriers.

Contents

List of Abbreviations

ACP	Advanced Care Planning
AHP	Allied Health Professional
BAS	Business as Usual
COPD	Chronic Obstructive Pulmonary Disease
GPC	Generalist Palliative Care
HSC	Health & Social Care
ICB	Integrated Care Boards
LLC	Life Limiting Condition
LMDM	Living Matters Dying Matters
NG	NICE Guidance
NICE	National Institute for Health and Care Excellence
PCLB	Palliative Care Locality Boards
PCiP	Palliative Care in Partnership
PEOLC	Palliative and End of Life Care
PfG	Programme for Government
PHA	Public Health Authority
PPCN	Paediatric Palliative Care Network
QI	Quality Improvement
QS	Quality Standard
RPPCN	Regional Paediatric Palliative Care Network
RQIA	Regulation and Quality Improvement Authority
SPC	Specialist Palliative Care
SPPG	Strategic Planning and Performance Group
TYPEOLC	Transforming Your Palliative and End of Life Care
WHO	World Health Organization
UK	United Kingdom

Key Points

- Northern Ireland's palliative and end of life care (PEOLC) services demonstrate both strengths and areas for development. The existing delivery model provides a foundation for comprehensive care, but challenges remain in achieving full integration across care settings and consistent service availability, particularly outside regular business hours. Strategic initiatives have established important frameworks, but implementation remains incomplete in several core elements of comprehensive palliative care.

- Quality assessment faces significant challenges due to fragmented data infrastructure and limited standardisation in measurement approaches. Evidence strongly suggests that investment in comprehensive data collection and analysis would support quality improvement efforts and enhance service delivery and equity.

- Research into public perceptions reveals significant knowledge gaps and misconceptions about palliative care in Northern Ireland, creating barriers to timely access and appropriate use. Initiatives like the Heart of Living and Dying program show promise for addressing these barriers, but a more comprehensive and coordinated approach to public education and engagement would further enhance understanding and appropriate and timely use of palliative care services.

- Moving forward, priorities for Northern Ireland include strengthening integration between hospital and community palliative care services, developing more comprehensive data collection systems aligned with international standards, expanding 24/7 specialist palliative care availability, and implementing coordinated public awareness initiatives. These goals align with the current regional palliative care work plan (2023-26) being taken forward by the Palliative Care in Partnership (PCiP) programme.

- The experiences of exemplary systems, particularly those in comparably-sized regions, offer valuable insight for adaptation to Northern Ireland's specific context. With continued investment and strategic development, Northern Ireland has the potential to build upon existing strengths to develop a comprehensive, high-quality PEOLC services accessible to all who need them.

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: Global Perspectives: How Other Countries Fund and Deliver Palliative Care

Paper 4: Equity, Access, Coordination and Integration of Palliative and End of Life Care

Paper 5: Future planning and need for palliative and end of life care services

1. Current Provision of PEOLC Services

Mapping the provision of PEOLC in Northern Ireland is challenging due to limitations in available data and the complexities of existing reporting systems. While efforts are made to collect and report on various aspects of healthcare, there are inherent difficulties in capturing a full picture of PEOLC pathways in Northern Ireland. Some relevant data does not appear to be routinely recorded or readily accessible, making it difficult to assess the extent and effectiveness of service provision. Detailed information was requested from the Department of Health on 7th August 2024. Some, but not all of this information was received on 3rd December, 2024.

This situation reflects broader challenges in health data collection, where systems have developed over time to meet different needs but may not always provide a seamless or comprehensive overview. Addressing these data gaps could support a clearer understanding of PEOLC services and patient experiences, helping to inform future planning and delivery in this important area.

1.1 Delivery of Palliative Care Services for Adults

1.1.1 Generalist Palliative Care Services

The Living Matters, Dying Matters (2010-2015) strategy distinguished between generalist and specialist palliative care. Generalist palliative care is the primary level of care delivered by multi-disciplinary teams in various settings, including primary and community care, hospitals, and care homes (Table 1). It is provided by core healthcare professionals such as GPs, district nurses, Allied Health Professionals (AHPs), social workers, and community pharmacy staff.

This care focuses on individuals living with long-term conditions and those in the last year of life. Many of these individuals receive support at home or in care homes. This type of care is not specifically commissioned but is a fundamental component of holistic health and social care delivery.

Table 1: Generalist Palliative Care Services

Palliative Care Key Worker

A Palliative Care Key Worker is allocated when a person is identified as being in the last year of life. Typically, the district nurse serves this role due to their ability to provide care at home and their availability during out-of-hours periods.

The key worker:

- Identifies individuals nearing the end of life
- Acts as the main contact for coordinating care
- Provides care during the final weeks and days of life
- Offers bereavement support to families

District nurses operate seven days a week, with two HSC Trusts offering 24/7 services. Their established communication pathways with GPs and other healthcare professionals make them ideal for this role.

Other Generalist Palliative Care Support Services

For patients needing more than basic generalist care, additional support is available:

- **Marie Curie** offers a range of community nursing services alongside district nursing.
- All HSC Trusts have arrangements in place with Marie Curie to provide Hospice at Home and out of hours Rapid Response Services. Services vary across HSC Trusts with regard to operational arrangements, existing core services, hours and monetary value.
- **Hospice at Home Services**: Independent hospices offer similar services in some localities, although these are typically outside formal commissioning arrangements.

The Department of Health funds a limited Hospice at Home service through the Northern Ireland Hospice, but this is under review as part of a broader evaluation of Day Hospice services.

1.1.2 Specialist Palliative Care Services

A significant proportion of people experience a range of complex problems that cannot always be dealt with effectively by generalist services. Specialist palliative care (SPC) addresses complex symptoms and care needs requiring advanced expertise. Delivered by multi-disciplinary teams, this care includes physical, psychological, social, and spiritual support for patients and their families. SPC services are delivered in four main ways in Northern Ireland (Table 2).

Table 2: Specialist Palliative Care service in Northern Ireland

Inpatient Hospice and Specialist Palliative Care Units

The Department of Health's Strategic Planning and Performance Group (SPPG) commission inpatient SPC beds in four independent hospices:

- **Northern Ireland Hospice** (18 beds)
- **Marie Curie Hospice** (18 beds)
- **Foyle Hospice** (9 beds)
- **Southern Area Hospice** (12 beds)

These beds are commissioned on a 50/50 funding model introduced by the Department of Health in 2004/5

Two additional HSC Trust-led SPC inpatient units exist:

- The **Macmillan Unit** (12 beds) at Antrim Area Hospital.
- A 10-bed consultant-led SPC ward at **Omagh Hospital and Primary Care Complex** within the Western Trust

Hospital-Based Specialist Palliative Care

All acute hospitals and most community hospitals in Northern Ireland have access to a SPC multi-disciplinary team which might include

- Palliative medicine consultants,
- Speciality doctors,
- SPC nurses,
- SPC AHPs (physiotherapist, occupational therapist, dietician, speech and language therapist),
- Palliative care social workers; and
- Palliative care pharmacists.

The composition and staff numbers of these hospital-based teams varies across HSC Trusts and hospital sites.

Specialist Palliative Care Community Teams

SPC community teams provide care to patients with complex needs in their homes or care homes. All HSC Trusts have SPC multidisciplinary teams which usually include SPC nurses, SPC AHPs, and palliative care social workers. The composition and staff numbers of these teams differ across individual HSC Trusts.

The service is delivered through various contracts:

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

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

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

- **As a result of these multiple contracts and monitoring processes, it is not possible to currently review the activity or performance of community SPC nursing services at a regional population level.**

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

The growth to date in SPC roles has been facilitated mostly by demography funding/ reprofiling of funding within HSC Trusts to meet patient demand and complexity or through significant investment from Macmillan Cancer Care. Macmillan has pump prime funded a significant proportion of the SPC posts with HSC Trusts over the last 10 years. Such arrangements have been progressed by HSC Trusts and accordingly, the **Department does not have oversight of those developments and associated funding arrangements which are in place.**

Day Hospice Services

Existing Department of Health contracts with all four of the commissioned independent hospices have an element of day hospice funding included.

In some instances, day hospice services have been supplemented by funding from other sources, such as Cancer Charities Fund, St. James Place or the Big Lottery, without the knowledge or engagement of the Department.

The Palliative Care Service Team (within PCiP structures) is currently reviewing the current arrangement. The aim is to find a way forward for Day Hospice services given the changes to need and complexity which has been identified.

The review aims to ensure an element of standardisation in approach, tailored to the need of the local population, whilst ensuring value for money and reducing duplication of effort within the system.

1.2 Delivery of Palliative Care Services for Children

Children's palliative care services face unique challenges compared to adult palliative care due to several factors.[1] Firstly, PEOLC services for children are delivered over a longer period, often spanning years, as children with life-limiting conditions typically have a more prolonged disease trajectory.[2] This necessitates continuous and complex care that is more intensive and multidisciplinary in nature.[3] Additionally, issues of consent are more complicated in children's palliative care, as medical decisions are usually made by family caregivers rather than the patients themselves.[4] The transition from children's to adult services presents another layer of complexity, requiring careful planning and coordination to ensure continuity of care. There is also a greater need for integration between health and social care or hospice services to provide holistic support to the child and their family. Finally, the care trajectory for children is less predictable, adding uncertainty and requiring flexible and responsive care plans.[5]

In 2019, a Regional Paediatric Palliative Care Network (RPPCN) was created, and this is chaired by a Paediatric Palliative Clinical Care Lead. The network is made up of key clinical and nursing leads from each HSC Trust as well as the Northern Ireland Children's Hospice. The network works closely together on two main areas:

- Identifying key priorities for delivery in line with the Strategy and putting in place measures to deliver same; and
- The network acts a vehicle for the region to identify areas of best practice and share clinical opinion on specific cases.

To date, the network has developed ante-natal care pathways, rapid discharge plans, advanced care plans (ACPs) and has agreed pathways regarding pain relief. Currently the network is also working on other key issues including:

- The provision of 24/7 end of life care; and
- How best to develop closer ties with colleagues in the Republic of Ireland.

To support the delivery of paediatric palliative care, each HSC Trust has a paediatric Consultant Clinical Lead. These consultants work collaboratively across HSC Trusts to ensure sharing of best practice regionally. In addition, a Regional Paediatric Palliative Care Consultant acts in a leadership role across paediatric palliative care in Northern Ireland.

The RPPCN has identified three key priorities which they are currently working to deliver:

- The amendment and improvement to ante-natal care pathways
- ACPs; and
- Assessment of the current provision on 24/7 end of life care

The Northern Ireland Children's Hospice is the only children's hospice in Northern Ireland. The Department of Health has a Service Level Agreement (SLA) in place with them for the delivery of agreed commissioned services for bed nights and community support services. Relative to the total cost of commissioned services, funding has been in the range of 30 per cent for bed nights and up to 50 per cent for community support services. In 2022/23, the Department provided funding of £1.857m to the Northern Ireland Children's Hospice (more detail on funding is provided in paper three of this series).

1.3 Challenges in Delivering PEOLC in Northern Ireland

Despite end-of-life care being needed by almost everyone, there are currently significant challenges with ensuring that high-quality PEOLC is available to everyone, whether provided by core health and social care services, or for those with more complex care needs requiring specialist support.

The challenges are multifaceted and interconnected. From funding constraints and workforce shortages to geographical inequities and data deficiencies, these issues require a comprehensive and coordinated approach to address them. While progress has been made in many areas by the Palliative Care in Partnership (PCiP) programme, significant work remains to ensure equitable, high-quality PEOLC services for all residents of Northern Ireland.

1.3.1 Funding Constraints and Sustainability

Northern Ireland's PEOLC services face significant funding constraints, with a 50/50 statutory/voluntary funding model leading to variable access and service provision across the HSC Trusts. The reliance on multiple funding streams, including the Department of Health, HSC Trusts, and voluntary sector, creates a complex commissioning landscape.

Information provided to us by the Department of Health acknowledges this complexity. With respect to community SPC teams, *“As a result of these multiple contracts and monitoring processes, it is not possible to currently review the activity or performance of community SPC nursing services at a regional population level”*. Additionally, as most of the growth in SPC roles over the past 10 years within HSC Trusts has been funded by Macmillan Cancer Care, the *“Department does not have oversight of those developments and associated funding arrangements*”.

This complexity is exacerbated by the lack of multi-year budgets, hindering long-term planning and investment in staff development and service improvements. Multiple funding streams pose challenges for transparency, accountability and monitoring. Tracking quality, activity levels, and performance against contracts becomes increasingly difficult when resources are drawn from various sources. This fragmentation also increases the risk of service duplication in some areas while leaving gaps in others, ultimately affecting the consistency and comprehensiveness of PEOLC across Northern Ireland.

This fragmentation of services across healthcare sectors can impact coordination and integration between SPC services and primary, community, acute and ambulance service potentially leading to discontinuities in patient care. This is most problematic during out of hours periods (evenings, weekends, and holidays). The absence of shared electronic patient records between services further exacerbates coordination difficulties. Additionally, issues related to the prescribing, access, and administration of medicines present a unique challenge in palliative care settings, especially beyond normal working hours.[6]

The long-term sustainability of PEOLC services is a major concern.[7,8] While charitable organisations have played a vital role in implementing best practices, the reliance on non-statutory funding raises questions about the long-term viability and equity of service provision. Recent media reports have highlighted the closure of beds in the children's hospice due to funding withdrawals from the Department of Health, underscoring the precarious nature of PEOLC funding in Northern Ireland.[9,10]

1.3.2 Workforce Challenges

Northern Ireland faces staff shortages in health and social care, particularly in SPC. Recruitment and retention of healthcare professionals, including GPs and SPC staff is problematic. This shortage is part of a broader challenge in the Northern Ireland health system, where waiting lists are proportionately much higher and rising compared to the rest of the UK.[11] In 2023, nearly 20 per cent of GP training posts were unfilled, and the vacancy rate reported by the Department of Health for consultant positions was 7.6 per cent, although research by the British Medical Association (BMA) Northern Ireland, placed this figure closer to 20.3 per cent.[12]

The 'palliative key worker' model, primarily implemented through district nursing, aims to provide coordinated care for PEOLC patients. However, district nurses UK wide-have expressed concerns over high workloads and stress levels, which may compromise the effectiveness of this model.[13] Across all UK regions, district nurses report large amounts of unpaid overtime, insufficient time to devote to patients and unmanageable caseloads.[14] The aspiration for 24/7 access to SPC services faces significant challenges given the current workforce constraints. The National Audit of Care at the End of Life (NACEL) 2022 noted that no hospitals in Northern Ireland had a SPC service available 24 hours a day, 7 days a week.

A recent literature review, which included two studies from Northern Ireland, [15] highlighted the challenges faced by GPs when providing palliative care in the UK. Key themes included, lack of resources to comprehensively meet patient needs; inadequate handover processes and communication with secondary care staff and multidisciplinary teams (MDTs); difficulties in communicating with patients and carers; and a lack of sufficient training to handle the complexities of palliative care—especially in cases involving non-malignant conditions.

A comprehensive overview of the SPC workforce in Northern Ireland is essential to ensuring the delivery of an accessible, equitable, and high-quality service. Such an overview would include:

- The current SPC workforce whole time equivalent (WTE) in all care settings
- Where that workforce is providing specialist services 7 days per week
- The provision of, and access to, the wider workforce of specialist advice on a 24/7 basis

The findings from an overview of the SPC workforce in Cheshire and Merseyside are presented below, emphasising the importance of capturing this level of detailed information. The SPC services in Cheshire and Merseyside cater to a population of approximately 2.7 million people, in contrast to around 1.9 million in Northern Ireland.

This process provides a thorough overview of services, enabling the estimation of the whole-time equivalent (WTE) specialist workforce across the region. This can then be compared with recommended workforce levels. Crucially, it facilitates the identification of risks and an evaluation of their potential impact. Figure 1 and Table 3 from the report illustrate the strategic planning approach, with Figure 1 summarising the key findings of the overview and Table 3 detailing the identified risks and their impacts.

Figure 1: Key Findings - Overview of the Specialist Palliative Care Workforce across Cheshire & Merseyside

- The Consultant and Associate Specialist workforce across is substantially below recommendations (WTE gap of 12.1 in hospitals and 9.4 in community services)
- In 5 of the 8 acute hospitals in 1 large specialist tertiary hospital there is 1 WTE or less Consultant or AS provision
- 6 out of 11 hospitals (acute and specialist) have no specialty grade doctor in palliative care
- 7 out of 10 place-based partnership areas do not meet the recommendations for speciality doctors. There is a gap in provision of 4.3 WTE speciality grade doctors working in a community setting
- In 3 out of 9 place-based partnership areas the number of CNSs providing community services is at or around the recommended level per population, however this is based on a 5-day working week therefore is likely to be inadequate for provision of 7-day services
- In Merseyside there is access to face to face 9-5 7/7 SPC provision in all community services and all but one hospital
- In Cheshire there is no access to 9-5 7/7 SPC provision in community or hospital
- 9 out of the 10 hospices accept admissions on a 7/7 basis but criteria and frequency vary
- In all place-based partnership areas health professionals have access to 24/7 SPC telephone advice
- 9 out of 10 hospices have an MDT which substantially or fully meets the recommendations for core professionals
- In NHS provided services the SPC MDT is most frequently comprised of doctors and nurses with minimal or no dedicated time from other AHPs
- 1 out of 10 hospices has the recommended number of specialist beds for the local population

Table 3: Overview of the Specialist Palliative Care Workforce across Cheshire and Merseyside

Risk	Impact
There are 21.5 WTE fewer doctors in SPC at Consultant and AS level than recommended	Reduced access for patients and health professionals to specialist symptom control and advice during normal working and out of hours which compromises optimum clinical treatment and care. The current Consultants and AS doctor workforce is required to provide out of hours cover with frequent and onerous on call rotas. Out of hours cover is vulnerable, especially where there are fewer senior medical staff. This has the potential to compromise optimum clinical treatment and for patients to be admitted into the acute setting
5 of 8 acute hospitals have 1 WTE or less SPC Consultants or AS doctors	Access to supervision and support for Clinical Nurse Specialists (CNSs) working in SPC teams in community and hospital may be limited so 7-day access to SPC face to face assessment will not be supported, compromising clinical care and ability to support the patient in the place of their choice
In 3 place-based partnership areas the number of CNSs in the Community SPC team is not sufficient to support the provision of 7 day working	Stretching the workforce numbers to accommodate 7-day compromises response times, patient assessment and review and support for health professional colleagues e.g., education.

In C&M SPC services in hospital and community are primarily delivered by the CNS workforce	Reliance on one professional group means that maintaining services requires a sustainable workforce
There are no 7/7 SPC services in community or hospice in Cheshire	Patients do not have access to SPC assessment or advice at weekends and bank holidays which may result in inadequate symptom management or inappropriate hospital admissions

The Department of Health may be able to furnish the Committee with a more comprehensive overview of services, to both identify risk and to inform planning.

In 2019, the Association of Palliative Medicine of Great Britain and Ireland produced an overview of the palliative care workforce in the UK.[16] Their analysis drew on data from three sources including the 2017-18 census, Royal College of Physicians.[17] At that time, Northern Ireland had 20 palliative care consultants (16.3 WTE) equating to one WTE consultant per 114,822 people. This was slightly better than the UK average of 126,976 people per WTE palliative medicine consultant (Table 4). In Northern Ireland, 65 per cent of consultants were female—a trend also observed across the UK. Additionally, 60 per cent of palliative care consultants in Northern Ireland were over 45 years old, with the UK's average intended retirement age being 61.2 years.

Table 4: Workforce planning analysis and informatics

Country	Number of consultants	Number of consultants (WTE)	Population per WTE
England	517	436.1	127 538
Northern Ireland	20	16.3	114 822
Scotland	49	39.7	136 645
Wales	36	28	111 613

In Northern Ireland, there were seven palliative medicine specialty trainees (STR). Across the UK, there is an average of 1 WTE STR per 356,847 people, while in Northern Ireland this ratio is 1 WTE STR per 279,229 people. This data is critical for workforce planning.

Regarding children’s palliative care services, the 2024 report Short Lives Can’t Wait recommended that, as part of the HSC Workforce Strategy 2026, the Department of Health should publish the number of community children’s nurses employed by the HSC service and fund additional posts to address gaps. The report also emphasised the need to train more children’s nurses in delivering palliative care across various settings and urged the Department of Health to invest in GRID training for at least one paediatric consultant in Northern Ireland.

1.3.4 Geographical Inequities and Access

Access to PEOLC services varies significantly across Northern Ireland, with particular challenges in rural areas. The 'Hospice at Home' model, while beneficial, faces difficulties in achieving geographical equity. Not all patients have equal opportunities to die in their place of choice due to variations in service availability and resources across different regions.[18]

Access to SPC hospital services is limited, with less than one third of hospitals in Northern Ireland having a specialist palliative care telephone service available 24/7.[19] This lack of round-the-clock support can lead to unnecessary hospital admissions and poorer patient outcomes. A recent report by the Nuffield Trust and the Health Economics Unit reported that the UK public purse spends five times the amount supporting people in the final year of life as hospital inpatients then it does supporting them with primary, community health and hospice care.[20] [21]

1.3.5 Role of Data in Quality Improvement

Measuring quality in palliative and end-of-life care (PEOLC) is a complex process. It requires evaluating both administrative data and Patient-Reported Outcome Measures (PROMs) to capture outcomes that matter to patients and their families. Systematic data collection helps to identify service gaps and unmet needs, guiding the development of targeted services and effective resource allocation. [22] Outcome measurement also supports benchmarking between services and fosters opportunities for shared learning. Additionally, routine documentation of symptoms and problems ensures consistent clinical assessments, enhancing the continuity of care.

In Northern Ireland, fragmented health information infrastructure poses significant challenges, particularly in the primary and community care sectors. This fragmentation limits visibility into system performance, complicates service comparisons, and hinders the tracking of patients as they transition between care settings.

A recent UK survey emphasised that outcome measures for end-of-life care services should take a more holistic approach. These measures should account for a person's full range of wishes, needs, and preferences at the end of life and adapt flexibly as these needs evolve. [23]

Investing in robust data infrastructure is critical to fostering continuous learning and adaptation, forming a strong foundation for quality improvement in PEOLC services. Northern Ireland's relatively small healthcare system offers an opportunity for more coordinated approaches, similar to those adopted in comparably sized regions internationally. The data requirements outlined in Section 1.3.2, "Workforce Challenges," highlight the importance of collecting data to identify and address gaps in service provision. However, this must be complemented by data that evaluates the quality-of-service delivery from both the healthcare provider's and the patient's perspective.

Efforts to improve coordination and service quality are detailed in the Regional Palliative Care Work Plan (2023–26).[24] Notably, over half of the plan’s 51 workstreams are focused on Priority Two: “Co-ordination and Quality Improvement.”

1.3.10 Public Perception and Service Uptake

Although hospices in Northern Ireland have a relatively high "reach" compared to the rest of the UK, public perceptions and misconceptions about palliative care continue to hinder service uptake.[25] These misconceptions are particularly common in areas with higher levels of deprivation and lower educational attainment, resulting in inequitable access to and use of PEOLC services. (Section three provides a more detailed analysis of public perceptions in Northern Ireland).

Efforts to improve this situation are ongoing, as outlined in the Regional Work Plan. However, despite these initiatives, misconceptions and low levels of awareness persist, particularly in more deprived areas of Northern Ireland.

2. Quality and Experience of Care

2.1 Evaluation of End-of-Life Care in Northern Ireland

Although data on the quality and experience of care in Northern Ireland does not extend to all care environments, the **National Audit of Care at the End of Life** (NACEL) is a comprehensive evaluation of the quality and outcomes of end-of-life, focusing on the experiences of dying individuals and their significant others during their final hospital admission. NACEL employs a multifaceted approach using data collection and scoring system.[26]

In Northern Ireland, NACEL is commissioned by the Northern Ireland Public Health Agency (PHA), on behalf of the Regional Palliative Care in Partnership (PCiP) Programme.[27] The audit is delivered by the NHS Benchmarking Network (NHSBN) with an overall aim of improving the quality of care delivered to people at the end of life in acute and community hospitals.

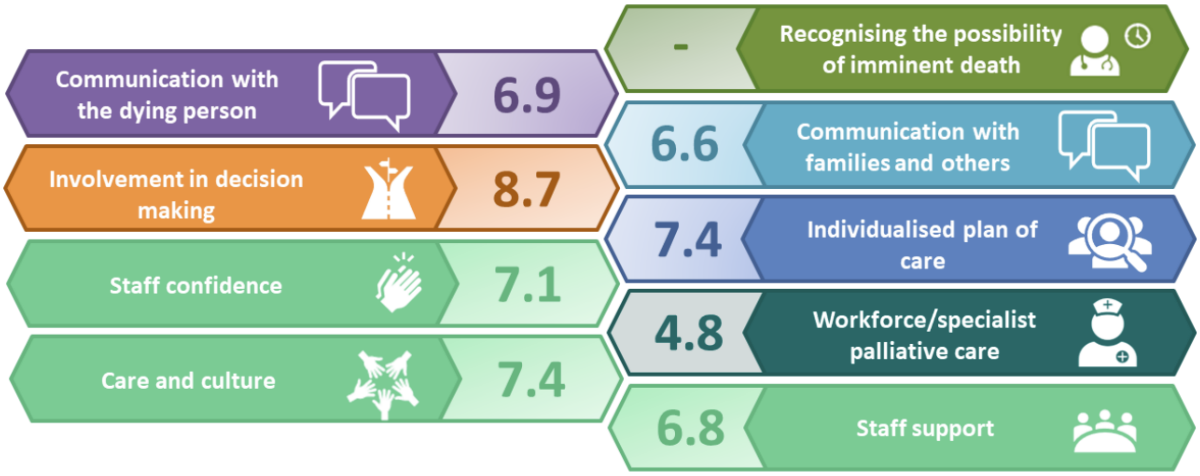
The audit examines:

- **Communication**: evaluates the effectiveness of communication between healthcare providers, patients, and families.
- **Individualised Care Planning**: assesses the extent to which care plans are tailored to the unique needs and preferences of the dying person.
- **Symptom Management**: reviews the adequacy of symptom control measures, including pain management.
- **Support for Families**: measures the support provided to families and significant others during and after the patient's death.

The Audit is closely aligned with NICE Quality Standard 13 *End of life care for adults*,[28] NICE Clinical Guidelines NG31 *Care of dying adults in the last days of life,*[29] and NICE Quality Standard 144, *Care of dying adults in the last days of life*.[30]

The fourth round (2022/23) of the audit summary scores for Northern Ireland are provided below. The audit comprises an **organisational level audit**, a **case note review** and a **staff reported measure**. The information is presented under nine themes, derived from the *Five priorities for care:*[31]

Figure 2: National Audit of Care at the End of Life (NACEL): Fourth round of the audit summary scores for Northern Ireland[32]



Key Findings:

Recognising the possibility of imminent death -

- The possibility that the patient may die within the next few hours/days was recognised in 93 per cent of cases audited (*an increase from 86 per cent in round three*).
- The median time from recognition of dying to death was recorded as 63 hours (*a reduction from 84 hours in round three*).

Communication with the dying person 6.9

- Of the 93 per cent of patients recognised to be dying, the majority had documented evidence within their case notes of a discussion about the possibility of death, or if not, a reason recorded why (*an increase from 82 per cent in round three*).
- Over a third of category one cases had no documented evidence of a discussion about the risks and benefits of hydration and nutrition options being discussed with the patient, this was an increase from just under a quarter in round three (a recommendation on this was included in round two to encourage improvement).

Communication with families and others 6.6

- The possibility that the patient may die had been discussed with families and others, or a reason recorded why not, in 98 per cent of deaths (*up from 96 per cent in round three*).
- Continued high compliance on the recording of conversations about an individualised plan of care with families and others, with 86 per cent of Category one deaths having documented evidence, or a reason why not recorded (*93 per cent in round three*).
- There is room for improvement in documenting discussions with families and others on the possibility of drowsiness, as a result of prescribed medications, and the risks and benefits of hydration and nutrition options, with over two thirds of cases having no documented discussion, and no reason recorded.

Involvement in decision making

8.7

- The regional results from the case note review show strong compliance with involving patients in decision making, where 76 per cent of category one deaths had documented evidence of the extent to which the patient wished to be involved in decisions about their care, or a reason recorded why not.
- Discussions with families and others on continuing or stopping life sustaining treatment was better documented than discussions with the patient. thirteen per cent of category one deaths had no documented evidence of a discussion with the patient, or a reason recorded.

Individualised plan of care

7.4

- Results from the fourth round of the Case Note Review showed that 83 per cent of category one deaths had an individual plan of care in existence (*an increase from 77 per cent in round three*).
- Documented evidence of an assessment of wider needs such as spiritual/religious/cultural and social/practical shows a slight reduction since 2021. This suggests an area for improvement in documenting these needs.

Workforce / specialist palliative care

4.8

- The results show consistent access to specialist palliative care, where 100 per cent of hospitals have access to a service (*100 per cent in round three*).
- However, face-to-face access eight hours a day, seven days a week is not yet available anywhere in Northern Ireland, and a 24/7 telephone service is available for 30 per cent of hospitals only.

Staff confidence

7.1

- Staff completing the survey expressed confidence in recognition of dying, communication, involving both the dying person and those important to them in decision making and accessing specialist palliative care advice, with less than ten per cent stating they strongly disagreed or disagreed with positive statements of confidence in these areas.

Staff support 6.8

- Training was identified as a potential area for improvement with only 41 per cent of respondents stating they had completed training specific to end of life care within the last three years.
- Of staff responding to the survey, 72 per cent felt managerial support was available to help provide care at the end of life, (*this rose from 60 per cent in round three*).

Care and culture 7.4

- Although 79 per cent felt able to raise a concern about end-of-life care, this should be closer to 100 per cent. That only 85 per cent answered positively that they felt they work in a culture that prioritises care, compassion, respect and dignity, is also a concern.
- Only 53 per cent of staff agreed that deaths were actively reviewed and action plans implemented to improve end of life care.

2.2 Comparison with England and Wales (Round 4 Audit Results)

A notable difference between Northern Ireland and England & Wales (see figures three and four below) relates to access to face-to-face SPC services, eight hours/day, seven days per week. In England & Wales SPC services were available in 60 per cent of hospitals surveyed, whereas none had this facility in Northern Ireland. In England and Wales, 85 per cent of staff felt confident that they could recognise when a patient might by dying imminently, whereas this figure was 75 per cent in Northern Ireland. In Northern Ireland, a higher percentage of case notes recorded that the patient might die within hours compared to in England and Wales (93 per cent versus 87 per cent).

Figure 3: National Audit of Care at the End of Life (NACEL) Northern Ireland: Overview of key findings from the fourth round of the audit report (2022/2023)[33]

National Audit of Care at the End of Life 2022
Northern Ireland
Key findings at a glance

20 Hospital/site overviews (H/S)

389 Case Note Reviews (CNR)

685 Staff Reported Measures (SRM)

(CNR – Cat 1) 93% Case notes recorded that the patient might die within hours or days

(CNR– Cat 1) 86% Case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care

(CNR – Cat 1) 98% Case notes recorded a discussion (or reason why not) with families/carers regarding the possibility the patient may die

83% Case notes recorded an individualised plan of care

18% Case notes recorded a preferred place of death as indicated by the patient

(CNR – Cat 1) 76% Patient's hydration status was assessed daily once the dying phase was recognised

(CNR – Cat 1) 76% Case notes recorded extent patient wished to be involved in care decisions, or a reason why not

(H/S) 30% Hospitals have a telephone advice service available 24 hours a day, seven days a week

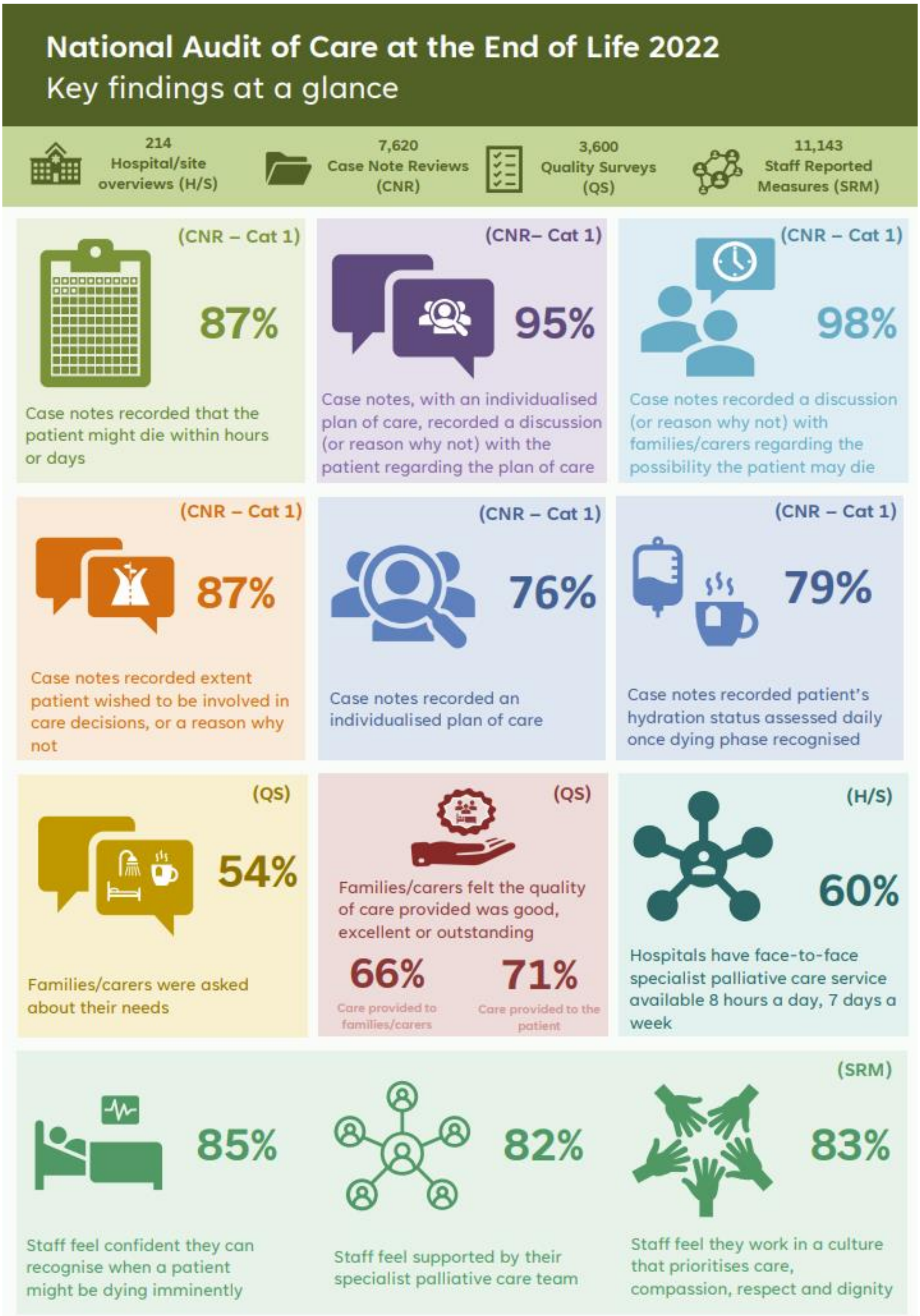
(H/S) 0% Hospitals have face-to-face specialist palliative care service available 8 hours a day, 7 days a week

75% Staff feel confident they can recognise when a patient might be dying imminently

78% Staff felt supported by their specialist palliative care team

(SRM) 85% Staff feel they work in a culture that prioritises care, compassion, respect and dignity

Figure 4: National Audit of Care at the End of Life (NACEL) England and Wales: Overview of key findings from the fourth round of the audit report (2022/2023)[34]



National Audit of Care at the End of Life 2022
Key findings at a glance

214 Hospital/site overviews (H/S)

7,620 Case Note Reviews (CNR)

3,600 Quality Surveys (QS)

11,143 Staff Reported Measures (SRM)

(CNR – Cat 1) 87% Case notes recorded that the patient might die within hours or days

(CNR– Cat 1) 95% Case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care

(CNR – Cat 1) 98% Case notes recorded a discussion (or reason why not) with families/carers regarding the possibility the patient may die

(CNR – Cat 1) 87% Case notes recorded extent patient wished to be involved in care decisions, or a reason why not

(CNR – Cat 1) 76% Case notes recorded an individualised plan of care

(CNR – Cat 1) 79% Case notes recorded patient's hydration status assessed daily once dying phase recognised

(QS) 54% Families/carers were asked about their needs

(QS) Families/carers felt the quality of care provided was good, excellent or outstanding

66% Care provided to families/carers

71% Care provided to the patient

(H/S) 60% Hospitals have face-to-face specialist palliative care service available 8 hours a day, 7 days a week

(SRM)

85% Staff feel confident they can recognise when a patient might be dying imminently

82% Staff feel supported by their specialist palliative care team

83% Staff feel they work in a culture that prioritises care, compassion, respect and dignity

2.3 Recommendations of the NACEL Audit Team

The fourth round of NACEL recommendations for Northern Ireland remains consistent with previous findings, emphasising the need for clear, sensitive communication and individualised care for dying patients. Recommendations suggested that HSC Trusts should integrate these recommendations into their local action plans, aligning with regional palliative care efforts. They should also ensure clinical teams discuss medication side effects, hydration, nutrition, and advance care planning with patients and their loved ones, documenting all communications. Individualised care plans should address emotional, psychological, social, spiritual, and cultural needs. Furthermore, anticipatory medication use should be communicated and recorded, and staff should receive training to enhance end-of-life communication skills.

Recommendations for the Department of Health in collaboration with the Palliative Care in Partnership Programme (PCiP) included working toward 24/7 specialist palliative care advice and embedding end-of-life care training in induction and mandatory programs, fostering staff competence in recognising and managing dying patients' needs.

2.4 Regional Palliative Care Work Plan 2023-26

To address these recommendations the PCiP Regional Palliative Care Work Plan 2023-26 (updated October 2024)[35] has 51 workstreams across four priority areas:

Priority 1: Early Identification and Timely Intervention: including regional roll out of the AnticiPal system in General Practice; proactively working with HSC professionals to identify patients in need of PEOLC; and developing a new regional ‘identification and pathways in ED project’.

Priority 2: Coordination and Quality Improvement: including a wide range of workstreams relating to the Hospice Quality Indicators (QI) Project; assessing quality of care (via NACEL); developing integrated care systems further; securing out-of-hours access to SPC systems; and service development with respect to pharmacy personnel, palliative care key workers and moving to a 7-day model for SPC nursing.

Priority 3: Palliative Care Education and Training: including implementing advanced communication training; developing post-graduate education pathways for a range of HSC staff; and a training framework to support a broad range of staff and developing a regional career framework for SPC nursing.

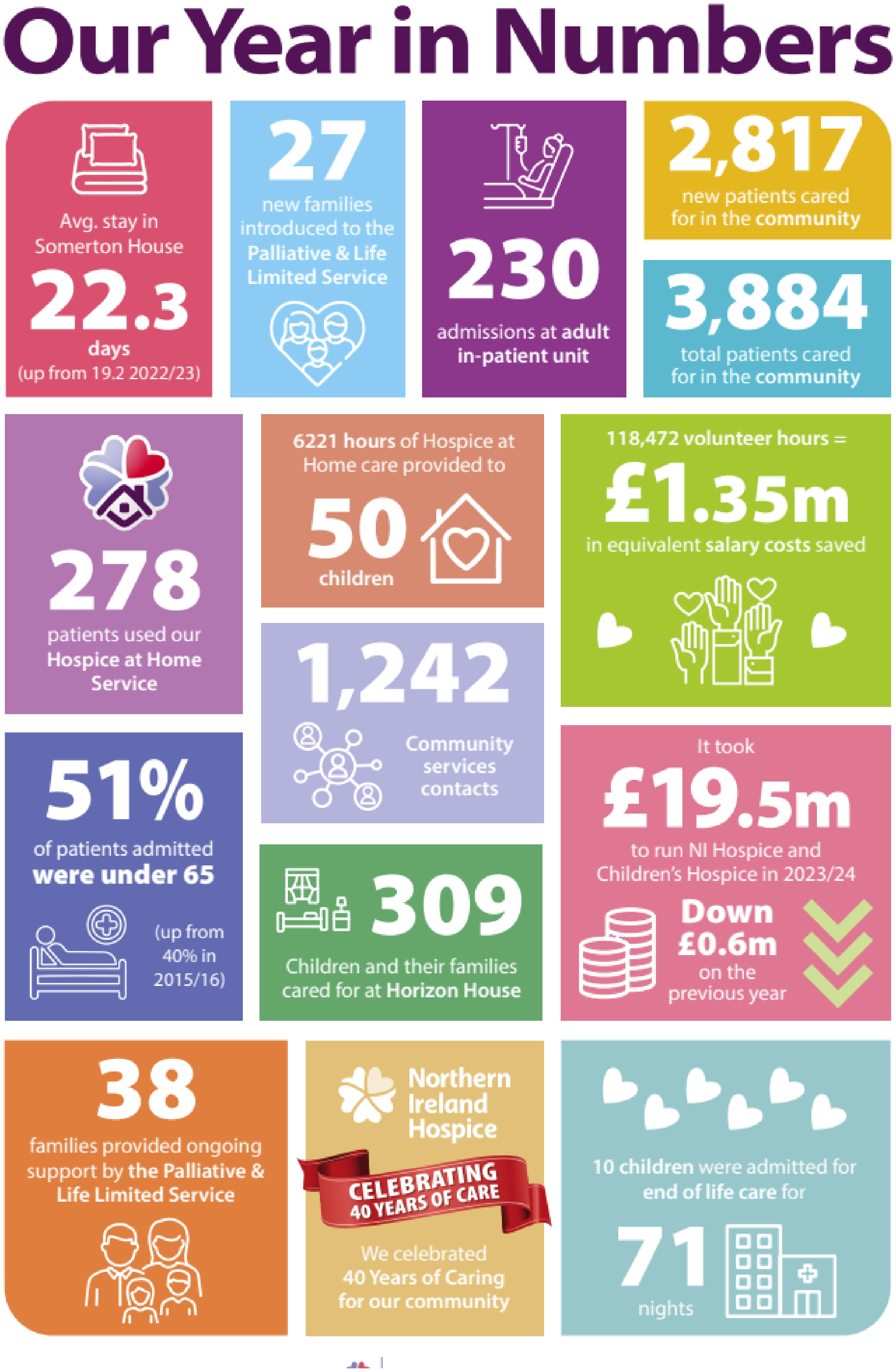
Priority 4: Public Health Approach to Palliative Care: including planning of activities for annual palliative care week; PCiP website redesign and update; and proactive work to identify hard to reach groups.

2.5 Northern Ireland Hospice Impact Report

Hospice care in Northern Ireland is widely regarded as being of a high standard, emphasising quality of life and patient-centred care. The Northern Ireland Hospice's 2023/24 impact report highlights its activities and achievements during this period.[36] Figure 5 illustrates these outcomes, including 230 admissions to the adult in-patient unit and care provided to 309 children and their families at Horizon House. The Hospice at Home Service supported 278 patients, delivering 6,221 hours of Hospice Home Care to 50 children.

In addition to activities at its two hospices, the report outlines the provision of community services, hospice outreach programs, and education and training initiatives for healthcare professionals. These include courses on Advanced Communication Skills and the Essentials of Palliative Care Certificate.

Figure 5: Northern Ireland Hospice Impact Report 2023/24 – Our Year in Numbers



Our Year in Numbers

Avg. stay in Somerton House
22.3 days
(up from 19.2 2022/23)

27 new families introduced to the **Palliative & Life Limited Service**

230 admissions at **adult in-patient unit**

2,817 new patients cared for in the **community**

3,884 total patients cared for in the **community**

278 patients used our **Hospice at Home Service**

6221 hours of Hospice at Home care provided to **50** children

118,472 volunteer hours = **£1.35m** in equivalent **salary costs** saved

1,242 Community services contacts

51% of patients admitted **were under 65** (up from 40% in 2015/16)

309 Children and their families cared for at **Horizon House**

It took **£19.5m** to run NI Hospice and Children's Hospice in 2023/24
Down £0.6m on the previous year

38 families provided ongoing support by **the Palliative & Life Limited Service**

Northern Ireland Hospice
CELEBRATING 40 YEARS OF CARE
We celebrated **40 Years of Caring for our community**

10 children were admitted for **end of life care** for **71** nights

2.6 End of Life Survey Findings from the UK

A recent UK-wide survey on death and dying revealed that the top priority for individuals in their final days and last year of life was freedom from pain and other symptoms. This was closely followed by the desire to be in the company of loved ones and to maintain personal dignity and self-respect. Interestingly, many participants did not express a strong preference for dying at home, despite this often being used as a performance indicator for care services.[37]

The National Audit of Care at the End of Life (NACEL) provides a comparison of care provision and quality between Northern Ireland and other UK regions. However, comparable data to evaluate care quality across multiple settings is not available. The ***Better End of Life 2024*** report,[38] based on an extensive survey conducted in England and Wales, highlights several significant challenges in end-of-life care:

- Over half of deceased individuals had used ambulance services in their final three months, and nearly half had at least one visit to an Emergency Department (ED).
- Around one in eight spent more than 30 days hospitalised during this period.
- More than one-third of individuals passed away in a hospital setting.
- Although most had contact with community healthcare professionals, such as GPs and district nurses, access issues remained—one in five had no GP contact in their final three months.
- SPC reached approximately half of the patients, with a focus on those with cancer, but older individuals had less access to these services.
- Fewer than half of respondents reported having a designated care coordinator, placing significant burdens on informal carers, many of whom felt unprepared and unsupported.
- Nearly half expressed dissatisfaction with certain aspects of care, and one in seventeen lodged formal complaints.

- Almost one-third of respondents indicated that healthcare professionals had not informed them about the impending death of their loved one.

In the final week of life, common physical symptoms included poor mobility, weakness, and loss of appetite. Psychologically, nearly two-thirds of families experienced ongoing anxiety or worry about the patient’s illness or treatment, and over one-third of patients felt anxious or depressed most of the time.

Barriers to timely symptom relief included difficulties accessing services, healthcare professionals, and essential medications or equipment. Informal carers, who often supported appointments, medical procedures, and on-call needs, faced financial pressures, with half needing to adjust their work commitments.

Moreover, one in six carers experienced disturbed grief—particularly spouses and those who felt unheard by healthcare professionals. Despite this, only a quarter sought bereavement support.

3. Public Perceptions and Barriers to Palliative Care

3.1 Research on Public Perceptions in Northern Ireland

Despite the World Health Organization (WHO) advocating for palliative care to be recognised as a public health priority and integrated earlier into healthcare systems, evidence shows it is often accessed late in the course of illness. This delay can negatively affect both the quality and accessibility of care. International research also highlights limited public awareness and understanding of palliative care, with significant regional variations. [39,40,41]

In Northern Ireland, public perceptions of palliative and end-of-life care are shaped by a complex mix of social, cultural, and structural factors. Surveys consistently reveal widespread misconceptions and a general lack of awareness about what palliative care entails, mirroring trends seen across the UK and the Republic of Ireland.

Common misconceptions include equating palliative care solely with end-of-life care, associating it exclusively with cancer, and viewing a referral to palliative care as a loss of hope. These misunderstandings often lead to delayed referrals, preventing patients from accessing valuable services at the most appropriate time. Data from the Northern Ireland Life and Times (NILT) Survey indicated that although 44.6 per cent of respondents had direct experience of palliative care, just under a fifth (19.5 per cent) exhibited no understanding of the term palliative care and less than a third (28.5 per cent) had heard of the term advanced care planning.

Findings from a 2024 survey conducted by the All Ireland Institute of Hospice and Palliative Care (AIIHPC) further underscore these concerns:

- 69 per cent of adults in Northern Ireland reported feeling fearful when hearing the term "palliative care."
- 89 per cent associated palliative care solely with end-of-life care.
- 64 per cent believed palliative care was only for individuals with cancer.

Despite these challenges, there were also positive perceptions:

- 75 per cent acknowledged that palliative care could benefit individuals over an extended period, not just at the end of life.
- 75 per cent believed it would help them make informed decisions about their future care.
- 50 per cent felt hopeful and reassured when they heard the term "palliative care."

A decade ago, the Regulation and Quality Improvement Authority (RQIA) conducted a review of the *Living Matters, Dying Matters* strategy,[42] reaching similar conclusions. While various initiatives have been launched to raise awareness, a significant gap in public understanding persists. The review emphasised the need for a coordinated approach to public education, recommending that "raising public awareness of palliative and end-of-life care should be a core component of any new action plan." This highlights that ongoing misconceptions remain a major barrier to accessing and delivering optimal palliative care in Northern Ireland.

3.2 Changing Public Perceptions: Local Examples

The Heart of Living and Dying (HLD) initiative in Northern Ireland represents one such approach, described as "a facilitated two-hour group process which brings advance care planning into the public domain where members of the public are invited to participate in a supported conversation about what matters to them in their living and dying and to begin to plan ahead".[43] This initiative aims to normalise conversations about serious illness and end-of-life preferences in a supportive community context.

Similarly, the **"Compassionate Communities North West"** initiative works "towards changing attitudes and behaviour towards life, age, death and loss".[44] This community-based approach recognises that addressing misconceptions requires engagement beyond healthcare settings and can leverage existing community networks to promote understanding of palliative care approaches.

In the Northern Health and Social Care Trust, **"End of Life Companion" services** provide "support for patients, families and loves ones in need of support and reassurance, in the last days of life". [45] This approach focuses on practical support during the end-of-life period, potentially helping to normalise this experience and reduce anxieties among patients and families.

Examples of successful public engagement in other countries include death cafés, advance care planning workshops, community education programs, and media campaigns designed to normalise discussions about serious illness and end-of-life care.[46] These approaches share several key features: they normalise discussions about serious illness and death as part of life rather than taboo topics; they emphasise personal choice and autonomy rather than medical decision-making; they engage diverse community settings beyond healthcare facilities; and they provide structured resources while allowing flexibility for cultural and personal preferences.

The success of these initiatives suggests potential approaches for addressing Northern Ireland's awareness gaps. By combining healthcare-based education with broader community engagement, Northern Ireland could develop more comprehensive approaches to changing public perceptions about palliative care, ultimately improving access to appropriate services when needed.

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