

With the end in mind

Delivering
equitable, quality
and sustainable
hospice care for
Northern Ireland.

A shared vision for hospice care by:

Hospice Alliance Northern Ireland



evora
Hospice Care

**Foyle
Hospice**
Together we care



**Marie
Curie**
NORTHERN
IRELAND



**Northern
Ireland
Hospice**

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FOREWORD

There are moments in life when the quality of care matters more than ever. The beginning of life is one of them. The end of life is another.

We would never regard maternity care as an optional extra to the health service. Neither should we view palliative and end-of-life care that way. A person’s final days should matter as much as their first.

Across Northern Ireland, our four independent hospices provide specialist care to thousands of adults, children and families every year, in hospice settings, hospitals, people’s homes and communities. While we are independent charities, hospice care is not a peripheral service. It is an essential part of the Health and Social Care system, supporting patients, families and healthcare providers across Northern Ireland.

Hospice care is not a last resort. It is an essential part of healthcare, providing expert clinical care, symptom management, emotional support and reassurance at some of life’s most difficult moments.

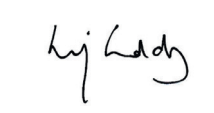
Yet planning and funding have not kept pace with growing demand for palliative care, nor is the importance of hospice care recognised in the wider health system. Hospices deliver essential healthcare but continue to rely heavily on charitable fundraising to sustain core clinical services. This is neither sustainable nor equitable.

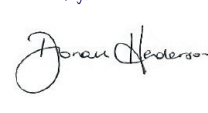
This report is not simply a call for more funding. It proposes greater partnerships between hospices in Northern Ireland and the Health and Social Care system, built on a simple principle: protect what works, expand what people increasingly need, and redesign together what must work better.

The evidence is clear. Hospices already deliver substantial volumes of specialist care alongside significant charitable investment. If hospice capacity is reduced, demand does not disappear. It shifts elsewhere in the system, often at greater human and financial cost.

Our ambition extends beyond protecting existing services. We want to see earlier access to palliative care, stronger Hospice at Home services, better integration with hospitals and primary care, a sustainable specialist workforce, improved coordination, and greater use of data to understand need and measure outcomes.

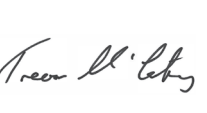
As the Chief Executives of the four independent hospices in Northern Ireland, we offer this report not as a case for hospices, but for those patients and families who need us most. The measure of a health service is not only how well it helps people live, but how well it cares for them when cure is no longer possible. Hospice care must be recognised as an essential part of healthcare.



Liz Cuddy OBE DL
Chief Executive
Evora



Donall Henderson
Chief Executive
Foyle Hospice



Heather Monteverde MBE
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EXECUTIVE SUMMARY

Northern Ireland is facing a significant and growing palliative care challenge. More people are living longer with complex, progressive and life-limiting conditions, while many who could benefit from palliative care do not receive the timely support they need. Demand is projected to grow substantially over the coming decade, placing increasing pressure on patients, families, hospices and the wider Health and Social Care system.

Hospice care is part of the solution. It improves quality of life, helps people manage complex symptoms, supports families and carers and enables more care to be delivered closer to home. It also provides specialist expertise, education and support across the wider Health and Social Care system. At its best, hospice care is not only about how people die, but how they live in the period before death, with dignity, comfort, choice and support for those closest to them.

The Hospice Alliance Northern Ireland has developed this report to set out a shared vision for the future of hospice care. Drawing on the collective experience of Northern Ireland's four hospice providers, it highlights the difference hospice care makes, examines the challenges facing the sector and presents a practical framework for delivering more equitable, high-quality and sustainable services in the years ahead. Our vision is simple: everyone in Northern Ireland who could benefit from palliative care can access the right support, at the right time, in the right place and in a way that reflects what matters most to them and their families.

The scale of future need is significant. Economic analysis commissioned by the Hospice Alliance estimates that up to 19,000 people could benefit from palliative care annually by 2036, representing growth of almost 17% compared with 2024. This increase will occur alongside existing unmet need, with research suggesting that around one in three people who die have unmet palliative care needs. The challenge is therefore not simply to maintain existing services, but to expand capacity and address gaps in access and provision.

The report highlights significant variation in access to hospice and palliative care across Northern Ireland. Geography, diagnosis, service availability, public awareness and when support is needed can all influence access to care. As a result, patients and families can have very different experiences depending on where they live and how they enter the system. Reducing unwarranted variation and ensuring access is based on need must be a central goal for the future.

The report also identifies growing concerns about sustainability. Hospice care delivers essential clinical services, yet continues to rely heavily on charitable income to fund core provision. Current funding and commissioning arrangements do not adequately reflect the scale, complexity or true cost of hospice care and contribute to uncertainty and variation across the sector.

Our independent economic analysis reinforces the case for investment. It suggests that replacing current hospice activity through statutory provision could cost up to £7.7 million more each year than delivery through hospices. When existing statutory funding

levels are taken into account, the potential additional cost exposure to the Health and Social Care system was estimated at up to £27.2 million annually. The conclusion is clear: hospice care represents valuable specialist capacity that patients, families and the wider system rely upon. The need currently met by hospices would not disappear if hospice provision reduced. Instead, it would fall elsewhere within an already stretched system, often at greater cost and with additional operational pressure.

Hospice care is not an optional addition to Northern Ireland's Health and Social Care system. It is a core part of the care people and families rely upon at some of the most vulnerable points in their lives. Investment in hospice care should therefore be viewed as investment in essential health service capacity, improving outcomes for patients and families while supporting a more effective and sustainable Health and Social Care system.

Recent policy developments, including the 2025 Committee for Health Inquiry into Palliative Care Services and the Department of Health's Health and Social Care Reset Plan, have created important momentum for change. This report builds on that momentum and importantly sets out the Hospice Alliance's own vision for strengthening hospice care and improving outcomes for patients, families and the wider system.

Our report calls for collective action under three connected pillars: equity, quality and sustainability and identifies five priorities for action:

- 1. Ensuring equitable access for all**
- 2. Expanding care closer to home**
- 3. Workforce capacity and capability**
- 4. Sustainable funding and commissioning reform**
- 5. Leadership, partnership and innovation**

Together, these priorities provide a framework for strengthening hospice care and improving outcomes for patients, families and communities. Some priorities will require decisions and action from government, commissioners and the wider Health and Social Care system, others can be progressed directly by the Hospice Alliance through collaboration, innovation, evidence generation and shared learning. All will require a commitment to partnership.

Maintaining the status quo is no longer an option. Without action, the gap between need and provision will widen, placing increasing pressure on patients, families, hospices and the wider Health and Social Care system. The opportunity now is to create a more equitable, high-quality and sustainable model of hospice care in Northern Ireland. Done well, this means more people receiving timely support, more care delivered closer to home, better experiences for families and more effective use of finite Health and Social Care resources.

With the end in mind, the Hospice Alliance stands ready to work with partners to turn this vision into reality.

ABOUT THE HOSPICE ALLIANCE NORTHERN IRELAND

The Hospice Alliance Northern Ireland brings together the region's four charitable hospice providers:

- Evora Hospice
- Foyle Hospice
- Marie Curie Northern Ireland
- Northern Ireland Hospice (including Northern Ireland Children's Hospice [1]).

Collectively, the four hospices deliver a range of specialist inpatient and community palliative care services across Northern Ireland, supporting over 13,000 patients and their loved ones each year through one of the most difficult times in their lives.

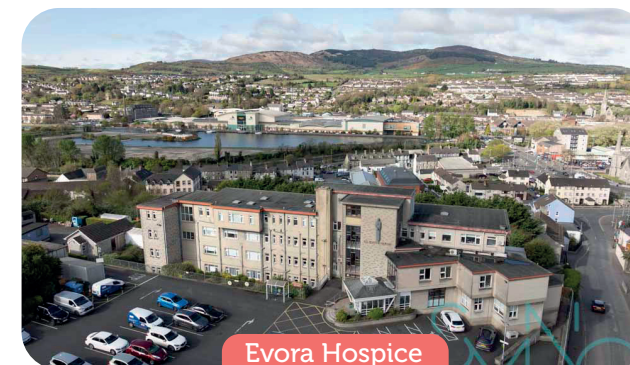


Hospice Alliance members are united in a shared commitment to deliver high-quality, compassionate care that enables people to experience the best possible end of life, shaped by dignity, choice and support for those closest to them.

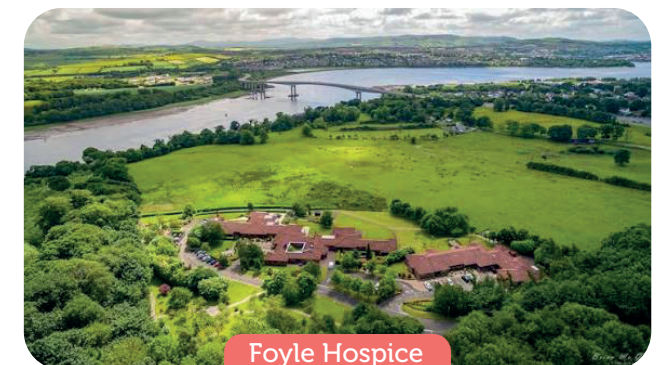
The Hospice Alliance provides a collective voice for the sector. It represents over 780 staff and 1200 volunteers and advocates for the essential role that hospices play.

Our hospice services at a glance:

- Over **13,000** patients, carers and loved ones supported by the Hospice Alliance Northern Ireland each year, including:
 - + almost **80,000** visits to patients at home
 - + around **10,000** outpatient appointments for physiotherapy, counselling and other support services
 - + over **19,000** days and nights of inpatient care
 - + nearly **10,000** appointments provided to patients' families, friends and carers, including counselling and bereavement support.
- **57** adult specialist inpatient beds across four hospices
- **Six** funded children's inpatient beds
- **72%** of hospice care delivered in people's homes [2]



Evora Hospice



Foyle Hospice



Marie Curie NI



NI Hospice

INTRODUCTION

Hospices in Northern Ireland play a vital role in delivering palliative and end-of-life care, supporting thousands of patients and families each year through specialist inpatient, community and bereavement services. They also make an important contribution to the wider Health and Social Care (HSC) system by helping people receive palliative care in their preferred place and providing tailored, specialist care that reduces the risk of crisis. This eases the burden on the health service, especially overstretched emergency departments.

However, the hospice sector is facing growing financial and operational pressures. Demand for palliative care is rising and becoming more complex, while access to services remains inconsistent across Northern Ireland. At the same time, funding arrangements, workforce capacity and system infrastructure are not keeping pace with need. As a result, hospice care is coming under increasing strain at a time when the need for these services has never been greater. Without action, more people will experience poor outcomes at the end of life, despite the known benefits of timely, quality palliative care.

In response to this challenge, the Hospice Alliance Northern Ireland has developed this report to articulate a shared vision for the future of hospice care. Drawing on the collective experience of Northern Ireland's four hospices, it sets out the value hospice care delivers for patients, families and the wider HSC system, the challenges that must be addressed and the actions required to ensure services remain equitable, sustainable and responsive to future need.

The publication of the Committee for Health Inquiry Report on Access to Palliative Care in 2025 has brought renewed focus to many of these issues and provides important momentum for change. The Inquiry's findings align closely with the challenges and opportunities identified through this report, however, importantly, this report represents the Hospice Alliance's own vision for the future of hospice care in Northern Ireland.

Our vision is focused on a shared end goal: that everyone in Northern Ireland who could benefit from palliative care can access the right support, at the right time, in the right place and in a way that reflects what matters most to them and their families. Delivering this vision requires a sustainable hospice care system, able to focus on delivering high quality care to all.

Achieving this ambition will require partnership across government, the HSC, primary care, the voluntary and community sector and people with lived experience. The sections that follow set out the evidence for change, the priorities for improvement and a practical framework for action to deliver more equitable, high-quality and sustainable hospice care in Northern Ireland.

While much of the evidence and analysis presented in this report relates to adult hospice and palliative care services, the vision and priorities are relevant across the age spectrum. Northern Ireland Children's Hospice provides the region's specialist paediatric palliative care service, supporting babies, children, young people and their families across Northern Ireland. Although the needs of children and young people may differ in important respects, many of the challenges and priorities identified in this report, including sustainable funding, workforce capacity and integrated planning are equally relevant to the delivery of high-quality paediatric palliative care.

1. HOSPICE CARE AND THE DIFFERENCE IT MAKES

Palliative care is a core component of a modern, patient-centred Health and Social Care system. It improves quality of life for adults, children and young people living with life-limiting or life-threatening illness, while also supporting families and carers through illness, dying, death and bereavement. Palliative care is delivered by a wide range of professionals and services, including GPs, District Nurses, specialist palliative care teams, hospitals, community services and hospices, working together to support people and families throughout their illness journey.

Importantly, palliative care is not limited to the final days or weeks of life. When introduced earlier, alongside curative treatment, it enables people to live as well as possible for as long as possible. Evidence shows that specialist palliative care improves quality of life and emotional wellbeing, with outcomes comparable to other established health interventions. These benefits are greatest when support begins at least three months before death, rather than being confined to the final weeks [3].

Within this wider system, hospices play a unique and important role. Hospice care was founded on the principle that every person matters and should be treated with dignity, compassion and respect until the end of life. It combines specialist clinical expertise with a holistic approach that recognises the physical, emotional, psychological, social and spiritual dimensions of care, placing equal importance on what matters most to individuals and those closest to them, as it does their purely medical needs.

Hospices are a key part of the wider HSC system. In addition to direct care, hospices provide education and support to health and care professionals, contributing to end of life care capability across services. In addition, hospices offer essential bereavement support to families, with a range of counselling and holistic services offered, including bereavement cafes.

Our hospices deliver care through multidisciplinary teams of staff, supporting people with increasingly complex needs across a wide range of conditions, including cancer, respiratory disease, neurological conditions, dementia, frailty and multimorbidity. Rooted in communities and supported by volunteers, hospices combine clinical excellence with compassion, practical support and human connection at some of the most challenging times in people's lives. Our work extends well beyond inpatient provision, with a predominantly community-based model of care. In Northern Ireland, most hospice activity takes place in people's homes or usual place of residence, with almost 80,000 home visits recorded in 2025–26.

What distinguishes hospice care is not only its specialist expertise in managing complex symptoms, but its ability to tailor care around what matters most to each individual. This may mean supporting important family moments, enabling familiar routines and relationships to continue, or helping people achieve personal goals and preferences at the end of life, whilst at the same time providing expert clinical care.

Mum spent almost all her working life in the Hospice as a nursing auxiliary. She was so good at her job, and so proud to tell everyone where she worked. I thought I understood what Hospice care was. I'd grown up surrounded by it, but being on the other side, I realised I had no idea. We were wrapped in love and kindness. Mum was treated like a queen in her favourite room, Room 9, with a fabulous view over the gardens and Newry Quay. I became her daughter again. I wasn't the carer, the organiser, the go-between. I had the time and space to just sit with her, to talk properly. I could leave knowing she was safe, lovingly cared for by her work family. The whole team were extraordinary, involving her in every decision and helping me through the hardest time of my life.

Emma, daughter of Elaine, who was cared for by Evora Hospice.

When palliative care is absent or delayed

Despite the known benefits of hospice and palliative care, many people do not receive timely support to experience the full difference it can make. Too often, specialist support is only introduced when needs have already escalated and a crisis has occurred, reducing opportunities to plan ahead, manage symptoms proactively and coordinate care around individual wishes.

The consequences can be significant:

- **For patients** - unmanaged symptoms may worsen significantly, alongside increasing anxiety, fear and uncertainty. People may have less opportunity to discuss their wishes, make informed choices or receive care that reflects what matters most to them.
- **For families and unpaid carers** - caring responsibilities can become overwhelming. Many are left navigating complex decisions and practical challenges without the support, information or reassurance they need. In some instances, unpaid carers are forced to give up work and can find themselves facing their own health challenges at the same time as managing the needs of their loved ones.
- **For professionals and services** - the absence of planned support can make care more reactive, with avoidable crises becoming more difficult to prevent and an increased burden on overstretched acute services.

Research suggests that around one in three people who die have unmet palliative care needs [4], demonstrating that a significant proportion of those who could benefit from support are either not identified or do not receive the timely care required to gain the full benefit.

For many people with palliative and end of life care needs, whether palliative care is available at the right time is nearly as important as whether it is available at all. Earlier access can improve symptom management, support informed decision-making and help people and families feel more confident and prepared for what lies ahead. It also creates more opportunity to focus on quality of life, personal priorities and meaningful moments with those closest to them.

As hospice providers, we see every day the difference that timely hospice care can make. Earlier identification and access to specialist support can help people live as well as possible for as long as possible, while ensuring care remains centred on dignity, choice and what matters most to each individual.

I work as part of the Urgent Hospice Care at Home team, covering East Belfast. I go out to visit people who are dying at home, doing things like giving them medication, providing personal care, changing syringe drivers, and assessing changing symptoms. I work directly with the district nursing team and will receive a mixture of planned and urgent calls. Some visits might be quick, other times the family need you to stay; so, I stay as long as is needed. There are about ten staff on our team at the minute, covering the whole of Belfast between 8am – 8pm. The district nurses cover the out of hours period.

Helping to provide a good end of life experience allows family members to become a wife, mother, father, husband, son or daughter again, as opposed to being a carer. It leaves them with good memories at the end, as they have the time and space to process what's happening, to reminisce, and the peace of mind that they've given their loved one a good death. Enabling people to die at home, in comfort, and according to their wishes, makes me proud to be a Marie Curie Nurse.

Naomi Campell, nurse in Marie Curie Urgent Hospice Care at Home team

Hospice care can make a significant difference to people and families facing serious illness - improving quality of life, supporting informed choice and helping care to be tailored around what matters most to each individual. However, ensuring that everyone who could benefit from hospice and palliative care is able to access this support in a timely way is becoming increasingly challenging. Rising demand, workforce pressures, variation in access, fragmented commissioning arrangements and long-standing funding challenges are creating growing risks for both service sustainability and future capacity. The next section explores these challenges and why they require urgent attention if hospice care is to meet the needs of Northern Ireland's population in the years ahead.

2. THE CHALLENGES FACING HOSPICE CARE IN NORTHERN IRELAND

Hospice care in Northern Ireland operates within a wider palliative care landscape that is facing significant and growing challenges. These challenges are interconnected and have developed over many years, creating significant issues for patients, families, service sustainability and the wider HSC system. Below we consider the key challenges in turn.

Key challenges:

- Demand for palliative care is increasing rapidly in both scale and complexity.
- Access to hospice care varies significantly across Northern Ireland.
- Statutory funding arrangements do not meet current costs and hospices are over dependent on charitable giving.
- Fragmented commissioning and contracting arrangements contribute to variation in provision.
- Workforce and system capacity is under pressure.
- Data and digital fragmentation reduce system visibility and coordination.
- Northern Ireland lacks an up to date region-wide Palliative Care strategy.
- Policy ambition has not yet translated into consistent action.

Demand for services

Demand for palliative care services in Northern Ireland is increasing because more people are living longer with complex, progressive and life-limiting conditions. However, future demand will be shaped not only by demographic change, but also by existing unmet need, variation in access, wider health system pressures and reliance on families and unpaid carers. The factors driving this demand are outlined below.

DRIVER OF DEMAND	WHAT THE EVIDENCE SHOWS	IMPLICATION FOR SERVICES
Population ageing	Significant growth in older population, with those aged 65+ projected to increase by around 50% and those over 85 by over 120% in coming decades [5]; around two-thirds of deaths already occur in those aged over 75 [6].	Substantial increase in overall volume of need, particularly among older people.
Rising multimorbidity and frailty	Increasing numbers of people living with multiple long-term conditions and frailty in later life. Two-thirds of adults aged over 65 are expected to be living with multiple health conditions (multi-morbidity) by 2035 [7].	More complex, longer-duration palliative care needs requiring coordinated, multidisciplinary support across settings.
Longer survival with life-limiting conditions	Advances in treatment mean more people are living longer with life-limiting conditions, such as cancer, heart failure, respiratory disease and dementia. As a result, more people may require palliative care support over a longer period of time.	Demand for palliative care services is increasing not only in volume but also in duration, requiring timely identification, ongoing support and coordinated care across settings.
More young people with life-limiting conditions are surviving into adulthood	Advances in treatment mean increasing numbers of young people with life-limiting conditions and complex care needs are living into adulthood. These young people face particular challenges when transitioning to adult services [8].	Greater need for planned, coordinated transition and age-appropriate support across children's, adult and hospice services.
Changing disease profile (non-cancer need)	Greater understanding that palliative care is increasingly relevant for a wider range of progressive conditions beyond cancer.	Need to ensure services are designed and commissioned to meet diverse disease trajectories, not just traditional cancer pathways.
Projected growth in people who could benefit from palliative care	A growth of 17% over the next 10 years to 2036 [9] with Northern Ireland expected to see the largest proportional increase in deaths requiring palliative care across the UK [10].	Capacity planning must account for significant future growth, while dealing with existing unmet need.

DRIVER OF DEMAND	WHAT THE EVIDENCE SHOWS	IMPLICATION FOR SERVICES
Existing unmet need	One in three people are estimated to have unmet palliative care needs [11].	True demand is already higher than service use suggests; future planning must account for both current gaps and projected growth.
Health system pressures and service gaps	Pressures on acute care, workforce shortages and limited community capacity are shaping future care pathways and outcomes.	Increased reliance on hospitals and reactive care, highlights need to strengthen community and integrated models of care.
Dependence on unpaid carers	Unpaid carers play a central role but face significant practical and emotional burden.	Demand extends beyond patients to families; services must include proactive carer support, including respite and bereavement support.

Understanding future demand

The drivers outlined above point to a significant increase in future demand for hospice and palliative care services in Northern Ireland. Recent analysis commissioned by the Hospice Alliance estimates that the number of people who could benefit from palliative care has increased steadily over time and is expected to continue growing over the coming decade. Considering the proportion of deaths that could benefit from palliative care, the analysis estimates that between 15,800 and 19,000 people could benefit annually by 2036, representing growth of almost 17% compared with 2024 [12]. While these projections are illustrative rather than formal forecasts, they highlight both the direction and scale of future need.

This growth is also unlikely to be evenly distributed across Northern Ireland. The analysis suggests that projected increases in palliative care need vary considerably across Trust areas, ranging from approximately 7% in the Belfast area to almost 23% in the Western area by 2036. This reinforces the importance of aligning future hospice capacity, workforce and investment planning with projected local need, while ensuring equitable access to hospice and palliative care services across Northern Ireland.

These projections must be considered alongside evidence that significant unmet need already exists. Research cited above estimates that around one in three people die with unmet palliative care needs [13]. This means that Northern Ireland is planning from a position of deficit, with current provision not meeting need. Future growth in demand will occur on top of existing gaps in access, capacity and service provision.

The planning challenge is therefore twofold: additional capacity is needed both to meet actual need **and** to respond to the further growth in demand expected over the coming years. Maintaining current levels of service will not be sufficient. The scale of additional capacity required is significant. Our analysis illustrates that the projected 17% growth would mean almost 2,900 additional inpatient bed days, around 12,900 additional community contacts and approximately 2,500 additional outpatient and day service contacts annually by 2036. Without planning for and investing in this additional capacity, the gap between need and provision is likely to widen, with more people experiencing delayed access to support, avoidable crisis and greater reliance on reactive care.

Demand is also becoming more complex. Increasing numbers of people are living with multiple long-term conditions, advanced frailty, dementia and progressive illness, often requiring support over a longer period of time. This creates greater need for specialist symptom management, proactive care planning, coordinated multidisciplinary support and practical support for families and unpaid carers. It also increases pressure across primary care, community services, care homes, hospitals and hospices.

Policy direction and public preference both point towards a ‘shift left’ and more care being delivered closer to home. However, this can only be achieved if community-based palliative care services have the capacity and capability to respond. This includes primary care, District Nursing, specialist community teams, Hospice at Home services, rapid response models, integrated multidisciplinary support and access to specialist advice when needs change.

For hospice care, the challenge therefore is not simply to maintain existing services, but to strengthen current provision, close existing gaps and expand capacity in line with future demand. This will require coordinated planning for workforce, community and inpatient provision, infrastructure and funding. Without this, rising need will place increasing pressure on patients, families, hospices and the wider HSC system.

Equity of access

Rising demand is occurring within a system where access to hospice and palliative care remains inconsistent across Northern Ireland. Hospice Alliance Northern Ireland collectively delivers a wide range of services including inpatient care, specialist community nursing, Hospice at Home, outpatient and day services and bereavement support. However, access to these services is not consistent across Northern Ireland, rather it is influenced by geography, service availability and when support is required.

Hospice services have evolved through a combination of statutory commissioning and hospice-led service development and funding. While inpatient hospice services are commissioned centrally by the Department of Health Strategic Planning and Performance Group (SPPG), community palliative care services have developed through a more complex mix of HSC Trust contracts, central commissioning and hospice-funded activity. As a result, the availability and scope of services varies regionally.

Rurality further influences access to care. In rural areas, longer travel distances, workforce pressures and fewer local support services can make it more difficult for people to receive

care close to home. Research from Hospice UK found that two thirds of respondents from Northern Ireland reported that they or the person they cared for did not receive the care and support they needed, while four out of five rural health and care staff reported insufficient staffing to support people with life-limiting conditions. Notably this challenge was reported more frequently than across the UK as a whole [14].

Access is also influenced by when support is needed. Evening, overnight and weekend services are not consistently available across Northern Ireland. When needs escalate outside normal working hours, families have limited alternatives to emergency services, resulting in unplanned hospital attendance and admission. Marie Curie's recent analysis of unscheduled care in the last year of life found that 59.3% of Emergency Department attendances occurred during out of hours periods [15].

These variations in access are reflected in outcomes, particularly when it comes to place of death. While around 80% of people state they would prefer to die at home or in a hospice, almost half of deaths in Northern Ireland (47%) occur in hospital [16].

Awareness and understanding of palliative care are additional barriers to access. Misconceptions that palliative care is only for the final days of life or is limited to cancer services can delay referral and engagement, particularly within more deprived communities. As a result, some people may not even be aware of available support until their needs have become urgent.

Access challenges can also arise during transition from children's to adult services. Advances in treatment and care mean more young people with life-limiting conditions are surviving into adulthood, often with complex needs. Without effective transition arrangements, young people and their families may experience uncertainty and fragmented support at a critical stage of care.

Overall, access to hospice and palliative care is influenced not only by individual need but also by geography, service availability, care pathways, commissioning arrangements and public understanding. This results in significant variation in patients' and families' experiences across Northern Ireland and means that access to support can depend, in part, on where someone lives or when they need care.

Improving equity of access will therefore require more than addressing current variation. It will also require service planning and investment that take account of projected growth in demand. Without additional capacity, rising need is likely to intensify existing differences in access linked to geography, diagnosis, time of day and local service availability

We support a wide population including people who live in very rural areas, and sometimes that brings additional challenges for patients and families, as well as for our staff. Longer travel times and the practical realities of rural living can make access to care more difficult, particularly when patients' needs change quickly. Our teams work hard to bring care as close to home as possible, but everyone should have the same opportunity to access hospice care, regardless of where they live.

Annmarie Casey, Director of Nursing and Clinical Care, Foyle Hospice

Funding and commissioning

Hospice care has its roots in communities seeking better care for people at the end of life and stepping in to meet needs that were not being fully addressed by statutory services. This community-led ethos remains one of the great strengths of the hospice movement, however, the funding and commissioning arrangements that have developed around hospice care have not kept pace with the growing demand, complexity and delivery of core health services by hospices.

Our hospices operate within a mixed funding model, combining statutory contributions with significant reliance on charitable income. While statutory funding is intended to cover 50% of service delivery costs in Northern Ireland, based on Department of Health guidance from 2004, the reality is a substantially wider gap, with the state typically funding between 30%-40%. The challenge is compounded by a funding formula based on a benchmark that does not adequately reflect the specialist nature, intensity and true cost of care delivery [17].

In 2025/26, the total cost of hospice care across Northern Ireland was approximately £33.95 million, of which only £13.4 million was provided through statutory sources. This left a funding gap of around £20.5 million that hospices were expected to bridge through charitable income. This gap is becoming progressively harder to close. Hospice Alliance commissioned research identified growing reliance on charitable reserves to maintain core service provision, which risks weakening financial resilience across the sector and highlights additional concerns about the long-term sustainability of the current funding model.

Within the wider health system, this model represents a notable exception. Unlike other core clinical services, which are fully funded by the state, hospice services rely on ongoing charitable contributions to sustain day-to-day operations. This includes not only enhanced services or innovation, but, critically, core service provision. By contrast, in other areas where independent providers deliver services on behalf of the state (for example, elective surgical provision), funding arrangements typically cover the full cost of delivery.

This funding model is no longer tenable. Rising operating costs, including workforce-related pressures and inflation, are not consistently reflected in statutory allocations. At the same time, the external fundraising environment is becoming more challenging and fragile. These pressures are particularly acute in children's hospice services, where statutory contributions form only 38% of total funding, with direct implications for capacity – Northern Ireland Children's Hospice currently operates only 6 of its 10 beds for a region wide service due to lack of sustainable funding.

These funding challenges are exacerbated by the way hospice and palliative care services are commissioned. Unlike many areas of healthcare where commissioning is based on an agreed specification of activity and cost, there is no consistent regional agreement for hospice care provision. While inpatient hospice services are commissioned centrally through the SPPG, community services are contracted through a mix of Trust and central commissioning, each with its own requirements, practices and assessment of costs. In

addition, some hospice services have developed in response to local need without any formal commissioning arrangements and are funded entirely by the hospices themselves. As a result, service models and funding arrangements vary across Northern Ireland, creating unwarranted variation in provision and contributing to inequities in access and sustainability.

The current arrangements also make it difficult to align funding with demand. As the Hospice Alliance we believe that existing funding approaches do not adequately reflect the complexity or true costs of specialist palliative care, particularly within inpatient settings where the underlying costing assumptions are widely disputed. The absence of a common framework for service specification, costing and commissioning limits strategic planning and contributes to variation in access and provision across Northern Ireland.

A more sustainable approach is required - one that formally recognises hospice care as the core health service it is, aligns funding with population need, reflects the true cost and provides greater consistency across Northern Ireland.

Our workforce

Delivering care to a growing number of people with increasingly complex needs requires a workforce with sufficient capacity, skills and flexibility. Our hospices are made up of a skilled and committed multidisciplinary workforce, including doctors, nurses, allied health professionals, support staff and an army of volunteers. This workforce plays a central role not only in direct care, but also in supporting primary care and hospital teams through advice, education and shared models of care.

Nevertheless, workforce pressures remain significant. Shortages across specialist roles as well as across the wider HSC workforce, particularly in primary care, impact the capacity of hospice services. Recruitment challenges, especially in rural areas, further constrain provision and the expansion of much needed services. Positive developments such as the extension of advanced and extended roles, including community prescribing have been shown to make a significant difference. These approaches are strengthening the ability of hospices to respond flexibly, support care at home and reduce pressure on other parts of the system.

The challenge is not simply one of workforce numbers. Future demand will require new skills and ways of working as digital technologies and data-enabled approaches become increasingly embedded within care delivery. As hospice providers, we recognise that while our workforce is a major strength, without sufficient capacity and capability, the ability of hospices to respond to increasing demand, support care closer to home and contribute to wider system transformation will become increasingly constrained.

Addressing this challenge will require a workforce plan linked to future demand, alongside continued focus and investment in specialist capacity, education and new roles that strengthen palliative care capability across the wider system.

Data, insight and system visibility

Effective planning for future demand requires a clear understanding of activity, outcomes, population need and service impact. However, hospice and palliative care data in Northern Ireland remains fragmented. Information is collected differently across organisations, with no agreed regional dataset or shared approach to measuring activity, outcomes and impact. This makes it difficult to develop a comprehensive picture of hospice contribution across Northern Ireland.

The absence of consistent measures and reporting also limits the ability to benchmark services, understand variation, identify unmet need and assess how demand is changing over time. As a result, planners and decision-makers do not always have access to the information needed to support strategic investment, service development and workforce planning.

Visibility of hospice activity within wider HSC systems remains limited. While hospices provide a substantial volume of inpatient, community, outpatient, bereavement and advisory services, this contribution is not always reflected within regional planning and performance frameworks. The lack of a shared approach to outcomes measurement also makes it more difficult to demonstrate the full value hospices deliver for patients, families and the wider system.

These challenges are compounded by digital fragmentation. Data is held across multiple systems and organisational boundaries, while limited interoperability and integration with regional systems, including Encompass, can constrain information sharing and coordinated care. This affects both day-to-day service delivery and the ability to develop a clearer picture of need, activity and impact across Northern Ireland.

Without better visibility, shared measures and stronger integration, it becomes increasingly difficult to plan for future demand, benchmark provision, demonstrate value and ensure investment decisions are informed by robust evidence.

Our economic analysis reinforces this point. Without linked patient-level data across hospice, community, acute, emergency, ambulance, primary care, social care and patient and family outcomes, it is difficult to understand the full costs, pathways and impact of palliative care. The development of Encompass and the use of unique health and care numbers provide important opportunities to improve this evidence base over time. Taking advantage of these opportunities will require a more coordinated approach to data, outcomes measurement and digital integration, ensuring that future planning, investment and service improvement are informed by robust evidence.

Policy and strategic context

The challenges outlined above exist despite a policy direction that increasingly emphasises early intervention and care closer to home – ‘the shift left’. The Department of Health’s 2025 HSC Reset Plan [18] sets out a clear ambition for a neighbourhood-based model of care, which aligns with the community based strengths of hospice

services. However, the strategic framework for palliative care itself remains rooted in the 2010 strategy Living Matters, Dying Matters [19], which has not been comprehensively updated. As a result, there is no current system-wide strategy reflecting today's levels of demand and complexity.

The 2025 Committee for Health Inquiry Report on Access to Palliative Care Services [20] identified this strategy gap and made 27 recommendations to support more sustainable and equitable provision. At the same time, compared to other UK nations and the Republic of Ireland, Northern Ireland lacks a clearly articulated and consistently applied framework for planning and delivering palliative care.

This creates a gap between policy ambition and delivery, contributing directly to variation in access, fragmented services and uneven patient experience. Nevertheless, many of the ambitions set out in current policy, including earlier intervention, integrated care and supporting more people closer to home, align closely with the strengths of hospice care and highlight the important contribution hospices can make to future service delivery.

What this means for Northern Ireland

The challenges outlined present a stark picture. Demand for hospice and palliative care is increasing, significant unmet need already exists and access remains inconsistent across Northern Ireland. At the same time, funding, workforce and commissioning arrangements are not keeping pace with future requirements. Without action, the gap between need and provision is likely to widen, increasing pressure on patients, families, hospices and the wider HSC system.

Yet the evidence also points to a significant opportunity. Hospice care already delivers substantial benefit and makes an important contribution to a more effective and sustainable HSC system. The next section considers why investing in hospice care is not only necessary to sustain and strengthen existing provision, but also represents a practical and cost-effective response to the challenges facing Northern Ireland.

3. INVESTING IN HOSPICE CARE

The challenges outlined above are significant and are likely to intensify as demand for palliative care continues to grow. Maintaining the status quo is not an option. Without action, increasing numbers of people will face avoidable crisis, inequitable access to support and poorer experiences at the end of life, while pressure on already stretched HSC services will continue to increase. There is also a growing risk that financial pressures will force hospices to reduce capacity, curtail services or scale back future provision, further widening the gap between need and provision. In some parts of the UK, financial pressures have already contributed to hospice service closures or reductions, highlighting the importance of ensuring hospice services in Northern Ireland remain sustainable for the future.

This section sets out the human, system and economic case for investment in hospice care. As the Hospice Alliance Northern Ireland, we believe that investment is not simply about sustaining existing services, it is about improving outcomes for patients and families, strengthening a proven model of care and delivering value for money for Northern Ireland. Crucially, investment is needed not only to address existing gaps in access, but also to ensure capacity keeps pace with the projected growth in palliative care demand over the coming decade.

The human case

Terminal illness affects far more than a person's physical health. It can bring uncertainty, loss of independence, difficult decisions and emotional strain for both patients and those closest to them. Families and unpaid carers often take on significant responsibilities while trying to navigate complex health and care systems at the same time as coping with the practical and emotional realities of their loved ones' declining health.

Hospice care helps patients and families navigate these challenges by providing specialist support when it is needed most. For patients, this can mean relief from distressing symptoms, greater comfort and more opportunity to spend time on the things and relationships that matter to them. For families and unpaid carers, it can mean having the confidence, support and guidance needed to care for a loved one during a difficult and uncertain period. Hospice care not only helps families navigate the end of life journey, but deal with the wider implications, including impacts on paid work and other caring responsibilities.

Research shows that specialist palliative care improves quality of life, symptom control and emotional wellbeing, with the greatest benefits seen when support is introduced earlier in the course of illness [21]. The impact of this care often extends beyond the period of illness itself. The quality of care people receive at the end of life can shape how families experience bereavement for many years afterwards. Knowing that a loved one was comfortable, treated with dignity and supported in accordance with their wishes can bring reassurance and help families come to terms with their loss.

The case is also wider than the individual level. The way care is provided at the end of life reflects the values of a society as a whole - it speaks to how we recognise dignity, compassion and human worth at times of greatest vulnerability. Hospice care is one part of a wider system of support that helps ensure people are treated as individuals, not simply as patients, and that families are supported before, during and after death. Investment in hospice care is therefore about more than sustaining services, it is about ensuring that people approaching the end of life receive the care, compassion and support that our society believes they deserve.

We regularly see patients referred to our hospice inpatient unit with symptoms that have become overwhelming and difficult to manage. Often, within a matter of days – or hours, the right combination of specialist medication, clinical expertise and holistic support can transform their quality of life. What matters most is that this gives people the opportunity to live well until they die, spending meaningful time with loved ones, having important conversations and focusing on what matters most to them.

Dr Clare White, Consultant, Northern Ireland Hospice

The system case

Evidence from Marie Curie highlights the extent to which people in their last year of life rely on emergency services in Northern Ireland. More than 80% experienced at least one Emergency Department attendance, while around one in five calls received by the Northern Ireland Ambulance Service related to people in their last year of life. Once individuals enter the acute care system, the impact continues to be significant - two thirds of Emergency Department attendances result in a hospital admission, with an average length of stay of almost 14 days [22].

These patterns reflect a system in which palliative care is often introduced too late and where the absence of coordinated, specialist support contributes to avoidable crisis. When needs escalate without a clear plan, care can default to emergency and hospital-based responses, placing additional pressure on already constrained services.

Hospice care provides a practical alternative to crisis-driven care. By identifying people earlier, proactively managing symptoms, supporting families and coordinating care across services, hospices help prevent avoidable deterioration and reduce the likelihood that emergency services become the default option. As providers of specialist expertise, our contribution extends beyond direct care delivery by supporting generalist teams across the system, including GPs, district nursing, care homes and hospital teams. This includes advising on complex symptom management, supporting clinical decision-making and building capability across the wider workforce.

Evidence from elsewhere in the UK demonstrates the contribution hospice-led models can make to reducing pressure on acute services while improving outcomes. Integrated hospice-led services have shown reductions in hospital admissions, reduced use of emergency care, improved discharge pathways and increased achievement

of preferred place of death. In Lancashire, an integrated hospice-led urgent and emergency care programme avoided more than 2,000 admissions while generating estimated savings of over £6 million [23]. In Liverpool, the IMPaCT model reported a 44% reduction in hospital admissions in the final 90 days of life and an estimated 5,800 bed days saved annually [24].

Case study: Integrated Community Care – Belfast Palliative Care Hub

The Belfast Community Palliative Care Hub brings together Belfast Trust, Northern Ireland Hospice and Marie Curie into a single, coordinated service.

It provides one point of referral, shared triage and integrated multidisciplinary support, alongside access to urgent advice and care at home.

Since launching in April 2025, the model has supported over 1,000 patients and illustrates how closer integration between hospices and statutory services can improve access to specialist support, better symptom management and reduce reliance on Emergency Departments.

This model shows how stronger coordination, rather than new services alone, can create a more joined-up system, making it easier for patients to access the right care at the right time.

Hospice care provides a practical and evidence-informed alternative to reliance on acute services. By supporting timely identification of need, proactive care planning and the management of complex symptoms in the community, our hospices can help to:

- reduce avoidable emergency presentations and hospital admissions
- support more timely discharge from hospital
- enable more people to remain in their place of residence, in line with their preferences.

The Department of Health's *HSC Reset Plan* and its emphasis on neighbourhood-based models of care align closely with the community-based strengths of hospice services. Delivering more care closer to home, reducing avoidable hospital use and supporting people through integrated multidisciplinary teams are core features of hospice care and reflect the wider shift towards prevention, early intervention and neighbourhood-based care. By helping more people receive timely support in their own homes and communities, hospices are well placed to contribute to this transformation while building capacity to meet future demand. Investment in hospice care can therefore support wider system transformation and the delivery of a more sustainable, person-centred model of care across Northern Ireland.

The economic case

As demand for palliative and end-of-life care continues to grow, the sustainability of our hospice services has become an increasingly important issue for the Hospice Alliance. The key question is not simply what hospice services cost, but what the consequences would be if this capacity were reduced or no longer available. To explore this, we commissioned independent economic analysis to examine the contribution made by our adult hospices and the likely implications for the HSC system if equivalent services had to be provided elsewhere. The analysis focused on inpatient care, community specialist palliative care and outpatient and day-care services delivered across the hospice sector during 2024/25.

The findings are significant. The analysis estimated that replacing current hospice activity through HSC provision could cost up to £7.7 million more each year than its current delivery through hospices. When current levels of statutory funding are taken into account, the potential additional cost exposure to the HSC system was estimated at up to £27.2 million annually [25]. These figures are indicative rather than formal budget-impact estimates, but they point to a clear conclusion: reducing hospice capacity would be a false economy. The need for care would remain, while the HSC would incur greater costs to meet it within an already overstretched system.

Importantly, these estimates are likely to be conservative. They do not include the costs associated with creating additional capacity, recruiting and training specialist staff, expanding infrastructure or managing increased demand on emergency departments, hospitals, primary care and community services. As a result, the wider cost to the HSC system could be considerably greater than the direct replacement costs identified.

The evidence also highlights an important quality consideration. While some hospice activity could be replaced elsewhere in the HSC system, there is no guarantee that replacement services would achieve the same outcomes for patients and families. Hospice care provides specialist symptom management, psychosocial care, bereavement services and support for carers that can be difficult to replicate. The consequence of allowing hospice capacity to diminish may therefore not only be higher costs, but poorer experiences and outcomes for those approaching the end of life and those closest to them.

Particularly strong evidence was identified for community, outpatient and day-care services. These services were found to be delivered by hospices at a much lower cost than comparable replacement provision, while supporting care closer to home and reducing reliance on acute services. This is especially relevant given policy ambitions to shift care out of hospitals and into communities.

Perhaps most critically, the analysis reinforces concerns about the sustainability of the current funding model. A substantial proportion of hospice care continues to be funded through charitable income rather than statutory sources. The analysis indicates that current funding arrangements do not fully reflect the true cost of delivering specialist hospice care and that continued reliance on charitable income and reserves is a growing risk to the long-term sustainability of services.

Demand for palliative care is projected to continue rising over the coming decade, while many people already experience unmet need. In this context, maintaining hospice capacity is not simply a matter of supporting charitable organisations. It is about protecting specialist health service capacity that patients, families and the wider HSC system rely upon. The economic evidence suggests that allowing that capacity to diminish would not remove the cost of care. Rather, it would risk transferring greater cost, pressure and complexity into a system that is already facing significant financial, workforce and capacity challenges. Sustainable investment in hospice care should therefore be viewed as an investment in better outcomes for patients and families, more effective use of finite resources and a more resilient HSC system for Northern Ireland.

Why investment matters

The case for investment in hospice care is clear. Without action, growing demand, existing unmet need and continuing pressures on funding and workforce capacity will increase the gap between need and provision, with consequences for patients, families and the wider HSC system. At the same time investment in hospice care offers clear benefits. Investment offers an opportunity to:

- **improve outcomes and experiences for patients and families**
- **enable more care to be delivered closer to home and in line with people's preferences**
- **reduce avoidable crisis and additional pressure on an already over-stretched HSC system**
- **deliver value for money and support more effective use of finite resources.**

The evidence presented above demonstrates that investment in hospice care is not simply about sustaining existing services, it is about ensuring Northern Ireland has the capacity, capability and infrastructure needed to meet rising demand, address unmet need and deliver more equitable, high-quality and sustainable care in the years ahead. The next section sets out the Hospice Alliance's vision for achieving this and the five priorities that will be critical to future success.

4. A SHARED VISION

Our vision is focused on a shared end goal: that everyone in Northern Ireland who could benefit from palliative care can access the right support, at the right time, in the right place and in a way that reflects what matters most to them and their families.

Delivering this vision requires action across three connected pillars: equity, quality and sustainability. These pillars are not separate ambitions, but rather are mutually reinforcing:

- **Equity:** More equitable access depends on sustainable funding, workforce capacity and reliable data.
- **Quality:** Higher-quality care depends on timely identification, stronger community provision, better integration across services and a shared commitment to patient safety, clinical effectiveness and continuous improvement.
- **Sustainability:** Sustainable hospice care depends on recognising the sector as a core part of Northern Ireland’s HSC infrastructure.

Achieving this vision will require shared action across the wider HSC system. Some changes will depend on decisions and actions by the Department of Health or HSC, while others can be progressed directly by the Hospice Alliance through collaboration, innovation, evidence generation and shared learning.

The five priorities below set out where change is most needed and where collective effort is likely to have the greatest impact. These priorities are relevant across the age spectrum and include the specialist paediatric palliative care services provided by Northern Ireland Children’s Hospice, which faces many of the same challenges and opportunities identified throughout this report.

EQUITY	QUALITY	SUSTAINABILITY
Priority 1: <i>Ensuring equitable access for all</i> Access based on need, not geography, diagnosis or circumstance.	Priority 2: <i>Expanding care closer to home</i> Priority 3: <i>Workforce capacity and capability</i> Care delivered earlier, closer to home and supported by the right skilled teams.	Priority 4: <i>Sustainable funding and commissioning reform</i> Priority 5: <i>Leadership, partnership and innovation</i> Funding, commissioning, data and leadership arrangements that enable delivery.

Priority 1: Ensuring equitable access for all

Everyone who could benefit from palliative care can access timely support based on need, regardless of diagnosis, post code or personal circumstance.

Why this matters

Access to palliative care remains inconsistent across Northern Ireland, with variation in service availability, care pathways, referral patterns and public understanding. Without action, opportunities to identify need earlier and provide timely support will continue to be missed, leaving some people with avoidable pain, distress and unmet need.

Action framework

<i>Actions required across the system</i>	• Strengthen referral pathways so that access is based on need and is not limited by diagnosis or local service availability. • Support timely identification of palliative care need across primary care, community services, hospitals and care homes. • Develop and evaluate consistent approaches to specialist palliative care advice, referral and coordination, including out-of-hours models. • Develop clear and coordinated transition pathways for young people with life-limiting conditions, ensuring continuity of care and support between children's and adult services. • Target investment and service development towards under-served geographies, populations and disease groups. • Improve public understanding of palliative care through community engagement and awareness-raising, e.g. through Compassionate Community initiatives.
<i>What the Hospice Alliance will do</i>	• Use shared intelligence and evidence to identify variation in access and help understand unmet need. • Work with partners to support timely identification and referral, particularly for people with non-cancer conditions, frailty and multimorbidity. • Strengthen community engagement and public understanding, including approaches that normalise conversations about serious illness, dying and bereavement.
<i>Success measures</i>	• Development of an agreed measurement approach and dataset • Evidence of reduced variation in access across geographies and patient groups. • Improved public and professional understanding of palliative care.

Priority 2: Expanding care closer to home

More people are able to receive coordinated palliative care in their home, or usual place of residence, with rapid access to specialist advice when needs escalate.

Why this matters

In line with policy ambitions, most people at the end of life would prefer to receive care in their home, usual place of residence or hospice rather than defaulting to hospital at times of crisis. However, this depends on community-based services having sufficient capacity, clear referral routes and access to specialist advice and coordination when needs change. Without action, more people will experience avoidable crises, as well as hospital admissions and be less likely to receive care in their preferred place.

Action framework

Actions required across the system	- Further development of community-based palliative care capacity and funding, including hospice at home, rapid response and specialist community support. - Strengthen integrated multidisciplinary models linking hospices, Trusts, primary care, district nursing, ambulance services and care homes. - Simplify referral and access pathways, including single points of access or coordinated triage where appropriate. - Use data on demand, hospital use and patient outcomes to guide service design and investment.
What the Hospice Alliance will do	- Develop, test and share models that support more people to remain at home or in their usual place of residence. - Work with system partners to design, test and evaluate rapid response, urgent advice and coordinated care models. - Champion simpler access pathways and shared approaches to triage, escalation and care planning.
Success measures	- Increased consistency of access to community-based palliative care across Trust areas. - Clearer access routes for patients, families and professionals. - Reduction in avoidable Emergency Department attendance and hospital admissions where new models are implemented. - More people supported to die at home or in their preferred place.

Priority 3: Workforce capacity and capability

A skilled and sustainable hospice and palliative care workforce, supported by a workforce plan that aligns capacity and capability with projected demand across all care settings.

Why this matters

Growing and more complex demand cannot be met without a skilled and sustainable workforce. This includes specialist palliative care staff, generalist teams across the wider system and the substantial contribution of volunteers. Workforce pressures in primary care, community services, hospitals and rural areas also affect the ability of hospices to expand care closer to home. Without action, increasing workforce pressures will lead to delays in access to specialist support and make it harder to provide consistent, high-quality care to patients and families.

Action framework

Actions required across the system	- Develop system-wide palliative care workforce plan aligned to projected demand and future service models. - Invest in specialist palliative care capacity across hospice, community and hospital settings. - Strengthen palliative care capability among generalist staff, including GPs, district nurses, care home staff, ambulance services and hospital teams. - Support new and enhanced roles, including roles that improve responsiveness in community settings. - Recognise hospice staff as integral to the wider palliative care workforce, with sustainable terms, conditions and support. - Build future workforce capability in digital care, remote monitoring, data-informed practice and safe use of AI-enabled tools where these support earlier identification, coordination and care closer to home.
What the Hospice Alliance will do	- Develop a shared hospice-sector workforce strategy linked to projected demand, service models and workforce risks. - Strengthen education, training, placements and clinical support for the wider workforce. - Explore and develop shared resource models, including new roles, digital capability and approaches that support recruitment, retention and succession planning.
Success measures	- Development and implementation of agreed workforce strategy - Improved understanding of specialist workforce gaps and future capacity requirements. - Increased education, training and support delivered to generalist teams. - New or enhanced roles tested and scaled where evidence shows benefit. - Increased workforce confidence and capability in digital care, remote monitoring and data-enabled approaches.

Priority 4: Sustainable funding and commissioning reform

Agreed regional arrangements for the funding, commissioning and delivery of hospice and palliative care services, providing patients with more consistent, equitable access to care.

Why this matters

Hospices deliver critical clinical services but are not funded or commissioned on the same basis as other health services. Current arrangements do not reflect the true cost of care, resulting in continued reliance on charitable income and reserves to sustain core provision. This creates a risk not only for individual hospices, but for the wider HSC system: if hospice capacity is reduced, the need for care will remain and the HSC may face substantially greater costs to replace services it currently funds only in part. The absence of a consistent regional approach to commissioning also limits the sector's ability to plan and invest for the future. Without reform, growing financial pressures could undermine the capacity of hospices to meet rising need and maintain equitable access to services.

Action framework

Actions required across the system	- Acknowledge hospice care as a core component of Northern Ireland's HSC system. - Develop and agree regional level service specification. - Agree funding principles that reflect population need, deprivation, service specification, workforce costs and the true cost of specialist care. - Develop a consistent regional approach to commissioning hospice and palliative care services. - Move towards longer-term, predictable and outcomes-focused funding arrangements.
What the Hospice Alliance will do	- Maintain a unified sector position on sustainable funding and commissioning reform. - Develop a shared outcomes and impact framework to demonstrate patient, family and system value. - Work with commissioners and policy partners to model future demand, service requirements and cost implications. - Use charitable income to support innovation, enhanced services and community connection.
Success measures	- Agreed definition of core hospice provision and the services to be funded and commissioned. - Funding principles developed and agreed against population need and true cost. - Progressive narrowing of the gap between statutory funding and cost of core service delivery, towards 100% funding of commissioned services. - Shared outcomes and impact framework adopted across Alliance members.

Priority 5: Leadership, partnership and innovation

Strong leadership, partnership and innovation that improve patient and family experience and support continuous improvement across the system.

Why this matters

Delivering this vision will require more than individual service improvements. Strong leadership, effective partnership working and shared accountability are needed to coordinate action across organisations, align priorities and support implementation at regional and local level. It will also require a commitment to listening to and learning from the experiences of patients, families, carers and bereaved people, ensuring that lived experience helps shape priorities, service improvement and future service design. Better data, digital integration and innovation can then provide the insight, evidence and infrastructure needed to drive continuous improvement and informed decision-making. Without clear leadership and coordination, progress across all of the other priorities will be slower and more difficult to sustain.

Action framework

Actions required across the system	- Empower and embed regional clinical and system leadership for palliative and end-of-life care. - Recognise the Hospice Alliance as an equal strategic partner and work collaboratively to co-design policy, commissioning frameworks, service specifications and service improvement initiatives. - Strengthen regional governance and coordination arrangements, including existing partnership structures, to support shared learning, implementation and collective action. - Develop a shared data and measurement framework covering activity, outcomes, patient and family experience, demand and system impact. - Improve digital integration and visibility of information across systems, in order that hospices achieve parity with trusts in terms of access to shared patient data. - Ensure digital and data-enabled innovation is accompanied by workforce development, clinical governance and support for staff to use new tools safely and effectively.
What the Hospice Alliance will do	- Act as a unified and constructive voice for the hospice sector in Northern Ireland. - Convene a programme of collaboration, continuous improvement and innovation across hospices. - Develop a common approach to collecting, analysing and reporting activity, outcomes, patient and family experience and quality measures, ensuring lived experience informs benchmarking, learning, service improvement and investment decisions.
Success measures	- Clearer regional leadership arrangements empowered and connected to delivery. - Hospice Alliance routinely engaged as an equal strategic partner in the co-development of regional policy, commissioning and service improvement frameworks. - Shared data and measurement framework. - New models of care piloted, evaluated and shared across the system.

5. FROM VISION TO ACTION

The publication of the Committee for Health Inquiry Report on Access to Palliative Care Services has created important momentum for change and work is already underway across a number of its recommendations, including the commissioning of an independent review of adult hospice inpatient bed costs, supported by the Hospice Alliance. This report is intended to contribute to that wider agenda by setting out the Hospice Alliance's perspective on the changes needed to strengthen hospice care in Northern Ireland and ensure it can meet current and future need.

The evidence presented throughout this report points to a clear challenge. Demand for hospice and palliative care is increasing, needs are becoming more complex and significant unmet need already exists. At the same time, hospices face growing pressures in relation to funding, workforce capacity and service sustainability. Without action, the gap between need and provision is likely to widen, with consequences for patients, families, communities and the wider HSC system.

However, the report also highlights a significant opportunity. Hospice care improves quality of life, supports families, helps prevent avoidable crisis and contributes to a more effective and sustainable HSC system. The evidence suggests that investment in hospice care is not simply an investment in individual services, but in a model of care that delivers benefits for people, communities and the wider system, while providing value for money. Crucially, the economic evidence also indicates that if hospice capacity is allowed to diminish, the need for care will not disappear. Instead, the HSC system could become responsible for both replacing that activity and funding services currently supported substantially through charitable income, transferring greater pressure and cost into a health and care system that is already under significant strain.

The five priorities set out in this report provide a framework for action. They are intended to support ongoing discussion, decision-making and improvement across the system and will require collaboration between government, HSC, primary care, the voluntary and community sector and people with lived experience.

Following publication of this report, the Hospice Alliance will work with partners, including the Department of Health, to translate these priorities into action and align them with existing policy and implementation programmes. We will undertake a prioritisation exercise to identify where collective effort can have the greatest impact and develop a focused programme of work aligned to the agreed priorities. This will provide a structured approach to advancing the actions set out in this report, sharing learning across hospices and supporting collaboration, innovation and improvement within the Alliance's areas of influence. Delivering the vision in full will also require decisions, investment and sustained action from government, commissioners and the wider HSC system. Progress will be reviewed regularly in light of emerging evidence, policy developments and population need.

The future envisioned in this report is one in which more people are able to live well for as long as possible despite serious illness. A future in which families feel supported rather than overwhelmed, where conversations about death and dying happen earlier and where fewer people experience avoidable crisis at the end of life. Above all, it is a future in which more people are able to experience comfort, dignity and choice, with care that reflects what matters most to them and those they love.

With the end in mind, the Hospice Alliance stands ready to work with partners to turn this vision into reality.

Hospice Alliance Northern Ireland



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