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Future Needs and Emerging Trends in Palliative Care

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

Contents

Key Points

Rising Demand Amid Constrained Resources

Palliative and end-of-life care (PEOLC) services for both adults and children in Northern Ireland are facing increasing demand, driven by an ageing population, a higher prevalence of chronic and complex conditions, and earlier identification of palliative needs. This demand is growing within a context of limited financial and workforce capacity, underscoring the need for strategic planning and resource allocation to meet future needs.

The Need for Coordinated Strategic Direction

Northern Ireland does currently have a comprehensive, up-to-date adult strategy for PEOLC. Previous strategies and reviews-such as the RQIA review and the Palliative Care in Partnership (PCiP) programme - have identified key priorities, including 24/7 access to specialist support and wider uptake of advance care planning. Full implementation of these priorities remains outstanding, and progress has been further impacted by external factors such as the COVID-19 pandemic.

Variation and Challenges in Evaluation and Investment

Many PEOLC services have evolved in response to local needs or opportunities, often without robust evaluation or standardised data collection. This variation makes it challenging for commissioners to assess value, scalability, and impact-particularly in a financially constrained environment. Enhanced data infrastructure and consistent measurement approaches could support quality improvement and informed decision-making.

Innovation as a Bridge to System Reform

Emerging innovations in service delivery-such as digital advance care planning platforms, nurse-led helplines, and integrated care pathways-offer pragmatic, lower-cost solutions that can be implemented in the short term. These models support families and frontline staff while broader reforms, such as a refreshed strategy or legislative change, are developed. The case studies contained in this briefing align with previous frameworks could complement more comprehensive system reform. These approaches offer practical ways to progress regional ambitions using updated tools and methodologies.

Targeted Innovations to Address Service Gaps

Innovative approaches are being developed to address persistent gaps in PEOLC, including:

- Anticipatory and advance care planning (ACP)
- Out-of-hours and 24/7 support
- Integrated digital and remote services
- Transitions between children’s and adult services
- Support for carers and bereavement
- Education and workforce development

Each of these areas represents a targeted response to identified needs and aligns with current regional work plans.

Advance Care Planning: An Underused Opportunity

Advance care planning remains underused in Northern Ireland, despite its potential to improve patient outcomes and align care with individual preferences. Innovations such as digital ACP platforms and community-based facilitation are expanding access and quality, helping patients articulate their wishes earlier and supporting more person-centred care.

Scalable Models for 24/7 Support

Accessible, round-the-clock advice and symptom management are achievable through scalable models, including nurse-led helplines, virtual consultations, and shared care planning tools. These initiatives can reduce stress for families, improve patient experience, and decrease reliance on emergency services.

Supporting Transitions from Children’s to Adult Services

Transitions between children’s and adult PEOLC services benefit from structured, co-designed models that promote continuity, build confidence in adult services, and maintain holistic support for young people and their families. Regional priorities include improving care pathways and enhancing collaboration across services.

Coordinating the Innovation Ecosystem

Co-ordinating service innovations as part of a broader ecosystem can maximise impact - integrating digital, clinical, community, and organisational elements. This approach enables resource sharing, minimises duplication, and fosters cross-sector learning and improvement.

Enabling Innovation Through Infrastructure and Leadership

Sustaining innovation requires investment in clinical and managerial leadership, research partnerships, ICT capability, and robust evaluation processes. Embedding these elements into commissioning arrangements can support continuous improvement, accountability, and the scaling of effective models.

A Strong Evidence Base for Commissioning Decisions

By moving beyond incremental funding uplifts for existing models, strategic commissioning can instead incorporate evidence-based innovations that improve quality, efficiency, and staff satisfaction. Effective commissioning should reflect changing population needs, greater clinical and system complexity, and heightened expectations for flexible, responsive care.

Other research briefing papers in this series:

Paper 1: Introduction to palliative and end of life care

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

Paper 3: How other countries fund and deliver palliative care

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

Paper 5: Future needs and emerging trends in palliative care

1. Introduction

Health systems across the globe are facing unprecedented challenges in delivering high-quality palliative and end-of-life care. Ageing populations, rising multimorbidity, constrained public finances, and increasing demand for personalised care are converging to exert pressure on existing service models. In this context, there is a pressing need for timely, scalable innovations in palliative care that are cost-neutral, cost-saving, or demonstrably cost-effective.

Palliative care, though recognised as an essential health service by the World Health Organization, often remains underfunded and inconsistently integrated across care settings. There is broad consensus among researchers, policymakers, and clinicians that more equitable, person-centred care is needed. Yet delivery mechanisms are frequently siloed and reactive, particularly at key transition points such as discharge from hospital, the shift from children's to adult services, or the onset of terminal decline. This briefing paper explores emerging models and practical innovations that address these challenges head-on, blending economic pragmatism with ethical imperatives.

The innovations profiled here span a wide range of domains - from clinical practice to community engagement and service delivery. They include examples of embedding palliative care in diverse settings such as primary care, care homes, and retirement villages; improving transitions between children's and adult services; providing 24/7 access to specialist support and advice; supporting carers through structured assessment and care planning tools; strengthening communication about dying and bereavement; enhancing access to key medicines and equipment in the community; establishing interoperable information-sharing platforms; developing metrics to evaluate palliative care quality, including patient- and carer-reported outcomes; and trialling innovative funding models to stabilise and scale services.

Innovations such as 'No Barriers Here' and 'Planning Ahead' highlight the importance of adapting advance care planning tools for underrepresented or marginalised populations. Further case studies address how real-time digital tools and the standardisation of emergency care plans (e.g. ReSPECT) can enhance information sharing across settings, while the CSNAT-I intervention and Macmillan’s REACT model demonstrate structured approaches to support unpaid carers and provide emergency home-based care.

There is also a growing evidence base around quality metrics, such as the use of the Supportive and Palliative Care Indicators Tool (SPICT), Clinical Frailty Score (CFS), and the development of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs). These enable health systems to prioritise and tailor care more effectively, while facilitating evaluation of service delivery and impact.

Importantly, successful implementation depends not just on the quality of the intervention, but on the process of introduction and adaptation. Evidence from other health systems suggests that innovations in palliative care are more likely to succeed when introduced incrementally, supported by piloting, championed by multidisciplinary leadership, and embedded in co-production processes involving patients, carers, and professionals. Mechanisms for shared learning, protected time for implementation, and meaningful alignment between commissioners and service providers are also key to effective translation into practice.

While substantial and lasting improvements to palliative and end-of-life care in Northern Ireland may ultimately require broader structural reform - such as legislative change, the redesignation of palliative care as a core healthcare service, or the development of a long-term strategic framework - these are complex processes that take time and are for decision-makers to consider. Other research briefings in this series examine these longer-term possibilities in more detail. While these approaches may offer routes to more systemic improvement, they are complex and require time to implement. In the meantime, this briefing paper presents a range of innovative models and approaches that have a strong evidence-base and may be considered by those commissioning or delivering palliative and end-of-life care in Northern Ireland and similar health systems.

2. Demand for Palliative and End of Life Care in Northern Ireland

2.1 Adults

Recent analysis by Marie Curie (2023), using official mortality statistics, estimated that approximately 90 per cent of people who died in Northern Ireland between 2017 and 2021 would have benefitted from palliative care. This is in line with estimates across the UK and reflects the growing need to address multimorbidity, frailty, and chronic illness in ageing populations. In 2021 alone, this would equate to nearly 15,000 people in Northern Ireland.[1]

Three different estimation methods were used to assess need. The minimal estimate - which used only the underlying cause of death - suggested about 73 per cent of deaths (around 12,000 people) between 2017 and 2019 required palliative care. During the pandemic (2020–2021), this dropped to 66 per cent because many COVID-19 deaths did not list chronic conditions as the primary cause. By contrast, the intermediate estimate, which included both underlying and contributory causes of death, captured the impact of multimorbidity and estimated palliative care need at 90 per cent of deaths. The maximal estimate, excluding only deaths from injury or pregnancy, puts potential need at 94 per cent.[2, 3]

These figures suggest that current planning based on the outdated 75 per cent benchmark underestimates true need. Moreover, the Office for National Statistics (ONS) projects that Northern Ireland will experience the largest proportional increase in deaths requiring palliative care of any UK nation, with a 32 per cent rise expected between 2023 and 2048.[4] Much of this increase will be driven by a doubling of the population aged over 85. Dementia, frailty, and complex multimorbidity are expected to rise substantially in this cohort, requiring earlier integration of palliative approaches.

2.2 Children and Young People

While the absolute numbers are smaller, the complexity and intensity of need in paediatric palliative care are significant. According to Fraser et al. (2020), the number of children and young people in the UK living with a life-limiting condition (LLC) increased from 52,633 to 86,625 over a 10-year period.[5] This rise is due in part to medical advances enabling more children with serious illnesses to survive into adolescence or adulthood.

The prevalence of LLCs is highest among children under 12 months, particularly those with congenital anomalies. Each year, around 2,000 children with LLCs die in the UK, all of whom require complex, multi-agency support across hospital, community, and home-based care. While not all will need specialist palliative care, many will - often for extended periods that blur traditional definitions of end-of-life care.[6]

In Northern Ireland, these trends are consistent, and children's services face increasing demand at a time of workforce constraints and funding pressures. Unlike adult care, the boundaries between complex disability, chronic illness, and palliative care are less distinct in children's services. This makes coordination and tailored service provision even more important.

As survival increases and more children live longer with profound needs, demand for children's palliative and hospice services is expected to rise. Planning should therefore consider not just end-of-life care, but a continuum of support that begins at diagnosis and may last many years.

3. Embedding Palliative Care in Every Setting

Ensuring that high-quality palliative care is available across every setting - not only in hospitals or specialist hospices - is a challenge for health systems seeking to deliver truly person-centred end-of-life support. Many patients with palliative needs reside in care homes, receive support from primary care, or live independently with fluctuating conditions that do not necessitate hospitalisation but do require skilled, compassionate care. Innovative models that embed palliative care principles across these environments have shown measurable impact.

The **Gold Standards Framework (GSF)** has been widely implemented in the UK to improve the identification of patients approaching the end of life, support advance care planning (ACP), and facilitate multidisciplinary care coordination.[7, 8, 9] GSF provides structured tools, education programmes, and benchmarking resources. Its implementation across primary care settings - such as in the **Frontrunners in Primary Care** project - has led to significant reductions in unplanned hospital admissions and increased the proportion of patients dying in their preferred place.[10]

An illustrative case from **Cape Hill Medical Centre** in Birmingham demonstrated the value of GSF in care homes.[11] Following implementation, hospital admissions dropped by a third (from 60-38), hospital bed days were halved (from 488 to 222), and deaths in hospital fell sixfold. Unscheduled GP home visits and telephone call requests fell, whereas scheduled contact from GPs increased from zero to two sessions a week, enabling proactive reviews. This intervention not only improved patient experience but reduced service burden and overall costs.

Retirement villages and extra care housing present unique opportunities for embedding GSF in community-based models. These settings often support individuals with frailty, dementia, and long-term conditions who may otherwise struggle to access coordinated palliative care. Pilot schemes show that GSF use in these environments fosters consistent, anticipatory planning and reduces crisis interventions.[12] [13]

Complementary to GSF is the **Daffodil Standards**, developed by the Royal College of General Practitioners and Marie Curie.[14] These provide quality improvement benchmarks for general practice and have been adapted for use in care homes, particularly in response to the COVID-19 pandemic. The standards promote a holistic, personalised approach and are recognised by regulators such as the Care Quality Commission (CQC). The **North Bristol Trust Care Home Interface Project (NCHIP)** exemplifies how secondary and community services can collaborate using such frameworks, ensuring that 'what matters most' to patients drives care planning.[15]

Hospice at home services are delivered in a variety of ways. A recent evaluation in England found they can support high-quality end-of-life care, with 73% of patients dying in their preferred place, usually at home. Despite differences in size, funding, and hours, services were generally linked to a ‘good death’ as reported by bereaved carers. Effective models shared features such as sustainability, integration, skilled staff, carer support, and hands-on care. Areas for improvement included greater use of volunteers and bereavement support. The research suggested that outcomes may be improved by securing financial sustainability and expanding access to a broader range of patients.

These examples share common features: structured training, strong leadership, cross-boundary coordination, and an emphasis on shared documentation and early identification. When implemented alongside digital tools and system-wide policy support, they offer replicable models for embedding palliative principles across healthcare settings.

4. Ensuring 24/7 Specialist Access and Responsive Support

Patients with advanced illness often experience rapid deterioration, unpredictable symptoms, or crises that arise outside of standard working hours. These moments can result in distress, emergency admissions, and treatment misalignment with patients' preference - especially when healthcare professionals lack timely access to palliative care expertise. Addressing this gap, several innovations now focus on providing round-the-clock access to specialist support, advice, and emergency care.

One of the most extensively evaluated models in this space is the **Gold Line** service, implemented in Bradford District and Craven.[16] Designed for individuals identified as being in the last year of life, the Gold Line provides a 24/7 telephone support line staffed by experienced clinicians who have access to the caller's shared digital health records. The Gold Line helps patients and carers manage symptoms, make informed decisions, and avoid unnecessary emergency admissions. Data from a York Health Economics Consortium (YHEC) evaluation found that 78 per cent of Gold Line patients achieved their preferred place of death, compared with a national average of 52 per cent. The model demonstrated a 23 per cent reduction in non-elective admissions and saved nearly 2,000 hospital bed days when scaled. With a cost of £240,000 to serve 1,000 patients, it achieved an estimated return on investment of up to £2 for every £1 spent.[17]

Similarly, **Marie Curie's REACT (Responsive Emergency Assessment and Community Team)** is a nurse-led home visiting service offering urgent response for patients with palliative needs.[18, 19] REACT enables timely interventions in the community, improving symptom control and reducing hospital conveyance. Although formal economic evaluations are limited, early service data point to high patient satisfaction and a reduction in emergency calls. The REACT model of palliative care is currently implemented in Northern Ireland. However, during his evidence session to the Committee for Health as part of the Inquiry into Access to Palliative Care, Professor Max Watson emphasised that acute care-at-home services are not universally accessible.[20]

The **IMPaCT (Integrated Mersey Palliative Care Team)** model exemplifies how a consultant-led, multi-professional team can coordinate end-of-life care across Liverpool and South Sefton.[21] IMPaCT's proactive identification and integrated case management approach led to 154 fewer acute hospital admissions in a six-month period for a cohort of 1,000 patients, saving 5,883 hospital bed days annually.[22]

Elsewhere, **Supportive Care UK** provides outsourced 24/7 specialist palliative advice to healthcare professionals working in care homes, general practice, or community settings.[23] This is particularly relevant in regions facing persistent palliative workforce shortages, such as rural Northern Ireland. The potential cost and workforce efficiency of such a solution should be further explored.

The **"Just-in-Case"** approach, which ensures anticipatory medicines and essential equipment are available in patients' homes, complements these models by providing practical tools to avoid crisis escalation.[24, 25, 26] When integrated with 24/7 advice and triage systems, such strategies create an ecosystem of care that is responsive, equitable, and efficient. Paramedics carrying just-in-case end-of-life care medication found that symptom relief was achieved, with no adverse events being recorded. An economic evaluation is being undertaken to further explore the cost-effectiveness of this approach.[27]

These services are not without implementation challenges. They require interoperable digital records, local buy-in, and clarity about clinical governance, particularly in cross-organisational settings. However, they represent some of the most replicable and cost-effective innovations currently available and offer a roadmap for service planners looking to improve out-of-hours support in end-of-life care.

5. Enhancing Advance Care Planning and Information Sharing

Advance Care Planning (ACP) plays a vital role in ensuring that individuals' values, goals, and preferences for future medical care are known and respected. When done well, ACP enhances the patient experience, reduces unnecessary or unwanted interventions, and supports care delivery in alignment with personal priorities. However, ACP remains underutilised in many health systems due to lack of awareness, clinician hesitancy, fragmented documentation, and unequal access.

Innovations in this domain address not only the mechanics of ACP but also its accessibility, cultural inclusivity, and integration across care settings. A good example of this is the **ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)** process, which supports shared decision-making between professionals and patients.[28, 29] ReSPECT produces a standardised, portable document summarising clinical recommendations for emergencies when the person cannot express their wishes. Widely recognised across England, it complements existing tools such as DNACPR forms and Advance Decisions to Refuse Treatment (ADRT).[30, 31] Its use is expanding across primary, secondary, and community care.

The *Advance Care Planning: For Now and For the Future* policy document for all adults in Northern Ireland was launched in October 2022, providing a framework for Advance Care Planning for all adults in Northern Ireland.[32, 33] The ReSPECT process and ADRT document forms an integral part of this policy document.[34]

Digital tools are increasingly being deployed to make ACP more accessible and consistent. The **"Planning Ahead" online platform** helps patients explore, document, and share their care preferences before engaging with healthcare providers.[35] It encourages reflection on values and enables people to arrive at ACP conversations prepared. General practitioners across several regions now routinely signpost patients to the tool, helping demystify the process.

The **"No Barriers Here" project** illustrates how ACP tools can be adapted through co-production to meet the needs of underserved populations – for people excluded by identity, culture, ethnicity and race.[36, 37] One such example, developed in partnership with Dudley Voices for Choice,[38] focuses on inclusive approaches for individuals with learning disabilities, aiming to address health inequalities and communication gaps that may otherwise limit their involvement in end-of-24/7 life decision-making. The project uses visual resources and action research to help staff initiate meaningful, person-led conversations.

Interoperability and information-sharing are key to the success of ACP. When clinicians can quickly access up-to-date care plans, duplication is reduced, and care becomes more coordinated. Two widely used systems include **Electronic Palliative Care Coordination Systems (EPaCCS)** and the **Urgent Care Plan** in London (formerly known as Coordinate My Care). [39, 40] These tools enable real-time access to preferences and clinical information across ambulance services, hospitals, GPs, and community teams. Despite variability in uptake and technical integration, evaluations have found improved alignment with preferred place of death and reductions in avoidable admissions.

Challenges persist, however. ACP remains more often associated with what patients do not want (such as resuscitation or hospital admission) rather than what matters most to them. A shift in emphasis is now advocated through charters such as **"What Matters to Me"**, which reframes planning as an affirmative, values-based process.[41, 42] Embedding this approach into the culture of healthcare delivery requires time, training, and strong leadership - particularly in systems under pressure.

Moreover, effective ACP relies on broader engagement beyond the clinical setting. Public health approaches, including **death cafés**,[43] [44]**death positive libraries**,[45] educational campaigns, and compassionate communities, are all contributing to a shift in death literacy. These societal initiatives complement clinical tools and help normalise conversations about dying, fostering an environment where ACP is more likely to be embraced by both professionals and the public.

The future of ACP innovation lies in inclusive design, digital integration, and value-driven engagement - building systems that both record and honour the wishes of people approaching the end of life.

Ambulance services play a key role in ensuring that individuals' care preferences are honoured, facilitating a 'good death'—one that is dignified and ideally occurs in the setting of their choice. Effective communication of advance care decisions is crucial in this context. Transfers at the end of life can be either planned or unplanned, and ambulance clinicians often face the challenge of making rapid, critical decisions with limited information. This underscores the importance of developing end-of-life care pathways for ambulance services through robust inter-organisational collaboration. Such pathways can significantly enhance the likelihood of achieving preferred outcomes for patients. [46]

6. Supporting Carers and Families

Unpaid carers, often family members or close friends, play a critical role in supporting people with life-limiting conditions, particularly in home-based and community settings. Despite their centrality, carers frequently experience emotional, physical, and financial strain, often with insufficient support from formal health and social care systems. The COVID-19 pandemic further exacerbated these pressures, making carer support a priority for palliative care innovation.

A well-evidenced response to carer needs is the **Carer Support Needs Assessment Tool Intervention (CSNAT-I)**.[47] This structured, person-centred intervention allows carers to identify, prioritise, and articulate their needs using a comprehensive tool based on 15 key support domains. Carers are then guided through a tailored support planning process in partnership with trained facilitators.

Evaluations show that CSNAT-I not only improves carers' experiences and wellbeing but also reduces carer burden and avoids crisis escalation. Crucially, the CSNAT-I framework is free for NHS and non-profit use, making it a cost-effective, scalable innovation for system-wide adoption.[48]

Innovative bereavement support services are also emerging as integral parts of palliative models. One such programme is **Marie Curie's "Companions in Grief"** service in Scotland.[49] This volunteer-led model pairs trained lay companions with recently bereaved individuals for structured emotional support in the weeks following a death. By offering continuity and empathy at a time of vulnerability, the initiative addresses loneliness and mitigates mental health risks—both of which can drive unplanned health service use.

Community-led approaches such as the **Compassionate Communities NI "Plan Ahead" day** seek to empower families earlier in the disease trajectory.[50] These initiatives blend education, peer support, and advance care planning within a community development model. Outcomes include improved death literacy, more open conversations about dying, and reduced anxiety among both patients and families.

Several models now also integrate carer engagement directly into multidisciplinary team (MDT) processes. For example, the **IMPaCT service in Merseyside** ensures that carers are routinely assessed, informed, and supported through case coordination meetings.[51] Embedding carer perspectives within professional workflows is key to ensuring that services align with the lived experience of both patients and those who care for them.

The importance of such innovations is not only moral but economic. Carers provide the majority of end-of-life care in Northern Ireland, often delaying or avoiding the need for residential or hospital-based services. However, if unsupported, carers are at higher risk of becoming patients themselves—experiencing burnout, depression, or physical illness. Carers NI estimates that carer's in Northern Ireland save the health service £5.8 billion annually.[52, 53] Furthermore the ill health of carers can lead to direct and indirect costs for the health service.

Despite these clear benefits, barriers to implementation persist. Staff require time and training to deliver structured carer support, and carer engagement is often not built into commissioning frameworks or performance metrics. Moreover, data collection on carer outcomes remains limited, making it difficult to benchmark or track improvements over time.

Future development in this area could be supported by integrating **carer-reported experience measures (CREMs)** into routine service evaluation and commissioning.[54] In Northern Ireland, there is a strong carer culture and community, hence there is a significant opportunity embed structured carer support into all tiers of palliative care, to improve patient and carer outcomes and to utilise healthcare resources effectively.

7. Improving Access to Medicines and Equipment

The ability to manage symptoms effectively at home is central to high-quality palliative and end-of-life care. This often depends on timely access to medications - particularly those used for pain, breathlessness, agitation, and nausea - as well as the rapid provision of essential equipment such as syringe drivers, pressure-relieving mattresses, and mobility aids. Delays or gaps in provision can lead to uncontrolled symptoms, distress, and potentially avoidable hospital admissions.

One practical solution, as mentioned earlier - is the use of **"Just-in-Case" medication boxes**, which contain pre-prescribed drugs for anticipated symptoms in the last days of life.[55] These are typically stored in the patient's home and accessed by visiting clinicians as needed. Studies show that Just-in-Case systems can prevent unnecessary hospital conveyance, empower carers, and support community teams to deliver dignified end-of-life care. However, the evidence base for cost-effectiveness is still developing, and successful deployment relies on training, appropriate prescribing, and timely review mechanisms.

To support consistent practice, the **Royal Pharmaceutical Society**, in partnership with **Marie Curie**, has developed **Professional Standards for Palliative and End of Life Care in Community Pharmacy**.[56] These standards provide guidance on stock availability, advice-giving, and communication between pharmacists and prescribers. While adoption varies across the UK, some areas - including Northern Ireland - have begun aligning community pharmacy services with these emerging best practices, particularly in rural regions where access to urgent medication is more constrained.

Timely access to equipment is also essential. Delays in the delivery of hospital beds, oxygen supplies, or toileting aids can significantly impair quality of life and make it difficult for people to remain at home. Innovative local partnerships - such as pooled equipment budgets between health and social care providers - have demonstrated improved efficiency and fewer failed discharges. Some Integrated Care Systems (ICSs) in England are piloting automated equipment ordering systems linked to electronic care records, reducing friction and delay.

Another emerging area is the use of **pharmacy-based anticipatory prescribing**, where community pharmacists are empowered to work with palliative care teams to dispense urgent medication directly, without the need for repeat GP intervention.[57] Early feedback suggests that this model can significantly reduce wait times and out-of-hours pressure, particularly when linked to shared care records.

However, the optimisation of medicine and equipment access is not just logistical. It also requires cultural and educational shifts. Many community teams - especially those not traditionally involved in palliative care - may lack confidence in prescribing or using certain medications. Embedding structured education, such as that delivered through **Project ECHO networks**, can help build local confidence and standardise practices.

In sum, improving access to medication and equipment in the community is a low-cost, high-impact area of innovation. The challenges are mostly operational rather than conceptual, and the solutions already exist in practice. With enhanced commissioning support and better integration of pharmacy and equipment services into multidisciplinary palliative care pathways, these innovations are both scalable and sustainable.

8. Quality Metrics and Continuous Improvement

The measurement of quality in palliative care has historically lagged behind other areas of health care, in part due to the complexity and subjectivity of outcomes. Nevertheless, the development and use of reliable, patient-centred metrics is increasingly recognised as essential for improving care, informing commissioning, and enabling continuous service refinement.

One promising approach involves the use of **clinical tools for early identification**, such as the **Supportive and Palliative Care Indicators Tool (SPICT)**[58] and the **Clinical Frailty Score (CFS)**. These tools help clinicians recognise patients who may benefit from a palliative approach, prompting timely referrals and advance care planning. In one evaluation, the combined use of SPICT and CFS was associated with a 78 per cent reduction in A&E attendance and a 71 per cent reduction in hospital admissions for the identified population, while also improving the rate of deaths in patients’ preferred place.

Another approach centres on the use of **Patient-Reported Outcome Measures (PROMs)** and **Patient-Reported Experience Measures (PREMs)**.[59] These tools gather data directly from patients and carers on their symptoms, wellbeing, and experience of care. In palliative care, where priorities often include comfort, dignity, and family support, such measures provide critical insight beyond clinical indicators. Several services across the UK - including in Scotland, London, and Yorkshire - have begun embedding PROMs and PREMs into routine palliative care pathways. However, challenges remain around standardisation, IT integration, and ensuring feedback translates into action.[60]

The role of learning collaboratives and quality improvement networks is also growing. During the COVID-19 pandemic, **Hospice UK's Project ECHO** became a major platform for peer learning and service adaptation.[61] The ECHO model of "All Teach, All Learn" facilitated rapid knowledge exchange among hospices, primary care teams, and academics, generating more than 15 research studies and supporting frontline adaptation through case sharing and scenario planning. As a quality improvement infrastructure, ECHO offers a scalable and low-cost way to support continuous learning and best practice dissemination – Marie Curie are currently reviewing an ECHO Impact and Evaluation Strategy. ECHO is currently being implemented in Northern Ireland.[62]

More traditional quality improvement (QI) projects also have a place. At **Ashford and St. Peter's Hospital**, a multidisciplinary QI project targeting the care of elderly inpatients led to a 53 per cent to 88 per cent reduction in discharge delays and a 38 per cent to 59 per cent reduction in delays to care home placements. Notably, the average length of stay decreased from 15 to 12 days, releasing 4,000 bed days per year and saving approximately £1.4 million - without requiring additional staffing or external funding. This project also improved staff morale and patient satisfaction, reinforcing the role of relational, team-based improvement work.[63]

The **GeriPall initiative at Epsom and St Helier** further illustrates how geriatric and palliative care can be integrated to improve outcomes.[64] Its hybrid model of in-hospital and virtual ward care supported more than 300 high-need patients during the pandemic and was shortlisted for national awards in patient safety and older people's care. Such initiatives demonstrate the potential of integrated models to generate cost savings while improving care quality.

Importantly, quality measurement should not be restricted to clinical outcomes. Carer burden, bereavement support, and continuity of care also need attention. Few health systems consistently measure these domains, yet they are often central to the palliative care experience. The integration of **Carer-Reported Experience Measures (CREMs)** into palliative quality dashboards could help address this gap.[65]

In recent years, the field has matured in its approach to measurement and improvement, moving beyond audits to embrace real-time data, lived experience, and cross-system learning. Northern Ireland, is well-positioned to lead in embedding meaningful metrics into palliative care commissioning and practice due to its population size and clinical leadership.

9. Transitions in Children and Young People's Services

Young people living with life-limiting conditions often face significant disruptions in care when they reach adulthood. While children's palliative care tends to be holistic, proactive, and family-focused, adult services may be more fragmented and less tailored to developmental and psychosocial needs. This discontinuity can cause emotional distress, unmet clinical needs, and reduced service engagement. Addressing the transition gap has become a growing priority for policy and practice.

The **“Improving Transitions for Young People” programme** led by *Together for Short Lives* funded ten pilot projects to explore how to improve the transition experience.[66] Evaluated by the York Health Economics Consortium (YHEC), these projects ranged from developing transition coordinators and digital “passports” to offering joint clinics and GP training modules. Key outcomes included improved coordination of care, greater familiarity with adult hospice services, and enhanced psychosocial wellbeing for young people and their families. Though cost-effectiveness was difficult to quantify robustly, several projects demonstrated reductions in emergency service use and duplication of care efforts.

One of the most comprehensive transition services is the **“Stepping Up” programme** at Acorns Children’s Hospice.[67] It provides young people aged 14 to 25 with vocational support, peer group activities, and tailored health transition planning. Early evaluations show reduced emergency healthcare usage and improved self-efficacy, highlighting how continuity and empowerment can reduce system strain while enhancing autonomy.

Here in Northern Ireland, the **All-Island Children’s and Young People’s Palliative Care Network** has begun testing joint working arrangements across the paediatric-adult interface.[68] Examples include nurse-led coordination clinics and shared documentation strategies. Feedback suggests that early introduction to adult services, coupled with parallel planning and person-centred transition assessments, helps to build trust and reduce family anxiety.

Innovative models like the **Horizon House** in Bristol provide transitional palliative support within a residential setting that bridges children’s and adult hospice care. The house offers both short breaks and longer-term stays for young adults, ensuring continuity in clinical and emotional support as they age out of paediatric services.

Despite progress, major barriers remain. Adult services are often not designed to meet the needs of individuals with complex disabilities who are accustomed to the wraparound support provided in paediatric settings. Commissioners may lack clarity on funding responsibilities, and young adults can be left without a clear care coordinator. Furthermore, the transfer process often occurs at a fixed age (e.g., 18) rather than based on readiness or individual development.

Key ingredients for successful transition services include early preparation, family engagement, flexible age boundaries, and integrated care planning. Co-production with young people and their carers has emerged as a cornerstone of best practice, ensuring that service design reflects real needs and preferences.

Given Northern Ireland’s scale and relatively integrated health and social care system, the region is well-placed to test and embed these models. Doing so could significantly improve outcomes for this vulnerable group, reduce long-term service costs, and ensure that palliative care principles extend equitably into early adulthood.

10. Conclusion

This report has presented a range of innovative approaches to improving palliative and end-of-life care - spanning clinical settings, communication strategies, carer support models, service reconfigurations, and system-level reforms. These innovations are not prescriptive solutions, but rather form a flexible and evolving menu of options that policymakers and commissioners may consider as they work to enhance the quality, sustainability, and equity of care for those at the end of life.

A unifying theme across all the examples is that innovation should be grounded in the values of compassion, personalisation, and dignity. Yet values alone are insufficient. Real-world adoption depends on pragmatic factors: strong leadership, supportive policy frameworks, coordinated commissioning, and meaningful stakeholder involvement. Without these enablers, even well-evidenced interventions risk becoming siloed or unsustainable.

Implementation science - the study of methods to promote the adoption and integration of evidence based practices into routine healthcare and public health settings - provides a useful lens here. Effective change often requires:

- **Piloting in real-world settings**, with mechanisms for feedback and adaptation;
- **Multidisciplinary leadership** to guide, embed, and normalise new practices;
- **Co-production with patients, families, and frontline staff** to ensure relevance, acceptability, and sustainability;
- **Aligned funding models** that reduce silos and reward outcomes, not just activity; and
- **Evaluation frameworks** that prioritise not only clinical and economic metrics but also lived experience, cultural fit, and equity.

Importantly, these innovations highlight areas where gaps remain. Carer support is still inconsistently embedded in service design. Digital systems for shared care planning are advancing but face challenges around interoperability and access. While quality metrics are improving, they should evolve to reflect broader aspects of wellbeing, bereavement, and social support. Transitions from children’s to adult services, though receiving increased attention, remain a vulnerable juncture requiring long-term investment and structural reform.

The options outlined in this research briefing present both opportunities and challenges for service commissioners. Many of the case studies included are adaptable and transferable, while others could serve as a foundation for locally tailored solutions, developed in collaboration with communities. The examples provided - ranging from low-cost digital tools and community-led initiatives to evidence-based clinical models – demonstrate that meaningful progress can be achieved in financially constrained environments.

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