Lincolnshire
Palliative and End of Life Care Strategy 2023-2028

Contents

Introduction

Welcome to the Lincolnshire Palliative and End of Life (PEOL) Care Strategy 2023-2028.

There's a long history of working together across Lincolnshire on PEOL care prior to COVID and whilst the pandemic certainly demanded the system work together it was quickly recognised that we needed to maintain the momentum and collective system approach into the future.

In the summer of 2020, the Lincolnshire PEOL programme worked with system partners and stakeholders (patients, carers and their families, staff from NHS organisations, the local authority, care home and domiciliary care providers, hospices and a range of third sector organisations) to gain a clear understanding of their experiences of PEOL care in the county, and consider the issues that they face in delivering PEOL care services together with gaining an understanding of their ambition for the future. The published report was extremely impactful and demonstrated that people are having poor experiences of their PEOL care.

Our response has been to develop the Lincolnshire Palliative and End of Life Care Strategy 2023-2028 based on clinical evidence and national guidance, whilst using local intelligent sources on population data and needs to personalise care. We believe that moving to a new model of care outlined in this strategy will address the needs of patients, families and carers for those who would benefit from PEOL care.

This strategy takes an ambitious and transformative approach to delivery of fully integrated PEOL care to ensure accessible, equitable, sustainable, responsive, personalised PEOL care for adults, for all ethnic or social groups, areas or settings and for disadvantaged groups including those diagnosed with frailty, dementia, learning disability and severe mental illness. Whilst our priority focus will be on adult ages, we will pay specific attention to those transitioning to adulthood. We will support the Lincolnshire childrens' and young people (CYP) team to develop a strategy for PEOL care that recognises the needs and wishes of children and their families.

Who provides Palliative Care?

The majority of palliative and end of life care services are delivered by core teams. Not all care can be provided by a single service or team.
The level of involvement from each service area will fluctuate throughout a patient's journey. This is not a stepped approach but a flexible model that responds to need. Each tier of provision is dependent upon the others to ensure a holistic approach to the health, wellbeing, emotional, social, and spiritual needs of the patient and their families and carers.

Integrated Specialist

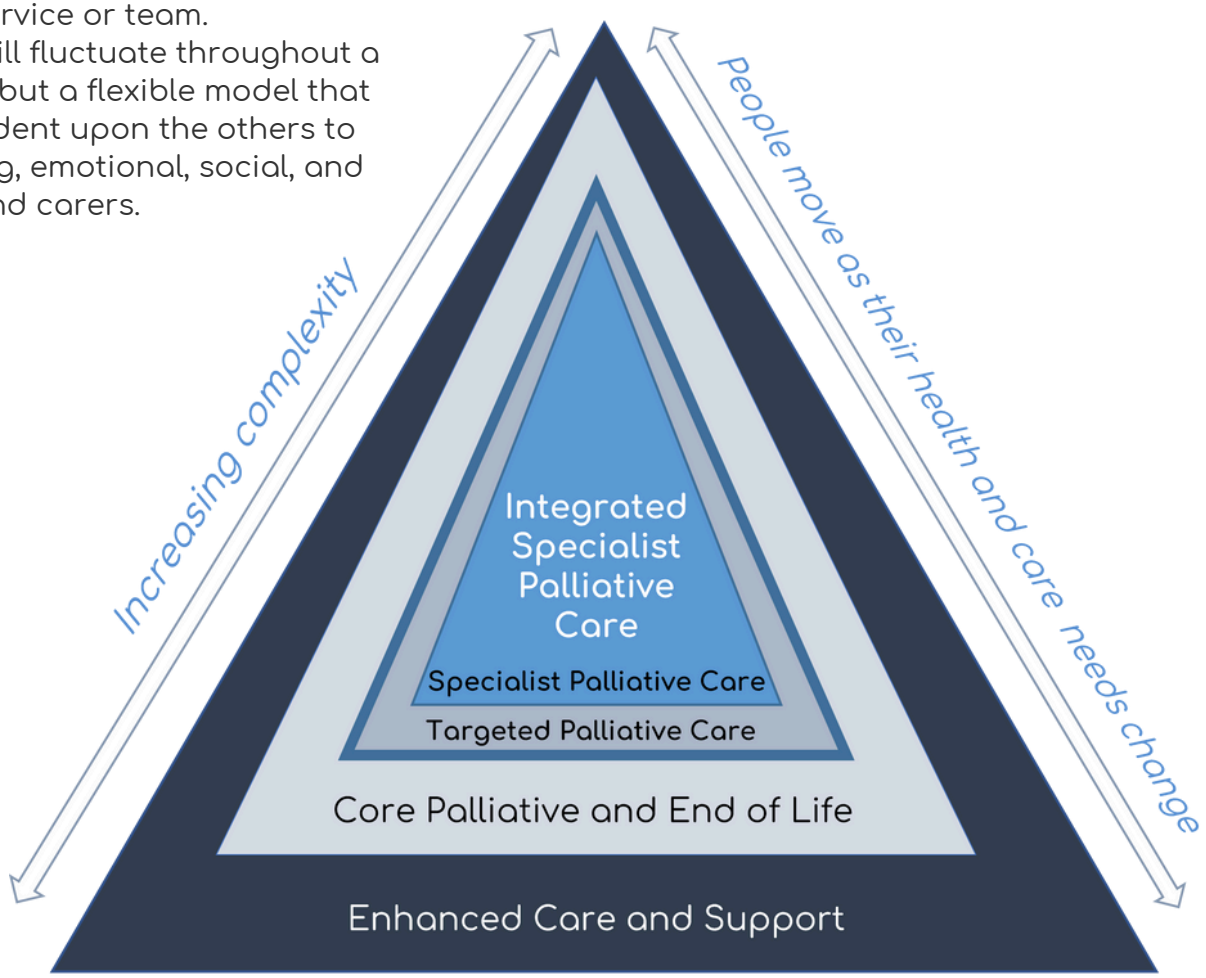
Includes services in hospices, community and hospital including:
Targeted Palliative care are direct and dedicated services delivered by a workforce with skills and experience in the specialism.
Specialist Palliative care manage complex palliative care problems that cannot be dealt with by the targeted or core services and are delivered by a workforce with specialist level skills and experience.

Core

Non-specialist palliative and end of life care delivered by primary, community, acute and urgent care services.

Enhanced

Non-specialist palliative and end of life care delivered by charity and voluntary sector organisations.



Note: These definitions are based on the National commissioning framework and PEOL adult service specification and adapted to reflect the Lincolnshire infrastructure.

What is Palliative and End of Life Care?

People who face progressive life-limiting illnesses, require different levels of health and social care at different points in their illness. Apart from care and treatment that is specific to their underlying condition(s), they are likely to have needs that are often referred to as palliative or end of life care, especially as they approach the last year(s) of their lives.

Palliative care is about improving the quality of life of anyone facing a life-limiting condition. It includes physical, emotional, social and spiritual care as well as practical support.

Palliative and end of life care involves communities supported by health and social care professionals and organisations working together to provide support to those who need it.

The national definition for end of life is the last year of life. It is an important part of palliative care and aims to help people live as well as possible and to die with dignity. This also includes support for anyone important to the person.

Throughout the trajectory of their illness, sometimes episodically, sometimes for prolonged periods, there may be a need for expert assessment, advice, care, and support from professionals who specialise in palliative care. These professionals work as part of multidisciplinary teams, providing care and support to the person and those important to them and/or supporting others to do so.

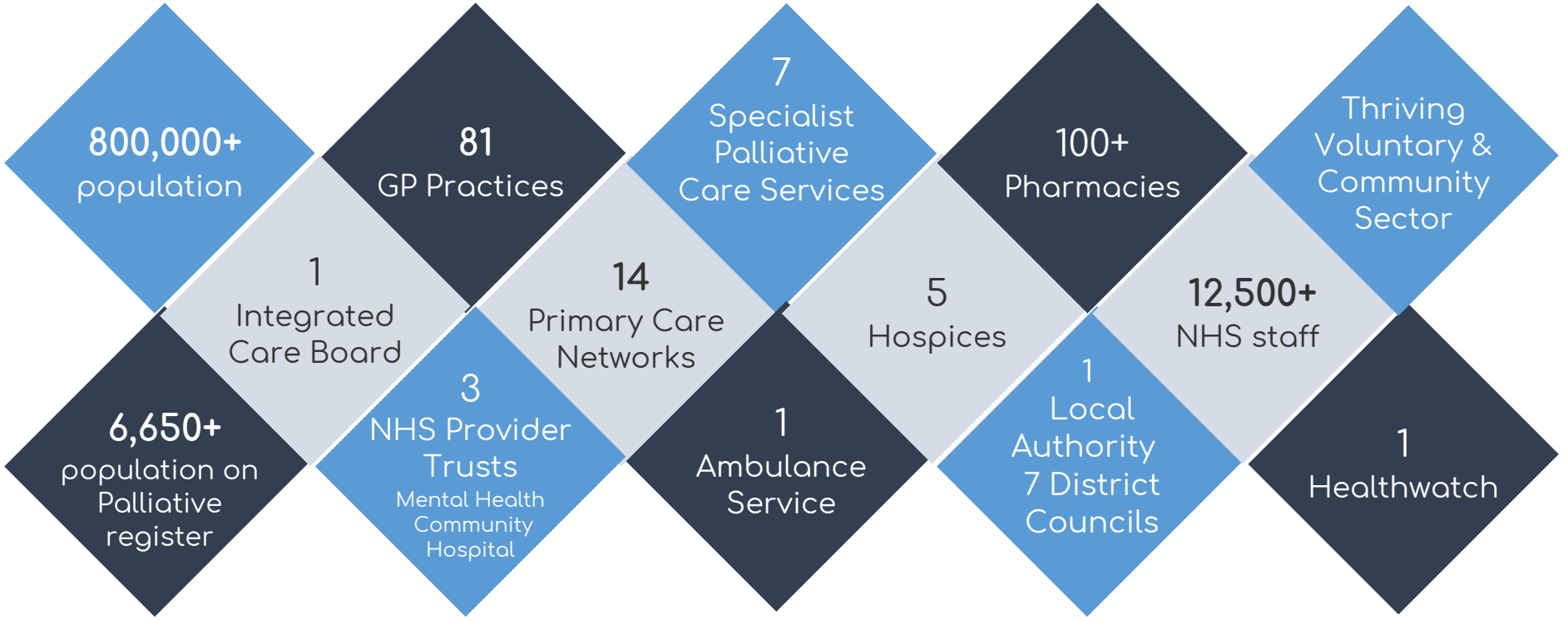
Specialist palliative care is required for people living with more complex needs which may be physical, psychological, social, and spiritual. The needs of this group cannot be met by the capability of their core team alone. This care requires a workforce with specialist skills and experience.

Our Local Picture

Just over 800,000 people are registered with a Lincolnshire GP.

The Lincolnshire Integrated Care System aspires for the people of Lincolnshire to have the best possible start in life, and be supported to live, age and die well.

We do this through a range of collaborative working arrangements:

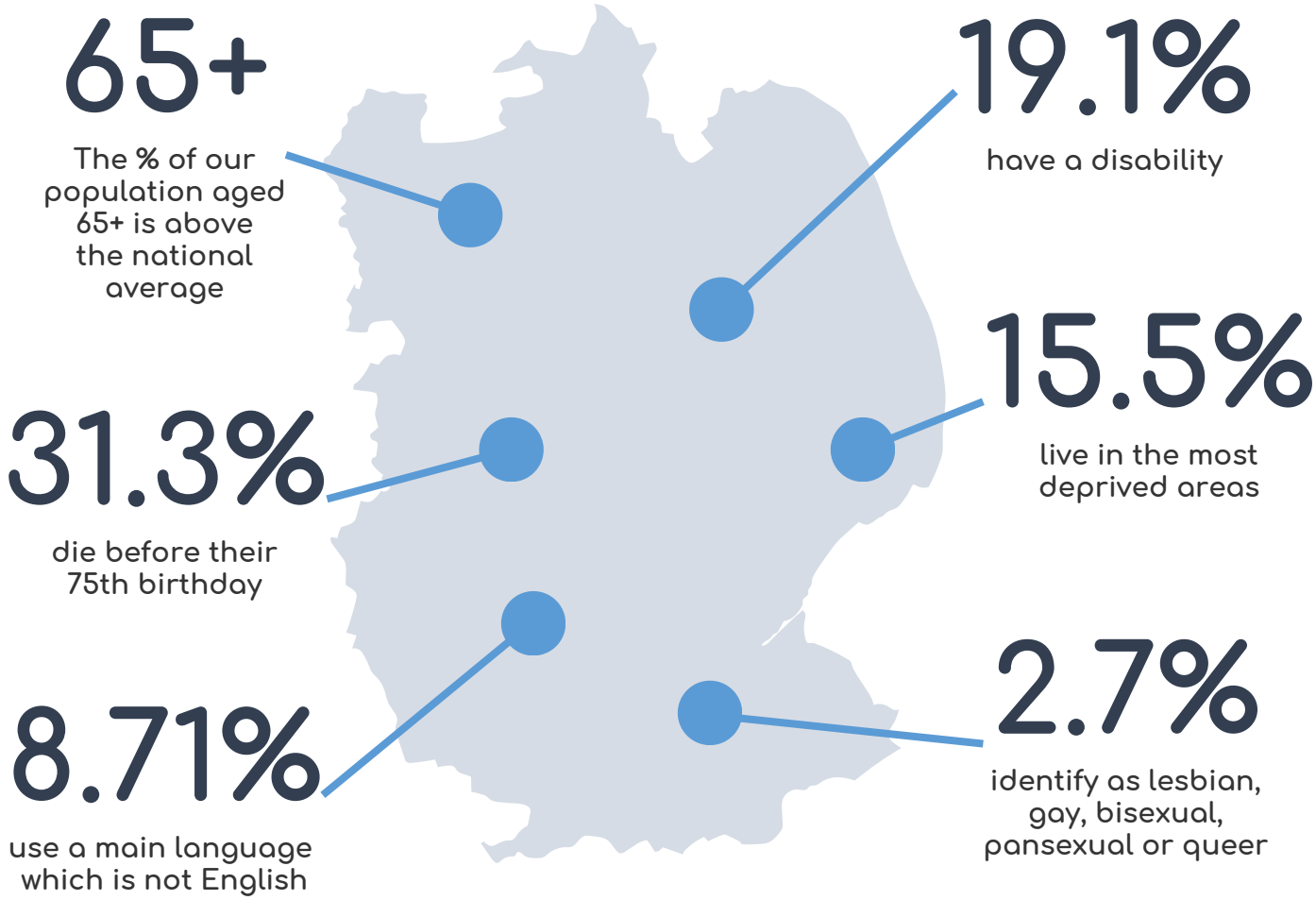


Those registered with a Lincolnshire GP may live outside of the county and may access services outside the Lincolnshire Integrated Care System.

Our Local Communities

Within Lincolnshire, we have a rich diversity in our communities.

We aim to provide palliative and end of life care to meet the needs of our diverse communities.



Context

Just over 800,000 people live in Lincolnshire, the combination of an ageing population, a rural geography and areas of high socioeconomic deprivation defines the specific challenge of delivering high-quality and effective services in Lincolnshire. Our population over aged 65+ is above national average, 31.3% die before their 75th birthday.

On average 0.82% of the Lincolnshire population are recognised as PEOL care at any point in time (national average 1%) with 12,138 individuals receiving palliative and end of life care in the last 12 months (23/24). Approximately one fifth of patients were on the PEOL register less than 4 weeks before death, reducing the benefits of palliative and end of life care and planning to ensure their place of care and death are met.

Currently 40.2% of patients who died were not on the PEOL register, but died of conditions where palliative care would have been expected. About a third of these people that did not benefit from palliative and end of life care had identified health needs so were known to the health system.

Personalised care planning including planning for emergencies and ensuring peoples' wishes are met provides the best opportunity for people to be cared for and die in the place they chose plus good care planning will avoid inappropriate admission to hospital. However around 65% of those recognised with weeks and days to live (EPaCCS) have Anticipatory Medication in place, only one third have Advanced Care Plans with over half having ReSPECT conversations. In addition, the after-death audit shows around 65% have had ReSPECT conversations which indicates these conversations are taking place in the last weeks, days of life. Further clarification is required on quality of prescribing and care planning.

Our after-death audit shows about one third of those who recorded their Preferred Place of Death managed to achieve their Preferred Place of Death (although only 60.3% actual place of death recorded). For those receiving specialist palliative care around 95% of patients had their place of care and death documented and an average 89% achieved this.

Context

Those who are recognised as palliative and end of life are disproportionately more likely to attend A&E, and be admitted than those with other identified health needs. Our number of admissions in the last year of life are higher in Lincolnshire than our peers. (1) (2)

Over the next 5 years as our population grows, if we do nothing for palliative and end of life care we will require 16 more inpatient beds. (3)

A recent (Sept 2023) VOICES Survey (Post-bereavement views of palliative end of life care in Lincolnshire 2022 – 2023) by HWLincs, recognised whilst progress had been made, the following remain challenges:

- Poor care co-ordination across services and care settings;
- Variation in signposting of support;
- Poor personalisation and quality of conversations about dying;
- Capacity of services and poor levels of responsiveness;
- Unclear roles and duplication of assessments where patients retell their story to multiple teams.

(1) Lincolnshire's GP clinical system and ICS Joined Intelligence Dataset
(2) A picture of End-Of-Life Care in England, November 2023, The Strategy Unit
(3) Health and Care Bed Requirements Across Lincolnshire, MS Insights, September 2023

How the strategy was developed

We co-produced this strategy speaking to the people of Lincolnshire:

- Those diagnosed with a life limiting condition
- Their families and carers
- People who had been bereaved

As part of the Provider Collaborative we engaged with staff and stakeholders from across Lincolnshire, including NHS providers, the local authority, care home and domiciliary care providers, hospices and a range of third sector organisations.

Members of NHSE exemplar programmes managed networks to develop and share best practice.

We held a full engagement on the draft strategy between April - July 2022 where we:

- Reviewed with our local Palliative and End of Life Care co-production group
- Socialised with leadership groups across Lincolnshire
- Held provider review workshops
- Held critical friend reviews with stakeholders
- Presented at an event in July 2022 to local, reginal and national partners

We held a series of meetings, group discussions, workshops and surveys commissioning Lincs Healthwatch and Whole System Partners where we:

- Gained a clear understanding of their experiences of palliative and end of life care in the county
- Discussed the issues that they face in delivering palliative and end of life services
- Gained an understanding of their ambition for the future

Our strategy is underpinned by statutory and policy guidance, national frameworks , thinktank reports, NICE guidance and quality standards, as well as local strategic aims. Appendix 2

Our vision

Our vision for Palliative and End Of Life Care in Lincolnshire:

We will improve the quality of palliative and end of life care in Lincolnshire and make better use of all health, social care, neighbourhood and voluntary sector resources to support these improvements.

Health and care agencies will work, together with communities, to identify all patients deteriorating from a life-limiting condition at the earliest possible stage. They will then provide the highest quality of care, communication and support to those patients and those who are important to them.

Palliative care will be co-ordinated and delivered within Primary Care Networks, to provide the best possible support for patients and their families. Palliative and end of life care services will work together and operate within a consistent framework and at the most appropriate level and setting to meet population health needs and provide equity of access to high quality personalised care across all parts of the County.

The provision of palliative and end of life care will form an important part of a wider framework of person centred, integrated care across Lincolnshire, designed to meet the needs of the local population.

Our objectives

Our objectives for Palliative and End of Life Care in Lincolnshire:

1. To increase our recognition of people deteriorating from a life limiting condition.
2. To increase the proportion of those on the Palliative register who have had high quality and timely conversations about dying.
3. To increase the proportion of people who have had advance care planning and holistic care assessments.
4. To improve people's care and experience by providing access to appropriate interventions that reflect patient's needs and wishes.
5. To increase the quality of our person centred care.
6. To increase the resilience and sustainability of palliative and end of life care services.

Delivery Plan

What is our delivery plan?

We have developed our delivery model to deliver the Palliative and End of Life strategy which will focus on 5 pillars:

- Enhanced Care
- Core Palliative and End of Life Care
- Single Point of Access
- Integrated Specialist Palliative Care
- Integrated Workforce

How will we deliver this plan?

- Capitalise upon our strong models of clinical and medical leadership which exist across the Lincolnshire system.
- Create governance and accountability frameworks which support change at pace and proactive management of risk.
- Develop a detailed implementation plan which specifies responsibilities for delivering milestones within agreed timescales.
- Develop a dashboard which supports measurement of impact, delivery of agreed Key Performance Indicators.
- Develop a process and dashboard to capture indicators that measure patient experience and outcomes.
- Design and implement a communication and engagement strategy to ensure changes are communicated and staff, patient and public voices are captured and utilised to support ongoing improvement and change.
- Adopt a culture of learning and continuous improvement.
- Adopt approaches to addressing Health Inequalities in communities through development approaches or personalised care planning.
- Adopt approaches that are responsive to age, culture, faith and ideology, disability, sexuality, and gender issues in relation to palliative care, dealing with them in a sensitive and inclusive way, including access to advocacy, translation, and interpretation services.
- Optimise the use of digital technology to be part of the best person-centred care and support, and to improve patient outcomes and experience.

Our delivery model for Integrated Palliative and End of Life will focus on 5 pillars

Enhanced Care - Self Care; Self Management

People, their families and carers will be supported to access enhanced care including complimentary therapies, support groups, practical support in accessing housing or the benefits system and emotional and psychological support including some bereavement services provided by experienced workforce.

Core Palliative and End of Life Care

Includes all health and care teams who provide direct palliative and end of life patient care and includes both home and bed based care.
PEOL care is rooted in General Practice who will provide care co-ordination including where there is a change of need or settings plus access specialist resources.
Patients who are likely to benefit from palliative care will be proactively identified and care needs will be met, aligned to the Gold Standards Framework (GSF) and Phases of Illness best practice.
Patients will be offered a conversation about what matters to them and an opportunity to discuss Advance Care Planning (ACP), including considering personalised recommendations for clinical care in emergency situations, Recommended Summary Plan for Emergency Care and Treatment (ReSPECT).
Each service will have a responsibility to co-ordinate care to support seamless transitions. This includes using shared care records including Electronic Palliative Care Co-ordination System (EPaCCS) to underpin effective communication.
All health and care staff will be supported by training and education provision, to attain and maintain expected standards and then to maintain their skills and capability.

Single Point of Access

A single point of access for palliative patients 24/7 to provide co-ordination of planned, unplanned, specialist and in-patient care for adults with a palliative diagnosis, families (all ages), carers (all ages) and professionals.
Supporting co-ordination and communication across these services is via a shared data template (EPaCCS) accessible via clinical systems and the shared care record.
A trusted assessor triage model will harness specialist palliative clinical capability to ensure that regardless of the reason for contact the caller will receive the right care in the right place at the right time.

Integrated Specialist Palliative Care

Includes Specialist and Targeted Palliative care services working as a single team across organisational boundaries under an integrated specialist palliative care clinical, quality and service leadership.
Provides a cross-organisational consultant led model of MDT working that supports safe effective evidence-based patient care.
Provides access to specialist palliative care and support to wider care teams (24/7).
Provides advanced symptom management.
Provides advice and guidance. For patients (adults), families (all ages), carers (all ages) and professionals.
Provides specialist advice, support, education, and training to the wider care team who is providing direct core level palliative care to the person.
Support for personalised care and support conversations, advance care planning, and emergency care and treatment planning; and supported self-management and shared decision making.
Has In-patient provision that is accessible, meets demand and admits people 7/7.
Adopts best practice and is responsible for supporting quality improvement and service development and research.

Integrated Workforce

A single team, working across organisational boundaries.

Enhanced Care

- Create mechanisms which support people, their families and carers to access, in-person or digitally enabled, personalised, support and advice and guidance which enables them to:
  - Access self-care and self-management resources,
  - Be signposted to a package of support e.g. connecting with community activities, befriending, bereavement services etc, supported by short term interventions from social prescribers,
  - Access carer support.
- Develop resources, including digital optimising use of digital technology through co-production and engagement.
- Develop and implement a promotional campaign to support access to Enhanced Care by people, families and carers.
- Raise awareness and confidence for clinicians and professionals to recognise the holistic needs of people, families and carers and support signposting to enhanced services.

Core Palliative and End of Life Care

- Improve identification and recognition of palliative and end of life need.
- Adopt and embed proactive risk stratification to identify those with unrecognised palliative need and recognising deterioration.
- Build capacity and capability for delivery of core care across all settings, include 7 day working.
- Improve responsiveness 24/7 for urgent PEOL care at home (care home/own home).
- Provide in-patient provision that is accessible, meets demand and admits people 7/7.
- Provide the capacity to support the co-ordination and continuity of care in every GP practice/ PCN.
- Ensure a digital technology / infrastructure that supports PEOL care including sharing records/information for MDT working and telehealth/self-help.
- Improve transfers of care for people at the end of life.
- Embed MDT working and the gold standard framework (GSF) in every GP practice/PCN.

Single Point of Access

- Implement a single point of access (SPA) for palliative patients, operating 24/7, through which patients, families, carers and professionals will be able to access advice and where support and care can be co-ordinated.
- Provide PEOL clinical triage – a 'trusted assessor model' (based on a PEOL specialism skill set) to enable co-ordination of care across organisational boundaries and services without duplication of clinical triage/assessment and ensure appropriate and timely care is accessed.
- Develop integration with wider health and care SPA.

Integrated Specialist Palliative Care

- Develop a single integrated clinical, quality and service leadership and governance model for Integrated specialist palliative care services.
- Develop the outcomes and implement a balanced score card in the context of identified concerns including for Quality, Patient Experience and Outcomes, Performance, Population Health Management, Health Inequalities, Workforce and Finance.
- Create a delivery and workforce model to enable the outcomes to be achieved. This includes physical, emotional, and psychological services.
- Establish a single integrated specialist palliative care team across organisational boundaries ensuring efficient and effective co-ordination and integration of services.
- Build capacity and capability for delivery of specialist care across all settings, include 7 day working.
- Improve responsiveness 24/7 for PEOL care at home (care home/own home).
- Provide in-patient provision that is accessible, meets demand and admits people 7/7.
- Provide specialist advice for health care professional.
- Optimise use of digital technology, system and infrastructure that improves communication and co-ordination between service providers and the wider core services and that is auditable and linked to patient outcomes.
- Optimise the use of digital technology to be part of the best person-centred care and support, and to improve patient outcomes and experience.
- Improve access to support people, families, carers and professionals to
  - Bereavement support for people with complex needs
  - Medication
  - Psychosocial support for patients and their families and professionals
  - Specialist equipment in the home
- Embed a system specialist MDT and operating practices to co-ordinate and manage specialist support.
- Provide peer support and patient reviews.
- Reconfirm the clinical framework adopted to support standardisation in different clinical settings.
- Identify opportunities to incorporate supportive palliative care in service delivery models.
- Adopt the principle of of quality improvement and evidence best practice and be responsible for supporting quality improvement and inform service development in both core and integrated specialist palliative care.
- Undertake research in line with the service's objectives., patient care and developing best practice.

Integrated Workforce

- Shared purpose and functions across teams to support more effective use of resources.
- Shared vision and values.
- Flexible workforce deployment to support fluctuations in demand.
- Multidisciplinary workforce development programme underpinned by shared professional standards.
- Provide peer support and review of practice.
- Attractive career pathways to support recruitment, retention and sustainability.
- Ensure the specialists have the capability and capacity to support ongoing PEOL training, education and continuing professional development (CPD) and ensure up to date policies and standard operating procedures in place that support PEOL care.
- Build learning networks, a community of practice for the workforce who provide direct PEOL care.
- Improve enhanced personalised advance care planning practices and documentation (including ReSPECT).

How will we know we have made a difference?

Our objectives and measures for Palliative and End Of Life Care in Lincolnshire:

To increase our recognition of people deteriorating from a life limiting condition:

- Increase % of patients identified as being in their last year of life on the GSF register
- Increase % of non-cancer patients on the GSF register
- Increase % of patients on the GSF register for between 6 and 12 months before death

To increase the proportion of those on the Palliative register who have had high quality and timely conversations about dying:

- Increased % of patients who have been offered and had a conversation about dying
- Increase in % of patients with resuscitation status recorded

To increase the proportion of people who have had advance care planning and holistic care assessments:

- Increase the % of patients who have been offered and have a completed and up-to-date ReSPECT
- Improve the quality of ReSPECT conversations and documentation
- Increase the % of patients who have an up-to-date Advanced Care Plan
- Increase the % of patients with anticipatory medication in place

To improve people's care and experience by providing access to appropriate interventions that reflect patient's needs and wishes.

- Reduction in number of A&E attendances in the last year of life
- Reduction in number of emergency admissions in the last year of life
- Reduction in LOS of emergency admissions in the last year of life
- Reduction in deaths within 48hrs of admission (excluding trauma, sudden deaths)
- Reduction in delays in (fast track) packages of care

To increase the quality of our patient centred care:

- Increase % of people who achieve their preferred place of death
- Increase % of people who achieve their preferred place of care
- Increase % of people with protected characteristics and high need with ACP/ReSPECT
- Increase % of carer identification, assessment offered and completed
- Increase % of patients with GSF coding / EPaCCS up to date
- Increase access to shared records

To increase the resilience and sustainability of palliative and end of life care services.

- No unwarranted variation with regards to access in services in line with agreed standards.

Our governance and accountability framework

We will collaborate through a system programme structure to:

- Manage, and lead delivery of the Lincolnshire Palliative and End of Life Strategy 2023-2028, with clear leadership roles and responsibilities through to the Primary Care and Communities Board.
- Bring together partners through delivery groups, with focussed task and finish groups, as necessary, to ensure successful delivery of plans and priorities of the pillars, supported by a co-production group of members with lived experience.
- Establish a clinical reference group to provide expert support to the programme plans, ensure best practice and clinical standards are adopted and embedded, identify and mitigate clinical risk and undertake horizon scanning, research and audit to identify opportunities to improve patient care and outcomes.
- Establish a quality group to undertake thematic analysis of all relevant quality feeds and agreeing the way forward, share insight and intelligence into opportunities for learning and improvement, identify and mitigate clinical risk, and provide assurance that concerns and risks are being addressed, and improvement plans are having the desired effect.
- Continue operational group arrangements to co-ordinate and provide updates from all stakeholders to report / escalate and co-ordinate actions as required, lead and mitigate operational risk and develop approaches to manage and operationalise business continuity, where there are significant challenges in demand and capacity.

Appendix 1: References

National:

Health and Care Act 2022 states a legal duty on ICBs to commission palliative care services under s3(1) NHS Act 2006 (as amended)
Policy and guidance: Statutory Guidance & Handbook, NHS Long Term Plan, Joint Forward Plans review findings,
National Frameworks: Ambitions Framework, Major Conditions Strategy; Commissioning and Investment Framework for Palliative and End of Life Care (and resources).
Thinktank reports: King's Fund , Nuffield Trust.
NICE Guidance & Quality Standards: Adults

Lincolnshire:

ICS ambition, aims and strategies
NHS Lincolnshire Joint Forward Plan 2023 – 2028 [published June 2023]
The PHM segmentation model
Development of Community Primary Partnerships
Integrated Community Care programme
Our Shared agreement 2024

Other Intelligence Sources:

Our delivery plans and priorities have been further informed by the following intelligent sources:
Lincolnshire's GP clinical system and ICS Joined Intelligence Dataset
Health and Care Bed Requirements Across Lincolnshire, MS Insights, September 2023
National Audit of Care at the End of Life (NACEL) Report 2022 (ULHT)
Ambitions Framework: a national framework for local action 2021-2026 - Our Self-Assessment
System Maturity Matrix Tool for Palliative and End of Life Care System - Our Self-Assessment
The Strategy Unit – A picture of end of life in England – Lincs benchmark
Learning from Deaths
National papers/research

Appendix 2: The National Framework

Ambitions for Palliative and End of Life Care

To support people to plan and consider wishes and preferences for their end of life care and treatment, we have a national framework to support the delivery of care: Ambitions for Palliative and End of Life Care.

The Ambitions Framework sets out 6 key areas of focus:

01 Each person is seen as an individual
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02 Each person gets fair access to care
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03 Maximising comfort and wellbeing
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04 Care is coordinated
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05 All staff are prepared to care
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

05 Each community is prepared to help
I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Appendix 3: Service Provision

Integrated Specialist Includes services in hospices, community and hospital : Targeted Palliative care are direct and dedicated services delivered by a workforce with skills and experience in the specialism. Specialist Palliative care manage complex palliative care problems that cannot be dealt with by the targeted or core services and are delivered by a workforce with specialist level skills and experience.	**Specialist MDT:** ULHT SPC team; LCHS Macmillan Team; St Barnabas Hospice **Targeted:** Organisations provide direct and dedicated palliative and end of life care services including Marie Curie.
Core Non-specialist palliative and end of life Care delivered by primary, community, acute and urgent care services	Community Nursing, CHC (fast track) Homecare Providers, Care homes, GP Practices,Adult Social Care, Ward Staff, Community and Acute Therapy, Mental Health Providers
Enhanced Non-specialist palliative and end of life care delivered by charity and voluntary sector organisations	St Barnabas Hospice Wellbeing Services; Butterfly Hospice, St Andrews Hospice, Sue Ryder Hospice

Appendix 4: Acknowledgements

We would like to extend our thanks to the people and organisations across Lincolnshire for their contributions to the Lincolnshire Palliative and End of Life Care Strategy 2023-2028 including:

- Patients, Families and Carers and the General Public
- General Practice (GP)
- Primary Care Network Association (PCNA)
- Lincolnshire County Council (LCC)
- Lincolnshire Community Health Services (LCHS)
- Macmillan
- Butterfly Hospice
- St Barnabas Hospice
- Marie Curie
- East Midlands Ambulance Service (EMAS)
- United Lincolnshire Hospitals Trust (ULHT)
- Lincolnshire Partnership Foundation Trust (LCHS)
- Neighbourhood Teams (LCHS
- PEOL co-production team
- Lincolnshire Medical Committee (LMC)
- Lincolnshire Pharmacy Committee (LPC)
- Lincolnshire Care Association (LINCA)
- Public Health