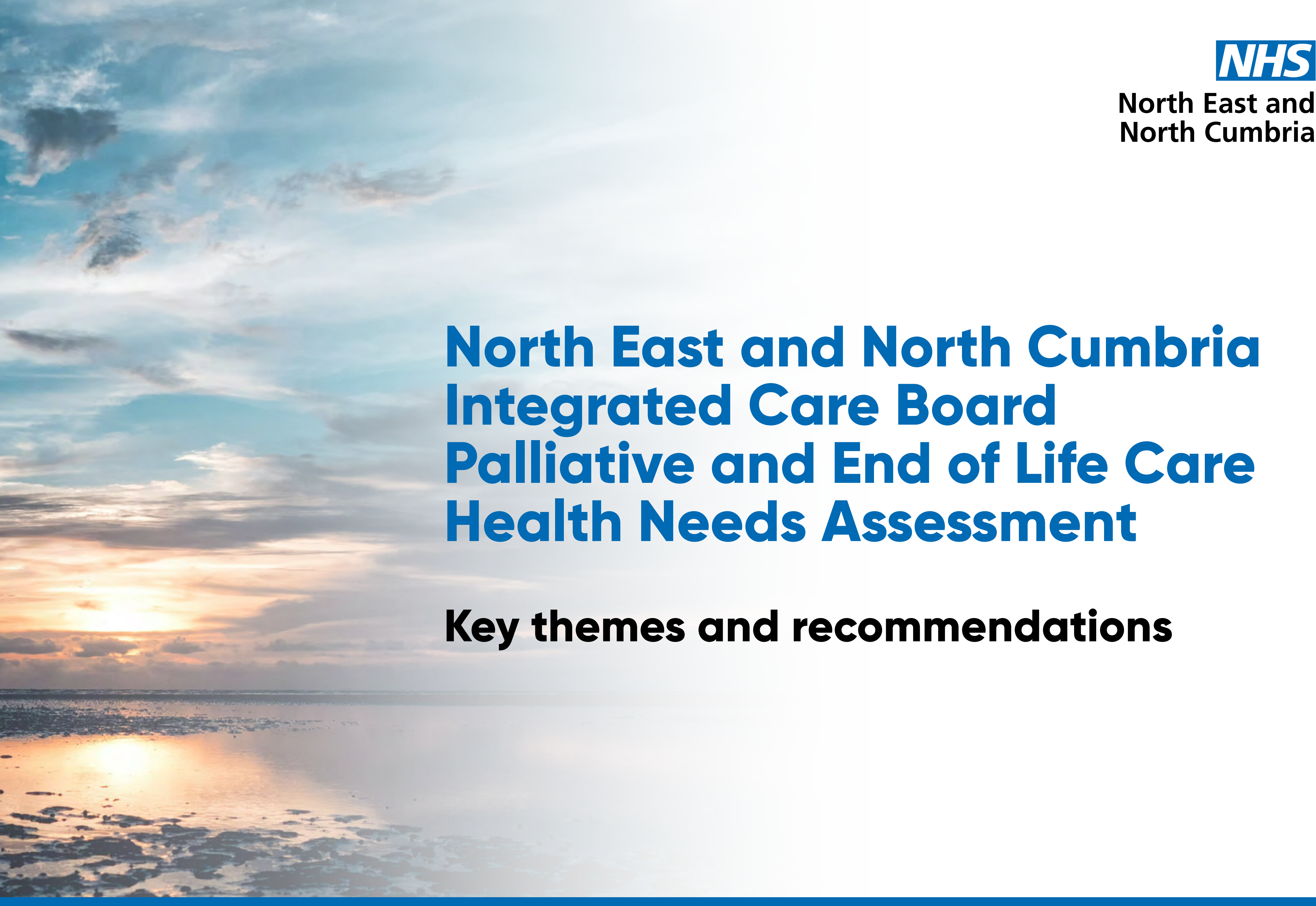

NHS
North East and
North Cumbria

North East and North Cumbria Integrated Care Board Palliative and End of Life Care Health Needs Assessment

Key themes and recommendations

Contents

About this Report	3
Foreword	4
Recommendations	5
Background	15
Data Summary	30
Evidence: Policy and Literature Review	33
Community Engagement	35
Workforce	38
Children and Young People's Palliative and End of Life Care Services	39
Place Summaries	40
Conclusion	41
Authors and Contributors	42
Good Practice Examples	43

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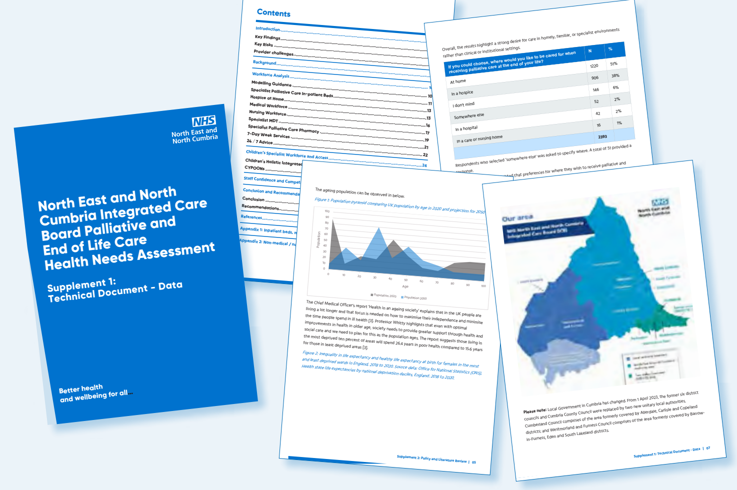
About this Report

The overall aim of this North East and North Cumbria Integrated Care Board (NENC ICB) Palliative and End of Life Care Health Needs Assessment (PEoLC HNA) is to provide a comprehensive overview of the current data, evidence and service provision. The HNA also looks at the future need for palliative and end of life care for the NENC population. This information will support the development of future commissioning intentions and guide the strategic approach across the region.

Supplemental reports

This work draws information from a range of sources and key stakeholders. Further information is contained within six supplements to this report:

- Supplement 1: Technical Document - Data
- Supplement 2: Policy and Literature Review
- Supplement 3: Community Engagement
- Supplement 4: Specialist Palliative Care Workforce Review
- Supplement 5: Children & Young People Specialist Palliative Care Review
- Supplement 6: Place Based Summaries of Palliative and End of Life Care Services



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5

6

Foreword

As Clinical Lead for the Palliative and End of Life Care (PEoLC) Network in the North East and North Cumbria, I am delighted that the PEoLC Network has produced this comprehensive review looking at the health and wellbeing needs of Palliative Care patients across our region.

For the North East and North Cumbria the number of Palliative and End of Life Care Patients is projected to increase by over

39% by 2043.

For each one of them, there is only one opportunity to deliver the high-quality care that they need.

For the first time in just over a decade, we can now understand the wishes and service requirements for our Palliative and End of Life Patients and their Carers here in our region.

This report also clearly explains the needs and various challenges that face us to enable our services and communities to deliver this care to a high standard. There is particular focus on our underserved communities.

Understanding our regional need allows us to build upon the excellent services already in place across our providers, work collaboratively to start bridging the gaps and helps us develop high quality, reactive and caring services to ensure that patients, their families and carers receive the best possible support at this important time in their lives. This Health Needs Analysis is fundamental to this work.

Thank you to the many people involved in this report.

KHall

Dr Kathryn Hall, General Practitioner
Clinical Lead for the Palliative and End of Life Care Network North East and North Cumbria

Recommendations

The recommendations that follow are drawn directly from a range of evidence including, data analysis, literature review and community engagement and in collaboration with key stakeholders.

Together, they set out a clear, system wide programme of change required to deliver equitable, high quality palliative and end of life care (PEoLC) across North East and North Cumbria.

The recommendations are intentionally explicit, action focused and aligned to ICB, providers, local authorities, place and neighbourhood teams, recognising that variation in access and experience will persist unless addressed through coordinated commissioning, delivery and leadership.

The recommendations should be reviewed and used by commissioners and providers as a foundation for PEoLC services across the region to support collaborative transformation. This will help ensure compliance with statutory duties, drive quality improvement, and promote more equitable care.

Recommendation 1

Embed strategic leadership for palliative and end of life care within neighbourhood health and place based governance

ICBs, provider organisations, neighbourhood teams and local authorities must ensure clear, visible leadership for palliative and end of life care, embedded within neighbourhood health arrangements and wider system transformation.

This should include:

- Explicit inclusion of PEoLC within place strategies, neighbourhood health plans and Joint Health and Wellbeing Strategies
- Clear accountability for delivery and improvement at system, place and neighbourhood level
- Use of population health need and Joint Strategic Needs Assessments (JSNA) to inform local priorities and address inequalities
- Ongoing assurance of progress, quality and equity through standard data collection and reporting

Recommendation 2

Level up access to 7 day and 24/7 specialist palliative care across NENC

ICB commissioners must establish and deliver a system wide programme of work to reduce unwarranted variation in access to specialist palliative care, ensuring equitable 7 day face to face services and 24/7 access to specialist advice for all populations, regardless of place, diagnosis, deprivation or age.

This should include:

- Clear minimum access expectations aligned to national service specifications and key clinical guidelines (i.e. NICE guidance for adults and children's care) and the need for multi-disciplinary team (MDT) provision
- A focus on areas with the greatest unmet need and highest deprivation
- Sustainable workforce and commissioning models that reduce reliance on goodwill
- Monitoring and assurance of access and service delivery, through contract commissioning teams at place.
- Provide feedback to commissioners regarding unmet need from routine care provision

Recommendation 3

Strengthen early identification of palliative and end of life care need across all pathways

ICB commissioners and providers must ensure earlier, consistent identification of people who would benefit from palliative and end of life care, including those with non cancer diagnoses, frailty and multiple long term conditions.

This should include:

- Systematic use of primary care palliative care registers across all practices
- Use of compassionate and timely prognostic indicator tools and digital systems to support timely identification
- Alignment with NICE guidance and quality standards for end of life care
- Shared responsibility across primary, community, acute and specialist services
- Improved public awareness and engagement in the above (see Recommendation 8).

Recommendation 4

Improve recognition of dying and response in the final days and weeks of life

Providers of health and social care services must consistently recognise when people are entering the dying phase and respond appropriately, to avoid unnecessary hospital admissions and support care in the person's preferred place of care and death (PPOC/PPOD).

This requires:

- Workforce confidence in recognising dying, including acute and rapid deterioration (e.g. National Audit of Care at the End of Life (NACEL) audit recommendation for specialist and generalist training)
- Clear escalation and de-escalation pathways across settings, including out of hours
- Access to timely clinical advice, medicines and practical support
- Ensure timely access to Continuing Health Care (CHC) funded care packages for care placement to support achievement of PPOC/PPOD
- Proactive and practical planning that supports safe discharge and crisis avoidance

Recommendation 5

Deliver universal, high quality advance care planning and coordination of care

ICB commissioners and providers (health, social care and third sector) must ensure universal access to high quality advance care planning (ACP) so that people's preferences are understood, reviewed and respected throughout their illness trajectory.

This should include:

- Universal, system wide implementation of the Deciding Right approach as a practice framework used by all settings
- Training for generalist and specialist staff to support confident, meaningful ACP conversations
- A public communication campaign to raise awareness of the Deciding Right initiative with residents, patients, carers and families.
- Facilitate choice through better information (see Recommendation 8)

Recommendation 6

Enable effective sharing of personalised care records across the system

ICB commissioners and providers must continue to prioritise digital interoperability for palliative and end of life care, ensuring that personalised care records are visible and accessible to all professionals involved in a person's care.

This should include:

- Preparation for wider system interoperability, including alignment with the Great North Care Record and National Care Records Service
- Consistent recording and sharing of Deciding Right documents
- Inclusion of hospices, community and social care services in information sharing solutions
- Recognition that digital readiness is essential for safe, coordinated out of hours care

Recommendation 7

Invest in a capable, confident and sustainable palliative care workforce (both generalist and specialist) to meet the requirements of the new National Service Framework Specification.

ICB commissioners and providers must ensure the workforce has the capacity, capability and confidence to deliver high quality palliative and end of life care, recognising that most care is delivered by generalist teams supported by specialist expertise.

This requires:

- Access to education and training for all relevant professional groups, across health and social care
- Focus on communication skills, managing uncertainty, symptom control and ethical decision making
- Embedding palliative and end of life care principles within pre-registration education and professional development pathways
- Embedding and monitoring requirements in relevant ICB contracts with providers

Recommendation 8

Embed community centred and public health approaches to palliative and end of life care

Partners across the integrated care system must work together to strengthen community capacity to support people who are living with serious illness, dying and bereavement.

This should include:

- Expansion and sustainability of compassionate community approaches across NENC
- Strong collaboration with voluntary, community and faith sectors
- Integration with neighbourhood health models and local authority wellbeing agendas
- Improve health literacy across the life course to increase public awareness, confidence and engagement with conversations about death and dying

Recommendation 9

Deliver a coordinated, equitable palliative care pathway for children and young people

ICBs and NHSE specialised commissioners must work together to deliver a coherent, system wide approach to children and young people's (CYP) palliative and end of life care, including effective transition to adult services.

This requires:

- A shared CYP palliative care model aligned to national guidance
- Early, proactive involvement of palliative care from diagnosis across the disease trajectory
- Improved identification, data collection and oversight of CYP palliative care need
- Clear transition pathways to prevent loss of continuity and support as young people move into adult services
- Equitable access for children with non-malignant life limiting conditions through supporting current Children's Holistic Integrated Palliative Care Service (CHIPS) service development to meet the national service specification requirements.

Background

Death and dying are an inevitable part of life.

After decades of a stable, slightly declining death rate, demographic trends mean that the annual number of deaths nationally, currently approximately

650,000

is steadily increasing. It will reach

780,000 **in 2040.**

People are living longer due to improvements in public health, vaccinations, and advances in medical treatment. Consequently, people are experiencing longer periods of ill-health before the end of life and more people are living longer with multiple health conditions. This is expected to place further pressure on health and social care services.

People approaching the end of their life experience a range of physical symptoms, as well as emotional and spiritual needs. To manage these issues effectively requires integrated and multidisciplinary working between teams and across sectors regardless of whether the person is in their home, in hospital, a care home, or hospice. Families and carers of people at end of life also experience a range of problems and will have their own specific needs which must be addressed before, during and after the person's death.

Nationally, as the Palliative Care report states, throughout the debate on the Terminally Ill Adults (Assisted Dying) Bill there has been broad agreement that palliative and end of life care services in England are inadequate. These services are under significant pressure, with providers struggling to fund and commission the right care, and individuals entering a 'postcode lottery' of care in their most vulnerable moments at the end of life. These issues are further compounded by a workforce declining in numbers, a lack of access to and use of effective data, a poorly equipped social care system, and an unsustainable funding model.

Both the collated data and intelligence and the literature review demonstrate that unwarranted variation exists in the quality of palliative care and end-of-life care people receive. It is also evident that there have been improvements: identification of palliative and end of life need is increasing, deaths outside hospital and in the individuals achieving their preferred place of death are increasing, and there are many pockets of excellent practice, and much that can be shared and implemented more widely and systematically.

This all-age HNA was conducted to evaluate current palliative care needs across the North East and North Cumbria to identify gaps in services, accessibility and care delivery for individuals in the palliative and end stages of life, with a particular focus on those who experience health inequalities.

The HNA collated and analysed data from many sources and was completed in collaboration with key palliative care stakeholders including staff from hospitals, hospices, primary care and pharmacies, individuals with lived experience and voluntary sector partners.

The findings will directly inform future commissioning decisions, service design, and system priorities. By combining population data, clinical evidence and lived experience, the Health Needs Assessment aims to create a shared understanding of how to deliver high-quality, equitable and compassionate palliative and end-of-life care across the North East and North Cumbria.

It is recognised that while there are many high quality services, and some people experience good quality end of life care, many people do not. The focus on supporting people to receive care and be supported to die in their preferred place of care, requires a future shift in culture and in service provision from the acute hospitals to the community.

Palliative and end of life care: past, present and future

Palliative care did not invent care of the dying. Families and communities have been caring for people dying for as long as humanity has existed. However, trends in care provision and place of death have changed.

In the early 20th century around

80% of people died at home, cared for by their families.

Today, only around

25-30% of people die at home,

and families and communities shared that talking about death is still hard and that families and carers need more support.

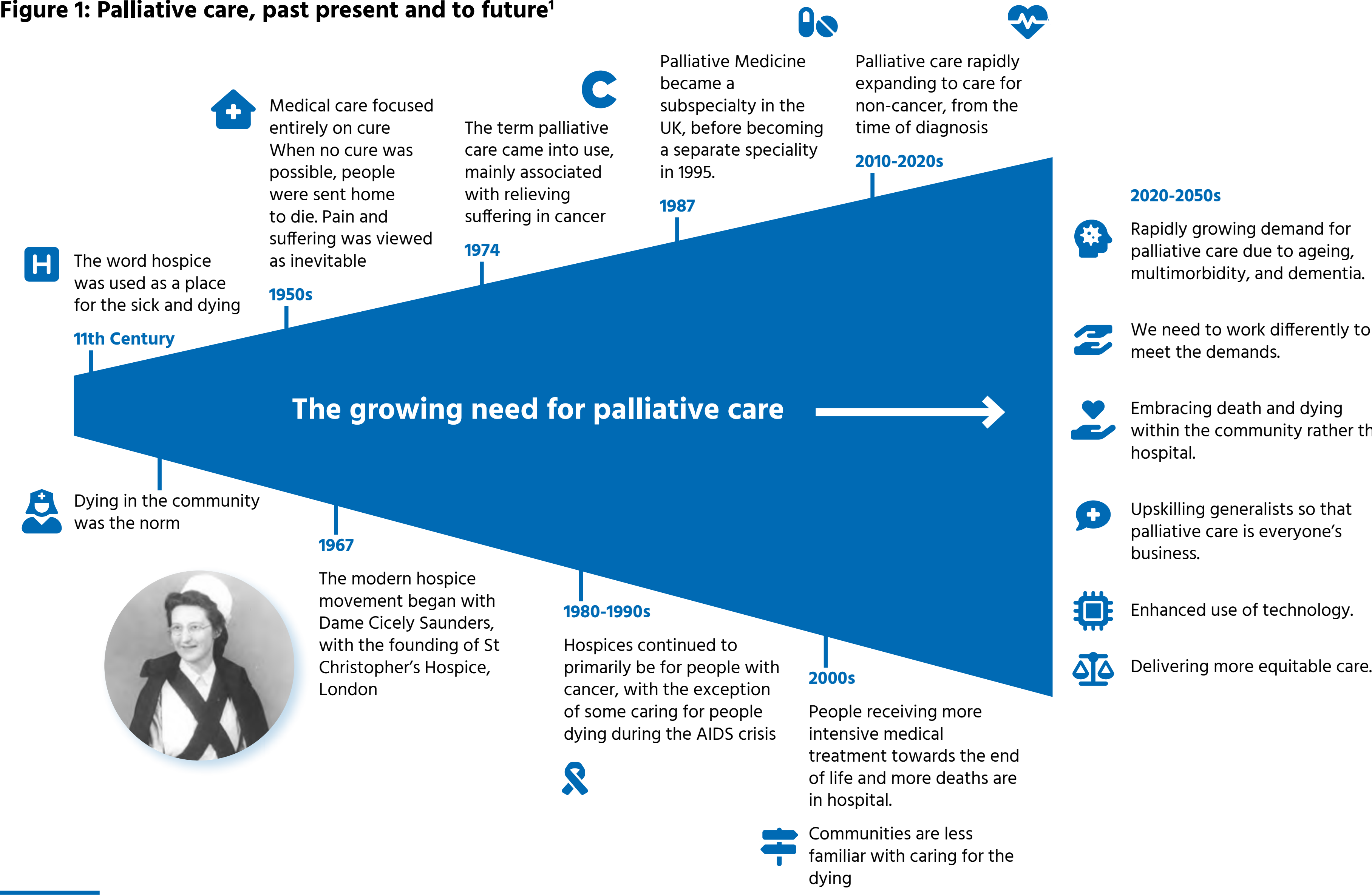
The growing ageing population and rising multimorbidity will almost certainly lead to a rise in palliative care need. Currently, around

75% of people approaching the end of life would benefit from palliative care.

The trend is starting to change, hospital deaths in the UK have fallen in the past decades, with an increase in the number of patients dying out of hospital since the publication of the End of Life Strategy in 2008.

Palliative and end of life care: past, present and future

Figure 1: Palliative care, past present and to future[1]



1 Palliative medicine in 2050: how will people live the last part of life? - ScienceDirect www.sciencedirect.com/science/article/pii/S2514664526000147

Background

NENC ICB is responsible for planning NHS services for the local population, which includes the care provided by NHS Trusts, GP practices, community pharmacies, NHS dentists, NHS opticians, and independent sector healthcare providers.

ICBs have four key aims:

Improve outcomes in population health and healthcare

Tackle inequalities in outcomes, experience and access

Enhance productivity and value for money

Help the NHS support broader social and economic development

The Health and Care Act 2022 states that ICBs have a legal responsibility to commission health services, including palliative care services, that meet their population needs, aligning to the commitments within the Ambitions for Palliative and End of Life Care: A national framework for local action. This responsibility is intended to ensure that “the palliative and end of life care needs of people of all ages, with progressive illness or those nearing the end of their lives, and their loved ones and carers, receive the care and support they need to live and to die well.” (Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards, 2022).

ICBs have legal duties and professional obligations to address health inequalities for PEoLC by improving access to services and reducing inequity of outcomes and experience. To support this, ICBs should utilise a population health management approach to planning PEoLC services.

The NENC ICB Better Health and Wellbeing for All, Joint Forward Plan 2023–2028 demonstrates the ICBs commitment to further developing PEoLC services and included the following work programmes:

- Improving access to care: this includes ensuring 24/7 generalist services and remote access to specialist palliative care (SPC) advice for staff and carers, in all places. As well as seven-day face-to-face SPC services in all places including the use of virtual wards or other models.
- Improving quality irrespective of age, condition, or diagnosis, with greatest improvement for locally identified priority groups.
- Develop the workforce across statutory and Voluntary, Community and Social Enterprise (VCSE) sectors with the support and capability to deliver high quality.

The NENC ICB have established a PEoLC HNA Steering Group to oversee the delivery of a programme of work that will enable access to good quality and equitable end of life care across North East North Cumbria. Membership of the PEoLC HNA Steering Group is made up of representatives from NENC PEoLC Clinical Network including, specialist palliative care, primary care, children and young people's services, pharmacy, local hospices and the PEoLC strategic groups from the nine localities across North East North Cumbria.

An essential step to developing appropriate palliative care for a community is to define the need for palliative care of that community. The PEoLC HNA Steering Group have committed to producing a Health Needs Assessments (HNA) for the whole of North East North Cumbria, as well as place summaries for the six localities.

Health needs assessment

There are three main types of health needs assessment:

1. **Epidemiological.** This approach considers the epidemiology of the condition, current service provision, and the effectiveness and cost-effectiveness of interventions and services.
2. **Comparative.** This approach compares service provision between different populations. Large variations in service use may be influenced by a number of factors and not just differing needs.
3. **Corporate.** This approach is based on eliciting the views of stakeholders - which may include professionals, patients and service-users, the public and politicians - on what services are needed. Elements of the corporate approach (i.e. community engagement and user involvement) are important in informing local policy. (ref: NEY PEoLC Strategic Clinical Network)

Higginson et al[2] conducted a systematic appraisal of needs assessments for palliative and end of life care and concluded that the three main categories of needs assessment are all appropriate to be undertaken alone or in combination, depending on the aims of the work, and made a recommendation to use the NHS Executive definition of need: 'the ability to benefit from health care', where benefit includes both clinical benefit and reassurance, supportive care and relief of carers.[2]

2 Higginson IJ, Hart S, Koffman J, Selman L, Harding R. Needs assessments in palliative care: an appraisal of definitions and approaches used. J Pain Symptom Manage. 2007 May;33(5):500-5. doi: 10.1016/j.jpainsymman.2007.02.007. PMID: 17482037. https://www.jpsmjournal.com/article/S0885-3924(07)00109-1/fulltext

3 Stevens A, and Gillam S. Needs assessment: from theory to practice. Br Med J. 1998; 316: 1448-1452

Key elements of the HNA include:

- An assessment of the palliative care needs of the population
- An assessment of the core service components required to meet those needs
- A mapping of the services currently available to meet those needs
- A comparison of what services are needed with what is already available in order to identify service gaps
- An assessment of the priorities for filling the service gaps

This HNA presents the NENC PEoLC system with relevant data and analysis to understand trends and appreciate the diverse needs of people of different ages, ethnicity and economic status.

"At such an incredibly difficult and emotional time, the professionalism, compassion and sensitivity shown by the nurses were truly remarkable. They provided expert clinical care while also offering kindness, reassurance and dignity, ensuring that she was comfortable and treated with deep respect at all times."
Hospice at home

The intention is that the HNA will help local clinicians, managers, commissioners, service providers and policy makers to improve PEoLC in the future by:

- Raising the profile of PEoLC and supporting local strategic and commissioning discussions
- Supporting early identification of patients who would benefit from advance care planning
- Promoting equitable access to PEoLC regardless of disease condition, place of care or socio-economic background of individuals.
- Identifying gaps in service provision and supporting the planning for projected increased demand for PEoLC
- Scope and support the delivery of the NHS Fit for the Future: 10 Year Health Plan for England

Definitions of End of Life and Palliative Care

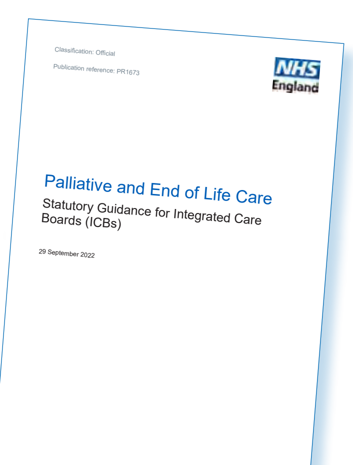
The terminology for end of life and palliative care is not always used consistently and does require clarity. For this HNA the following definitions have been used.

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening or life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards, 2022

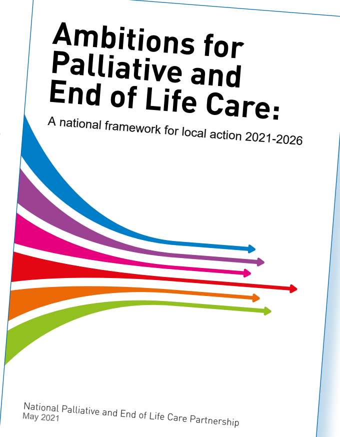
NICE uses a similar definition, referring to "the active holistic care of patients with advanced progressive illness".



End of Life Care

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events.

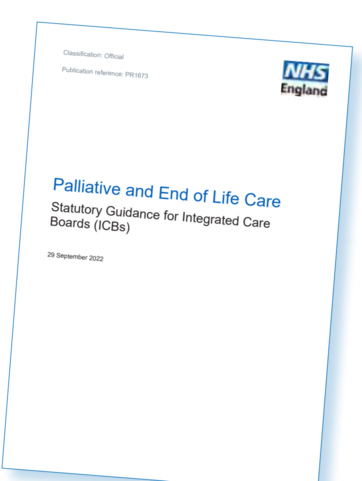
Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026



Advance care planning

Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

Consensus Definition of Advance Care Planning - Sudore et al 2017

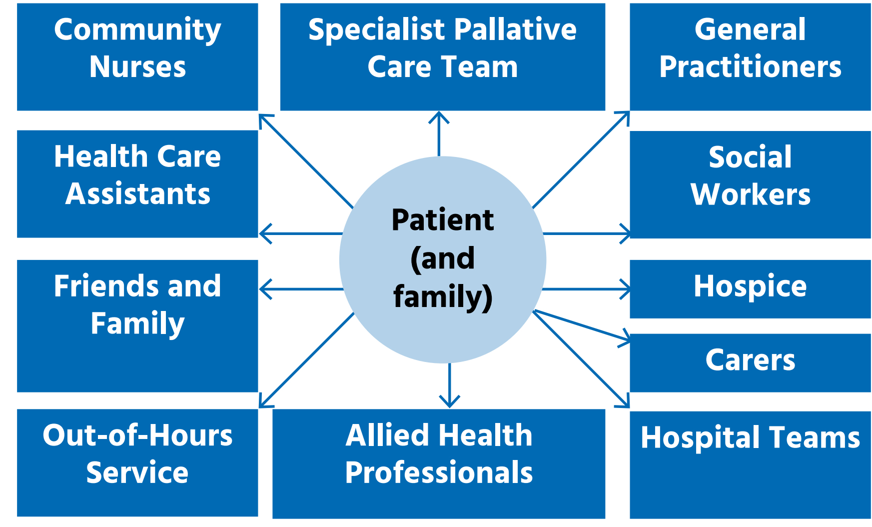


Specialist Palliative Care (SPC)

Specialist palliative care services are for people (all ages) living with more complex and/or long-term conditions which are life-limiting or life-threatening. The main components are:

- in-depth specialist knowledge (specialist consultant and specialist nursing services as a minimum) to undertake assessment and management of physical, psychological and spiritual needs to reduce symptoms, suffering and distress not only for the patient but for their family members (both adults and children). This might include a symptom management service
- supporting analysis of complex clinical decision-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment
- providing specialist advice and support to the wider care team who are providing direct core level palliative care to the person. (This is the NHS England service specification description of the specialist health services to be commissioned)

Figure 2: Relationship between specialist palliative care and end of life care



Overview of End of Life Care and Palliative Care Services

End of life care can take place in a number of settings such as care homes, hospices, hospital, or at home. Services are delivered by a range of health and social care professionals but is generally provided by two different types of health and social care staff:

- Generalist staff providing day-to day care to patients and carers in their homes and in hospitals e.g. hospital doctors and nurses, GPs, community nurses, pharmacists, paramedics and social workers. Generalist frontline teams provide the majority of care for most people in the last years of life, and predominantly in community settings.
- Specialist palliative care staff such as Consultants in Palliative Medicine, Clinical Nurse Specialists and Senior Pharmacists. These can be NHS or social care staff, or specialists working for charities such as hospices, Macmillan, or Marie Curie.

Care is usually delivered by a combination of generalist and specialist staff through multidisciplinary teams. Planning and coordination are key to providing good care and the Gold Standards Framework highlights the importance of practices holding multidisciplinary team meetings to consider the needs of people approaching the end of life. These meetings should involve a range of professionals, including GPs, district nurses, and social workers, with specialist palliative care staff to provide support and expertise. The level of care is set by the needs of the patient, with escalation of care as appropriate.

Hospices

Hospices provide essential specialist services in a variety of settings, including inpatient hospice care, care homes and people's homes. Hospices provide care which is free at the point of use. But, unlike in the NHS, it is not fully state funded. While they receive some statutory funding and grants, a significant proportion of their income is generated through charitable donations and fundraising activity. Across the North East care provision includes:

- **Children's Hospice Care:** While children's hospices deal with a small amount of end of life care most of the relationship is over many years with children with medically complex, life shortening conditions. This very complex cohort of babies, children and young people is small – but has significant palliative needs over many years.
- **Transition:** As NHS care improves, children are living much longer with complex conditions. As those children become young adults there are few services which can meet their needs, other services must develop. Hospices have a key role in supporting those ongoing care needs.
- **Specialised care at home services (hospice at home):** Accounting for 55% of care, this describes a non-specialist service in end of life care within a person's home, provided by a community team of nurses, occupational therapists and physiotherapists utilising their experienced end of life care skills and knowledge without the need for specialist palliative oversight. It includes routine symptom management, personal nursing care, psychological support and equipment assessment and provision, advanced care planning and coordination of services. For the majority of people in the last year of life, this level of care is sufficient and represents the core delivery model for end of life support, supporting admission avoidance or reactive hospital care. Specialist services are engaged when clinical complexity or refractory symptoms arise. This specialised care may be delivered by teams attached to an inpatient unit or an intendant organisation.

Strategic Role within the System

Hospices operate at the interface of health, social care, and community support, aligning closely with the principles of neighbourhood health and integrated care. Their ability to deliver proactive, person-centred, and coordinated care makes them key partners in supporting:

- People with frailty and complex long-term conditions
- End-of-life and palliative care pathways
- Carers and families
- Rapid response and crisis prevention
- Coordination across organisational boundaries

Their established relationships with patients, families, and wider system partners position hospices as trusted and effective providers of care closer to home.

Partnership and Commissioning Considerations

There is increasing recognition of the need to strengthen partnership arrangements between hospices, the NHS, and local authorities. Hospices contribute not only to health outcomes but also to wider social care priorities, including independence, prevention, and support for carers.

Future system development will require:

- More consistent and sustainable funding models
- Greater clarity on expected outcomes and population need
- Stronger integration with neighbourhood and community services
- Improved coordination across commissioning and delivery partners
- A shared understanding of roles across health and social care

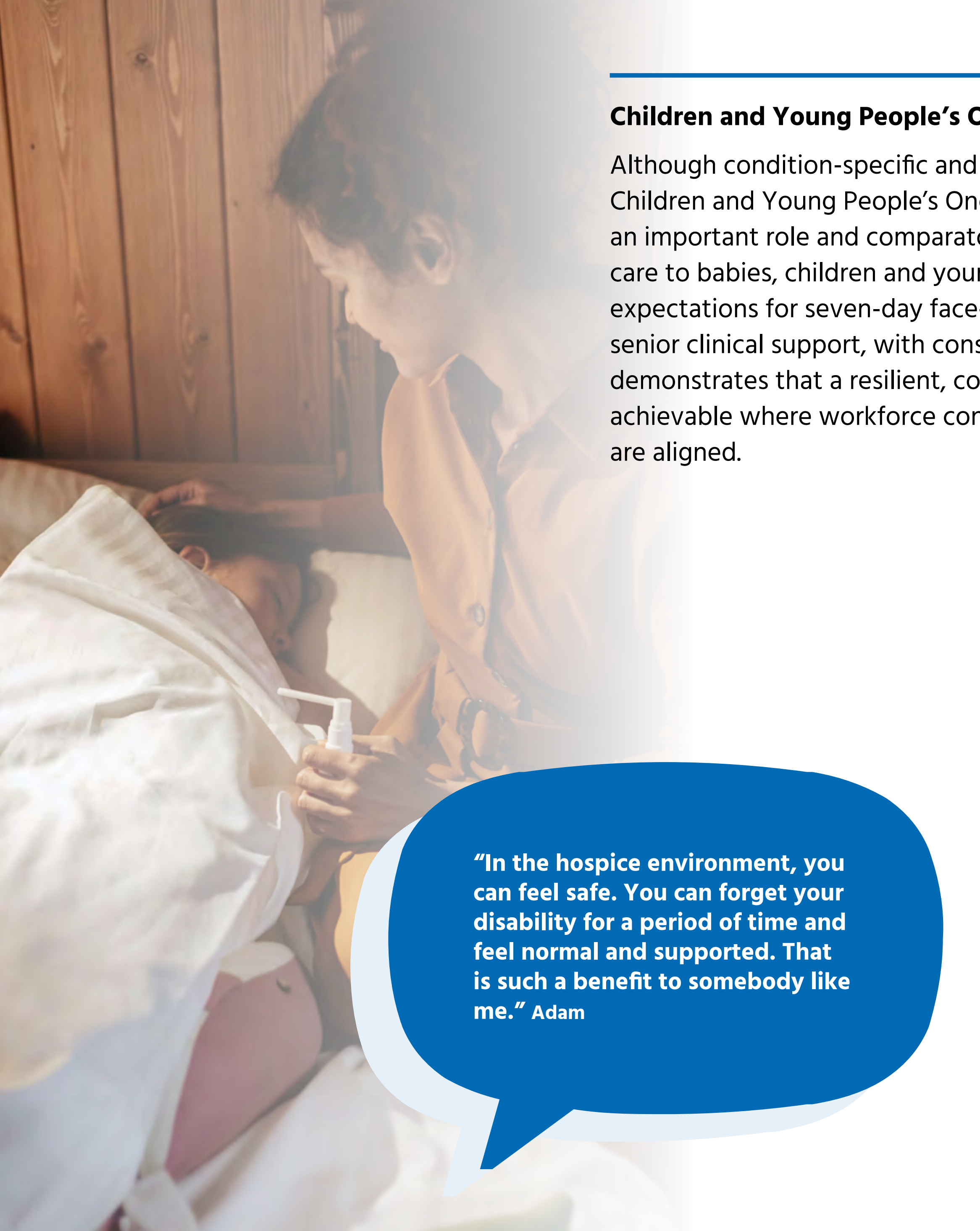
A key area of development is the transition from short-term, grant-based funding arrangements to more stable, multi-year contractual models. Moving towards longer-term commissioning frameworks would provide greater financial certainty for hospice providers, enabling strategic workforce planning, service development, and investment in community-based care models. This shift would also support a more mature partnership approach, aligning hospice provision with system-wide priorities and outcomes, rather than episodic or fragmented funding mechanisms.

As demand continues to grow driven by an ageing population, increasing complexity, and a policy shift towards community-based careen ensuring equitable access and long-term sustainability of hospice services will be a key priority for system leaders.

Children's Holistic Integrated Palliative Care Service (CHIPS)

CHIPS, based at the Great North Children's Hospital in Newcastle, operates as a regional specialist paediatric palliative care function across NENC designed to address longstanding inequity in access to specialist support for children and young people with life-limiting and life-threatening conditions.
The service was established in 2020 to ensure that access to specialist palliative care is needs-led and not dependent on diagnosis, particularly improving provision for children with non-oncological conditions who have historically experienced more variable access.

CHIPS provides specialist expertise across the disease trajectory, including antenatal and neonatal pathways, long-term complex conditions and end-of-life care, and interfaces with acute subspecialty teams, general paediatrics, community children's nursing, and condition-specific services. Its role is to support coordinated, anticipatory and responsive care across settings, rather than functioning as a standalone service, and it forms a core part of the wider system through which children's palliative and supportive care need is met in NENC.



Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS)

Although condition-specific and therefore outside the formal scope of this review, the NENC Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS) service provides an important role and comparator within the system. CYPOONS delivers specialist palliative care to babies, children and young people with cancer across NENC and consistently meets expectations for seven-day face-to-face care, 24/7 on-call access, prescribing capability and senior clinical support, with consultant oncology input available at all times. The service demonstrates that a resilient, continuous specialist palliative care model for children is achievable where workforce configuration, senior clinical availability and prescribing capability are aligned.

"In the hospice environment, you can feel safe. You can forget your disability for a period of time and feel normal and supported. That is such a benefit to somebody like me." Adam

At the same time, CYPOONS exposes significant inequity within the wider CYP palliative care landscape. Comparable levels of access and responsiveness are not consistently available to children with non-malignant life-limiting conditions, despite similar levels of complexity and need. This reinforces that current variation across NENC is driven by service configuration and historical investment decisions rather than underlying need, and that addressing this imbalance will be critical to delivering an equitable, system-wide CYP specialist palliative care offer aligned with national benchmarks.

National Guidelines and Standards

The findings and recommendations of this JSNA have been developed with reference to key pieces of national guidance and best practice in implementing high quality end of life care: (see Supplement 2: Policy and Literature Review)

Scan to view Supplement 2 →

PEoLC standards are underpinned by NICE guidance for adults and children's care, an NHS England palliative and end of life care standard, NHS England service specifications for adults and children's PEoLC, and an Ambitions Framework co-produced by the NHS with stakeholders. The majority of PEoLC is provided by NHS staff and services, but voluntary sector organisations, including hospices, also play a key role in service provision.

Relation to commissioning

The 10 Year Health Plan for England:

- states a commitment to shift healthcare out of hospitals and into the community, to ensure patients and their families receive personalised care in the most appropriate setting. Increasing access to high-quality, sustainable palliative care and end-of-life care will have a big role to play in that shift.
- provides opportunities for improved palliative care and end-of-life care, but also a focus on addressing key enablers to long-term improvement, such as the introduction of a single patient record and changes to financial flows to incentivise innovation and support the flow of money from hospital into community.
- strengthens the ask of ICBs to strategically commission services that respond to current and projected population need in the Strategic Commissioning Framework.
- clear requirements set out in the Medium-Term Planning Guidance that outline palliative care and end of life care as a priority cohort for neighbourhood implementation, contributing to reduced emergency admissions, bed days and ultimately patient experience.

Scan to view Supplement 1 →

Scan to view Supplement 2 →

Data Summary

The local picture

The NENC experiences a higher burden of disease and ill-health.

Whilst the four leading causes of death across the NENC; cancer, circulatory, respiratory, diseases of the nervous system have been consistent for many years and align with trends in England and Wales.

The NENC also has one of the highest rates of multiple long-term conditions (MLTCs) in England, with earlier onset and greater severity of multimorbidity compared with national averages. Overall, the NENC has an ageing population and in some areas super-ageing, with variation by area as given below. The NENC also experiences disproportionately high hospital utilisation in the last year of life, lower than average home and hospice deaths, and long-standing challenges in community care capacity. Understanding and meeting needs of this MLTC group is increasingly recognised as a public health priority and a growing challenge for health and care systems.

Equity in service provision is vital. Supplement 1: Technical Document and Data and Supplement 2: The Policy and Literature Review provide evidence of the PEoLC issues for specific communities such as BME groups, people with a learning disability, prisoners, LGBT, homeless people, and people with dementia.

Headline figures

Projections

30.5% **increase in over 65 year olds across the NENC region (2022-2047)**

- greatest increase in over **65** year olds population in Cumbria, North Tyneside, Northumberland.
- decreases in the over **65** year olds population of over **3%** were projected for Copeland and Barrow-in-Furness.

50.2% **increase in over 65 year olds on Primary Care Palliative Care Register**

- from **19,037** in 2025 to **28,600** in 2043.

Deprivation

- The NENC population is more deprived than the national average with **20%** of the NENC population residing within the **10%** most deprived areas nationally. NENC is ranked **6th** of all **42** ICBs for the proportion of Lower Super Output Areas (LSOA) in the most deprived **10%** nationally (MHCLG, 2025).
- The most deprived Local Authorities are Middlesbrough, Hartlepool, Sunderland, South Tyneside, County Durham.
- Implications of deprivation on the age of death, access to palliative care, and place of death (vs preferred).

Ethnicity

- The NENC population's ethnicity has changed from **91.3%** white (2021) to **83.4%** (2025), demonstrating an increase in ethnic diversity across the region. However, the percentage of palliative patients registered is **93.7%** white British. This may be reflective of this population change being driven by changes in younger cohorts.

Religion

- For first time (2021 census), less than half of the population described themselves as Christian, **46.2%.**
- Christian still most common response.
- Newcastle and Middlesbrough most religiously, ethnically and linguistically diverse.

Disability

- The North East of England has highest percentage of people with disability in England **21.2%** (Census 2021).
- Strong correlation observed to the most deprived local authorities

Cause of death

- The four leading causes of death across the NENC are cancer, circulatory, respiratory, diseases of the nervous system and have been consistent for many years and with trends in England and Wales.

Mortality

- The North East of England has the highest age-standardised mortality rate (ASMR) for males **(1,210.3/100,000)** and females **(908.4/100,000).**
- Death rate decreasing = people living longer
- Middlesbrough consistently experiences the highest mortality rates across the region, Newcastle's mortality rate also remains stubbornly high. All other NENC local authorities have a slight downward trend in their mortality rates.

Place of death (latest 12 months, November 2024 to October 2025, DHSC).

- Higher percentage of deaths in hospital **43.5%** NENC to **41.4%** England.
- Lower percentage of deaths at home **26.4%** NENC to **28.1%** England.
- Higher percentage of deaths in care homes **23.2%** NENC to **22.2%** England.
- Higher percentage of under **65** year olds die at home.
- Lower percentage of NENC residents died in a hospice **4%** NENC to **5.7%** England. However, this rate varies across the region.

Preferred place of death

- Across NENC **25%** dying in preferred place of death, range **17-36%** (PEoLC Dashboard).

Care homes

- There is capacity in the system in both care and nursing homes. However, increased demand with increasing age and complexity need to be considered to improve the rates of people achieving their preferred place of death.
- Projected **30%** increase for PEoLC in care homes from **130,375** (2024) to **170,000** in 2040.

Admissions in last 3 months

- All NE LAs (apart from 1) have increased rates of **3+** hospital admissions in the last year of life.
- PEoLC dashboard shows marked association to deprivation.
- The majority of these admissions are high cost no abnormality detected or treatment need.
- The majority of these admissions are high cost. Secondary care workforce lack confidence to discharge PEoLC patients which in turn impacts the length of stay for patients.

Children and Young People

- The prevalence of children living with life-limiting conditions has more than doubled between 2001 and 2017, rising from just over **30** per **10,000** to around **69** per **10,000,** equating to more than **4,000** children and young people living with life-limiting conditions at any one time.[4]

4 Together for Short Lives. Make Every Child Count: National and regional resources. Available at: https://www.togetherforshortlives.org.uk/resource/make-every-child-count/

Evidence: Policy and Literature Review

Scan to view Supplement 2 →

As part of this HNA an extensive literature review was conducted to identify key themes. The full literature review can be found in Data and Supplement 2: The Policy and Literature Review. Key themes include:

Ageing population

Clear evidence highlights the importance of maximising prevention and supporting independence. However, even with optimal improvements, there remains a need for greater support, particularly across health and social care services.

Frailty

Increased rates of frailty in areas of higher deprivation, peripheral, rural and coastal areas with sparse services and transport links.

Socio-economic status

Low socio-economic groups experience an increased risk of death in hospital, emergency admissions in final months of life, exacerbation of poverty especially for those supporting children and young people in need of PEoLC.

Health inequalities

Current significant inequalities and inequities in palliative care. Inequitable access to and experience of palliative care disproportionately presents in groups experiencing wider societal disadvantage and marginalisation, and in people with non-malignant conditions.

Palliative care inequity is especially prevalent in, although by no means limited to, some groups: people aged 85 years and over; people living in poverty and deprivation; minority ethnic groups; and people living in rural areas.

Multimorbidity

NENC has one of the highest rates of MTLCs in England with earlier onset and greater severity compared with national averages. This is accelerated across NENC by deprivation and poverty, association with preventable health behaviours and predictable clusters of diseases.

Those with MTLCs are projected to become main receivers of PEoLC now and in the future. This is therefore a growing public health priority.

Emergency admissions

NENC has disproportionately high hospital utilisation in the last year of life, lower than average home and hospice deaths, long-standing challenges in community care capacity.

Deaths in hospital and hospital use prior to death (England 2024)

- **47.0%** of the inpatient care provided by hospitals (measured in terms of days in hospital) for people **aged 85 year or older** is for people in their last year of life
- **68.8%** of all people who died in 2024, spent time in hospital during the **6 months** before they died
- **60.7%** of all people who died had a least one emergency admission in their last **3 months** of life, **6.6%** having three or more emergency admissions in their last **3 months** of life

Cause of death and place of death (England 2024)

- people who died of cancer were the most likely to die at home (**34.8%** compared to **28.1%** of all deaths) or in a hospice (**16.5%** compared to **5.5%** of all deaths)
- people who died of dementia were the most likely to die in a care home (**64.1%** compared to **21.5%** of all deaths)
- people who died of respiratory disease were most likely to die in hospital (**62.0%** compared to **42.3%** or all deaths)

Preferred place of death

51% congruence between preferred and actual place of death. Significantly associated with living situation, cancer diagnosis and prior hospital use.

Primary care

Good continuity of care, primary to palliative, experience better overall quality of end of life care, better experience for those older, female, white and least deprived.

Hospices

Ongoing lack of understanding of the function and contribution of hospices to PEoLC especially for children and young people and referral is very late in illness trajectory. Marked inequalities for inclusion groups.

Inequalities

Stark unmet need across ethnicity, homelessness, learning disability, carers.

Community Development

Growing research and best practice models including the Compassionate Communities movement.

Community Engagement

A central component of the HNA is listening to people's experiences, preferences and expectations. Understanding what matters most to individuals and families ensures that services are not only clinically effective, but person-centred and aligned with the NHS Ambitions for Palliative and End-of-Life Care.

A mixed-methods approach was used to maximise inclusion and reduce barriers to participation, this included a region-wide public survey, focus groups targeted engagement and one-to-one qualitative conversations. Healthwatch and Northern Cancer Voices were commissioned to lead targeted engagement with seldom heard and inclusion groups, including carers (including young carers), LGBTQ+ communities, disabled and neurodivergent people, people with learning disabilities, migrants and asylum seekers, people experiencing homelessness, people in rural and coastal communities, veterans, faith groups, and people affected by substance misuse.

"'Care provided by County Durham and Darlington Foundation Trust (CDDFT) to patients at the end of life should be considered an exemplar of high-quality, responsive palliative care delivery within the NHS.'"
Hospital care provision (CDDFT)

In total, 2,631 people across the North East and North Cumbria contributed to this work.

Across all engagement activity, people were clear and consistent about what matters most. Core themes included:

Comfort and pain relief are the highest.

Freedom from pain and good symptom control were described as fundamental to a dignified death.

Dignity, respect and not being alone matter deeply.

People want to be treated as individuals, with kindness, privacy and honesty.

Strong preference for home or hospice care.

Most people would prefer to be cared for at home if adequate support is available.

Earlier conversations are needed.

Many people have not discussed their wishes but believe that proactive, compassionate conversations would reduce fear and crisis-led decisions.

Carers carry significant burden.

Families often experience exhaustion, system complexity and lack of practical support.

Communication quality shapes experience and grief.

Clear, timely and culturally sensitive communication improves trust and outcomes.

Inequalities affect access and experience.

Some communities face additional barriers related to identity, geography, poverty or discrimination.

Public awareness of palliative care is limited.

Understanding improves when explained, but knowledge is currently low.

Hospitals are generally seen as a last resort.

Hospices are widely valued.

Implications for the system

The findings from this involvement work highlight consistent priorities alongside clear structural challenges. Together, they point to several system-wide implications for commissioning, service design and partnership working across the region.

These findings have informed the recommendations, including:

- **Strengthen early conversations and advance care planning** - Proactive planning can reduce crisis-led decision making and improve alignment with people's wishes.
- **Improve coordination and continuity of care** - Joined-up care is central to dignity, confidence and quality.
- **Address workforce pressures and care consistency** - Compassionate care depends on a supported and skilled workforce.
- **Strengthen support for carers** - End-of-life care quality cannot be separated from carer wellbeing.
- **Tackle inequalities and improve inclusive access** - Reducing inequalities is both a statutory duty and essential to equitable care.
- **Improve public awareness and understanding of palliative and hospice care** - Better understanding supports earlier engagement and informed choice.
- **Ensure dignity and compassion are consistent standards** - High-quality end-of-life care is defined not only by clinical effectiveness, but by humanity.

Scan to view Supplement 4 →

Workforce

An overview of Specialist Palliative Care (SPC) services and workforce across the NENC ICB was compiled by the NENC PEoLC Workforce Working Group established through the NENC Palliative and End of Life Care (PEoLC) Clinical Network and NENC ICB PEoLC Transformation Programme to:

- Establish an overview of the SPC workforce working in all settings across NENC
- Describe the issues and challenges when providing the workforce to deliver SPC services

The report (see Supplement 4) provides detail of the current workforce in place at the time of publication, and takes account of a broad range of publications and guidance improvement in palliative care. The key findings have informed the recommendations of this NENC PEoLC HNA.

The table below provides robust evidence that the SPC workforce capacity across NENC is under sustained pressure, with demand rising faster than workforce growth due to increasing complexity, deprivation, multimorbidity and non malignant disease. There is a clear imbalance between medical and nursing capacity, creating risk of unsafe role substitution and increased burnout and attrition risk within the speciality.

SPC inpatient bed provision remains below recommended levels across NENC, particularly against upper benchmarks for areas with high deprivation. Provision within the community and Hospice at Home does not yet consistently mitigate inpatient shortfalls, especially out of hours.

Table 1 Consultant workforce across all settings, combining population and bed-based requirements (i.e. 2 WTE per 250,000 population and 1WTE per 250 acute beds)

	Population	Actual Acute Beds	Actual Consultant WTE	Required Consultant WTE	Consultant WTE Gap
Durham, South Tyneside & Sunderland	**1,010,625**	**2317**	**9.9**	**17.4**	**-7.5**
North Cumbria	**324,819**	**536**	**2.05**	**4.7**	**-2.7**
North of Tyne & Gateshead	**1,085,997**	**3300**	**19.05**	**21.9**	**-2.8**
Tees Valley	**737,105**	**1557**	**7.15**	**12.1**	**-5.0**
NENC Total	**3,158,546**	**7710**	**38.6**	**56.1**	**-19.7**

The NENC PEoLC Workforce Working Group will continue to work together to take forward the specific recommendations in the Supplement 4.

Children and Young People's Palliative and End of Life Care Services

To support the NENC PEoLC HNA a review of Children and Young People's Palliative and End of Life Care Services has been completed (see Supplement 5). This review summarises need, current provision (system view), access and equity, experience and outcomes, and priority system requirements for CYP who may benefit from specialist palliative and end of life care, aligned to national benchmarks and available population evidence.

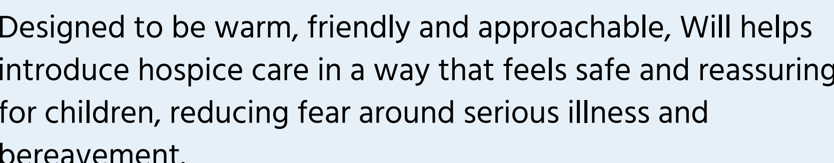
The report highlights that the need for CYP specialist palliative care across NENC is substantial, increasing and long term, driven by rising prevalence of life limiting conditions, improved survival and growing clinical complexity, and complexity of provider landscape, with many children requiring support over extended periods rather than only at end of life. Inequities and inequalities are evidenced regarding variation in access to services and support by diagnosis or address especially those in rural or dispersed areas of the region restricting access to care.

Again, the key findings from this report have informed the recommendations of this HNA.

Scan to view Supplement 5 →

News Story: Will O'Burn, a Friendly Face for Children and Schools

Will O'Burn, the much-loved mascot of Willow Burn who joined in February 2025, has played an important role in strengthening engagement with children, families and schools across North Durham.



Designed to be warm, friendly and approachable, Will helps introduce hospice care in a way that feels safe and reassuring for children, reducing fear around serious illness and bereavement.

Through school visits, events and activities, he encourages conversations about kindness, remembrance and caring for others, while helping families engage earlier and shaping a more child-friendly environment within the hospice. A key feature of his impact is the Coat of Memories, which offers children a tangible, comforting way to remember loved ones.

Building on this success, Will O'Burn features in a new children's book, Will O'Burn and the Friends Who Remember. The story gently explores themes of memory, loss and connection, providing a valuable resource for schools, families and hospice services to support emotional wellbeing and discussions around grief. Together, Will O'Burn and his story highlight how creative, compassionate approaches can enhance children's experiences and reinforce the hospice's role as a welcoming, supportive space for the whole community.

Place Summaries

Summary themes

An essential step to developing appropriate palliative care for a community is to define the need for palliative care of that community. The PEoLC HNA Steering Group requested that each place produce a summary document to support this regional HNA. This was to include a summary of their local population profiles highlighting any exceptionality, innovative and best practice, significant challenges and any key considerations or recommendations.

"The team's calm presence and genuine compassion brought enormous comfort to the whole family. Their support enabled respite to the family and helped in knowing she was in the safest and most caring hands." Hospice at home

All places noted the following regarding their resident and patient populations:

- A high prevalence of chronic industrial and long term conditions, particularly Chronic Obstructive Pulmonary Disease (COPD). These conditions often make it difficult for patients to remain in their preferred place of care and death, commonly their own home, resulting in considerable reliance on specialist palliative care teams.
- Cancer remains the most common underlying diagnosis for patients seen by the Palliative Care Service. However, there are increasing appropriate referrals coming in for patients with non-cancer diagnoses.
- Increasingly end of life care support occurs within nursing homes and includes symptom management, general end of life care guidance, and verification of death.

Across all places, the recommendations collectively call for: better coordination, 7-day and 24/7 access, improved digital integration, stronger MDTs, changing population need (ageing) and changing demands on PEoLC, workforce development, equity of access, community and bereavement support, sustainable commissioning, and more consistent use of data to drive improvement, reiterating key themes observed across all the workstreams and captured in the key recommendations.

Conclusion

This comprehensive HNA has highlighted significant increases in population need and significant challenges experienced across the system and by those in need of care.

This HNA also highlights excellent and innovative practice across the region, from ground-breaking collaborative research led by both academics and practitioners, strategy development and contract reviews (Tees Valley), quality improvement to improve patient navigation and experience (Deciding Right), collaborative resource allocation and service delivery (Durham), improved outcomes and patient care via the Hospice@Home service (North Cumbria), and public health approaches to palliative and end of life care (Gateshead).

There is much to be celebrated, championed, shared and considered for strategic commissioning, revised delivery and to support local North East and North Cumbrian residents to live and die well.

Authors and Contributors

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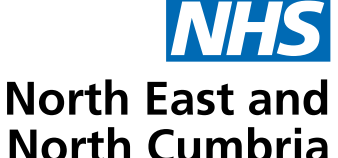
Good Practice Examples

“In 2025, the hospice redesigned its clinical referral process, creating a simpler and more consistent pathway into services. This has improved the quality of referral information, supported faster clinical decision-making, and made it easier for patients, families, and professionals to access hospice care.” Improving Access to Care

“When my daughter first came in, I was thinking ‘is she going to come out?’, but it was the best decision. What she has is terminal, but they’ve put so much in place for her to come home and have that quality of life. And when the time comes, this is where she wants to pass away, because in here you go with dignity.”

“Having a Palliative Care Link Worker as part of the team has hugely benefited patient care and supported the team with pressures associated to non-clinical complexities for patients on the case load.”

“The Wellbeing Service introduced a new Complex Clinic to provide rapid specialist review for patients whose needs change or symptoms worsen. This has strengthened early intervention, improved symptom management, and ensured patients receive timely, person-centred support.” Responding to Complex Needs



Death, Dying and Bereavement Bags (for those with learning disabilities) provide practical information, guidance, and tools to help ensure that people with learning disabilities are included in end-of-life conversations and receive compassionate care. The bags include easy read information and memory making activities and have already been ordered by health providers across the region.

"Having lived the experience, literally, I lived in the hospice for a few weeks. I have seen the ladies in the kitchen, whoever's doing laundry, care assistants, all the different grades of people, everybody cares just the same. It's real, you know, and they genuinely can't do enough for you."

Eden Valley Hospice and CNTW NHS FT