NHS
Lancashire and
South Cumbria
Integrated Care Board

Local Enhanced Service Specification:

Palliative and End of Life Care

Service Specification No.	
Service	**Palliative and End of Life Care (PEoLC) EARLY Identification and Advance Care Planning (ACP)**
Commissioner Lead	Lancashire and South Cumbria Integrated Care Board (ICB)
Provider Lead	**GP Practices in Lancashire & South Cumbria (LSC)**
Period	**1st April 2025 to 31st March 2026**
Date of Review	**January 2025**
Version Control	**2.3**

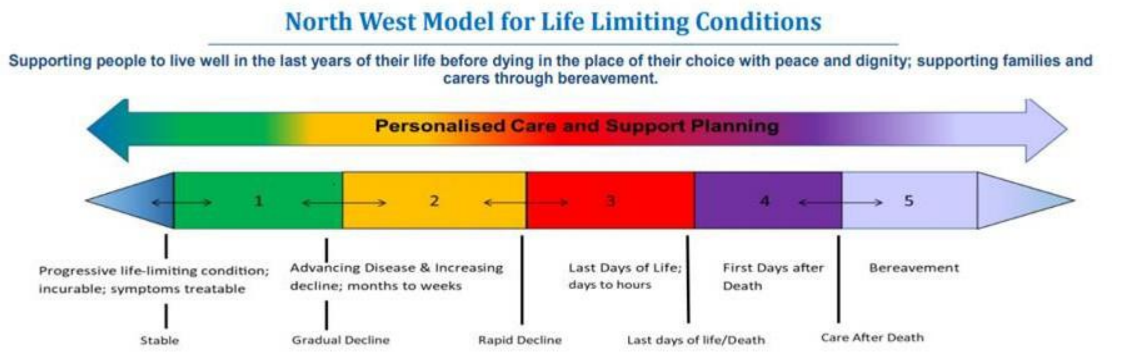
1. Population Needs and Background

1.1 National/local context and evidence base

Approximately 500,000 people die in England each year. That means about 1% of the population will die – i.e. with a list size of 10,000 patients, an average practice will have about 100 patient deaths per year. It is thought that 25% of deaths are unexpected from sudden causes and about 25% of deaths are due to a cancer diagnosis. People with advanced life-threatening illnesses and their families should expect good end of life care, whatever the cause of their condition.

The focus of PEoLC is to identify patients who are probably in the last 12 months of life, enabling care to be coordinated and supported through Advance Care Planning (ACP). Whilst also enabling avoidable unwanted and unnecessary admissions to hospital with care and death in the place of their choice, and good quality bereavement support for families and carers.

Through the Northwest Model for Life Limiting Conditions patients will be supported to live well in the last years of life:



The model spans a two-year period commencing twelve months before end of life and continuing to twelve months after death. Patients approaching the end of life will receive coordinated care from a range of health care providers.

We know that early identification is difficult – trying to predict when someone may be in the last 12 months of their life is not an exact science, but we know that if we can identify patients early enough, we can engage in ACP discussions and start to explore their wishes and preferences so they can live well, and then when they approach the end of their life (weeks and days) they can die well.

It is thought that 75% of the deaths of patients on a GP register each year can be anticipated. These are patients with conditions such as cancer, dementia, cardiovascular disease, respiratory disease, and frailty.

Data suggests that for all people, and for people dying of cancer and of non-cancer conditions, being registered with a general practice that has a high level of Electronic Palliative Care Coordination use is associated with a statistically significant higher probability of dying out of hospital.

Evidence that establishing a person's preferences for care at the end of life is likely to lead to outcomes in line with people's preferences. Most people who record their end of-life care choices, including their preferred place of care, prefer not to die in hospital.

We know that most people would prefer not to spend the last days of their life in a hospital, but nationally almost half of us do, and by using the **new** Electronic Palliative Care Coordination System (EPaCCS) template to list patients' preferences, and seeking consent to share via the LSC Shared Care Record (ShCR), we can improve the likelihood of patients being cared for in their place of choice.

1.2 PEoLC Statutory Duty for ICBs

There are wide reaching reforms within the Health and Care Act 2022, including the legal foundations for Integrated Care Boards (ICBs) and an amendment has meant that 'palliative care services' are included which specifies that ICBs have a legal responsibility to commission health services that meet their population needs.

The Ambitions for Palliative and End of Life Care (PEoLC): A national framework for local action 2021-2026 provides a framework to evaluate commissioning and delivery of palliative and end of life services. This builds upon the NHS Long Term Plan commitments for PEoLC, including increasing identification for people likely to be in their last 12 months of life and those people being offered Advance Care Planning (ACP), alongside ensuring workforce training supports this.

With growing numbers of residents living longer with more complex needs, LSC ICB recognised the need for a baseline of its current PEoLC service provision to understand any gaps within their population. As this is part of the statutory requirements, they utilised the national PEoLC Framework and locally amended Self-Assessment Tool and Places embarked on a 'Getting to Outstanding' journey to understand and help shape the future delivery of PEoLC across LSC.

1.3 Purpose of this specification

This specification is designed to improve PEoLC at all stages of a patients journey via the Gold Standards Framework (GSF) and EARLY Identification Toolkit to provide a planned system of care in consultation with the patient and family. The EARLY Identification Toolkit includes a clinical search tool along with a suite of resources to support implementation, including training guides.

It supports health care practitioners to:

1. identify patients in the last years of life.
2. assess their needs, symptoms, and preferences.
3. plan care to enable patients to live and die where they choose.
4. reduce number of emergency admissions for people in the last 90 days of life.

In the case of a child or young person the child's lead paediatrician should be advised an ACP would be beneficial if one is not already in place.

2. Scope & Service Standards

2.1 Aim

The aim of the service is to deliver a universal enhanced offer to patients in Lancashire and South Cumbria, setting out the services that General Practice are expected to deliver to their registered and temporary registered patients (where appropriate).

The service will support delivery of care in accordance with the GSF, a model to proactively manage palliative care in primary care settings. It is built around regular multidisciplinary meetings (MDTs) that identify and address the needs of PEoLC patients and their carers.

2.2 Service Description

The ask is to utilise the EARLY Identification Toolkit to support the provision of quality PEoLC for all.

Each practice to nominate a principal contact and a GSF/Palliative administrator.

Resources to support Primary Care in the early identification of people who may be in their last year of life and would benefit from an opportunity to discuss a personalised ACP, are available in the EARLY Identification Toolkit, which is then shared electronically (see digital and training sections).

For the template and searches to support the PEoLC LES, please refer to the Technical Guidance Document on the LSC ICB GP Intranet.

Further information to support the EARLY Toolkit can be found on the Chesire ePaige https://www.cheshire-epaige.nhs.uk/knowledge-base/category/primary-care/early-tool-primary-care/ **Please do not download the searches from here as they are already available to you via ES&R.**

Identification – Run the EARLY Identification Tool to generate a potential patient cohort list – see training section below.

1. **Clinical Validation -** clinically review the patient list generated to ensure appropriateness for inclusion onto a palliative care register, and to receive a personalised ACP discussion. (To ensure quality of ACP discussion participating practices should follow the universal-principles-for-advance-care-planning.pdf and access relevant training support, upskilling practice staff/retraining where appropriate including any newly appointed ARRS roles)

2. **Personalised Care and Support Planning -** contact patient/family to discuss the patient's current conditions and future care, wishes and preferences and a plan of care for emergency situations including, if appropriate, cardiopulmonary resuscitation (CPR).

3. **Sharing Information -** begin discussion, and complete LSC EPaCCS template in EMIS.

4. **Revisiting & Reviewing -** ensure the ACP is relevant and up to date, discuss at Palliative care meetings, re-run EARLY Toolkit as a minimum **every 6 months (twice in the contract year)**.

- Hold a **minimum of 4 multi-disciplinary Palliative Care meetings within the contract year** to discuss patients on the register as identified via the EARLY Tool. Where provision is available/appropriate suggested members are: District Nurses, ARRS, hospice led specialist palliative care teams, VCFSE etc. See EARLY-TOP-TIPS-additional-information-v1.4-reviewed-June2020-NWCSCNEI2.pdf (cheshire-epaige.nhs.uk)

- Liaise with wider community teams/services (for example: Integrated Neighbourhood Teams, District Nurses, Specialist Palliative Care Nurses, Enhanced Health in Care Home 'home rounds') in relation to meeting/discussing patients' needs on the register.

- Support all healthcare professionals or staff from partner agencies to identify PEoLC patients to the practice for inclusion on the register appropriately, alongside the practice's usual processes.

- Regularly review LSC EPaCCS template held, ensuring they are relevant and up to date, discuss at palliative care meetings and in-house clinical meetings where appropriate.

- Coordinate care for patients with other partners, ensuring care is joined up, unmet needs are identified and managed.

- Ensure correct completion of the LSC EPaCCS template, including seeking patients consent to share preferences such as preferred place of care/death via the LSC Shared Care Record (ShCR formally LPRES) – see Training section.

5. **Single repository of information -** participating practices to hold a single version of the truth ACP within primary care EMIS which supports healthcare professionals (primary, community and secondary care) who encounter a patient at end of life, to access up-to-date and accurate records relating to the patient's care preferences.

- Practices to ensure ACP patient information from trusted sources is updated/uploaded into a patients LSC EPaCCS template within EMIS within 2 days of receipt e.g. receipt of a paper based completed ACP template, or a letter from Hospice, Community Service or Acute Trust detailing the outcome of an ACP conversation. With consent to share ticked and ACP information updated within primary care EMIS this will facilitate the information being visible within the LSC Shared Care Record.

To access information and resources on the EARLY Toolkit click: EARLY Tool |
This is the Electronic Proactive Assessment and Information Guide for End-of-Life Care for Cheshire (EPAIGE) - NHS England sought permission for anyone working in palliative and end of life care in the North West to have access to this valuable resource.

2.3 Local Enhanced Care Home Service Spec 2025/26

Participating practices in this LES specification are encouraged to also review the Local Enhanced Care Home Service Spec 2025/26 ensuring ACP conversations are documented in the resident's electronic record, which should avoid a resident in having to repeat relevant information to the healthcare professionals involved in their care. This is part of home rounds under Enhanced Health in Care Home (EHCH) framework. Residents ACP wishes such as preferred place of care/death will need to be updated within Primary Care via the EMIS LSC EPaCCS template with the consent to share button ticked for this information to be visible via the LSC ShCR. See IT section.

2.4 Population covered

NHS Lancashire and South Cumbria ICB covers 196 GP Practices and has a total registered population of 1,853,016 (as of Jan 2024) patients.

The scope of this specification will cover all 196 practices and eligible registered patients along with temporary residents (where appropriate) that live within the geographical area of Lancashire and South Cumbria.

2.5 Any acceptance and exclusion criteria and thresholds

Only applicable to patients registered within Lancashire & South Cumbria.

2.6 Interdependence with other services/providers

- NHS Place Based Partnerships
- Primary Care / PCN's
- Local Acute Trusts
- Local Hospices
- Care Sector
- Community Services
- Integrated Neighbourhood Teams
- Enhanced Health in Care Homes Framework – Care Element 4/ LES Service Specification 2025/26

2.7 Applicable national standards (e.g. NICE)

The delivery of the commissioned service is underpinned by the appropriate standards, including but not limited to:

- NICE Quality Standards: Care of dying adults in the last days of life https://www.nice.org.uk/guidance/qs144
- NICE Quality Standards: End of life care for adults https://www.nice.org.uk/guidance/qs13
- NICE Clinical Guidelines: Care of dying adults in the last days of life https://www.nice.org.uk/guidance/ng31
- NICE Improving supportive and palliative care for adults with cancer. Cancer service guideline [CSG4] 2004 https://www.nice.org.uk/guidance/csg4
- End of life care for adults: service delivery - https://www.nice.org.uk/guidance/NG142
- NW Clinical Guidelines
- Relevant DOH publications
- Palliative Care Funding Review (2011) https://www.gov.uk/government/publications/independent- palliative-care-funding-review
- Ambitions for Palliative and End of Life Care NHS England » Ambitions for palliative and end of life care
- Gold Standards Framework https://www.goldstandardsframework.org.uk/
- NHS Long Term Plan
- The universal-principles-for-advance-care-planning.pdf

2.8 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

The Service is required to meet, as a minimum, requirements set out in the NHS Contract and the Care Quality Commission and the essential standards of quality and safety.

2.9 Applicable local standards

North West End of Life Care Model

2.10 Digital Recording

All personalised ACPs to be completed via the LSC EPaCCS template held within primary care EMIS – new template to be circulated. This revised 2025 template meets the Professional Records Standards Body PEoLC data and digital standards and is the **ONLY** template that should be used as it offers a consistent approach to PEoLC across LSC primary care and is coded for reporting and monitoring purposes.

To ensure the completed LSC EPaCCS template, and patient's preferences and what matters to them, are visible across LSC via the Shared Care Record (ShCR formally LPRES) the 'consent to share box' within the template **must** be ticked. If the patient does not want to share their record, then leave the box unticked, but this means the completed EPaCCS will not be visible outside of EMIS/practice, and available to other health care professionals involved in the persons PEoLC care.

Currently all LSC Acute Trusts, Hospices and community teams have access to the LSC ShCR, and if consent is provided, they will be able to see elements of the patients EPaCCS – for example preferred place of care/death.

To support delivery of this specification the commissioner lead will continue to work with the Commissioning Support Unit (CSU), and community teams using EMIS Community, to find an appropriate and standardised way of the EPaCCS information being communicated between EMIS Community and Primary Care EMIS. Working towards a one version of the truth ACP held by practices. It is known currently that community held ACP information cannot currently be published to the LSC ShCR via EMIS Community, this can only be done via records held within Primary Care EMIS.

2.11 Data standards

PRSB Standards - PRSB

3. Applicable quality requirements and CQUIN goals

Applicable Quality Requirements

Personalised ACP discussion (following the universal-principles-for-advance-care-planning.pdf)

4. Location of Provider Premises

Service delivery must be from the premises identified within the providers NHS Contract or where the service has been sub-contracted, the premises must be in suitable premises for delivery of the services set out in the specification.

5. Finance

Payment:

Fraud Policy

In the event of suspected fraud or other illegality being uncovered at any stage the ICB will implement the ICB Fraud Policy and will investigate.

Information supporting reported activity and monitoring information must be made available to the ICB or its representatives upon request. Failure to provide this information, or the provision of incomplete or inaccurate information, may result in suspension of payments or clawback, as well as further investigation by the ICB and its representatives.

6. Contract and Monitoring Arrangements

6.1 The Practice will:

1. Run the EARLY Identification Toolkit **(re-run every 6months, twice in the contract year)** and clinically validate the list generated.
2. Actively identify and record people living with a life-limiting disease, who may benefit from recording their health and social care preferences within the Primary Care EMIS advance care plan template (ACP).
3. Hold GSF/Palliative Care meetings and complete the LSC EPaCCS template for each patient discussed at MDT to enable monitoring of outcomes.

6.2 Practices will be monitored via completion of the template by the ICB PEoLC Strategic Leaders Group & Place based PEoLC Steering Groups. A baseline of actual numbers of patients on a GP register by practice/PCN has been extracted as of 31st March 2025 (using current Aristotle/EMIS data). This also includes a review of the no. of patients currently on a palliative care register with the consent to share box ticked.

Agreeing to this LES specification practices will demonstrate in 2025/26:

- Percentage increase in the number of patients at the end of life identified and recorded electronically.
- Percentage/number increase who have had an ACP discussion which is recorded in the correct way as outlined in this specification.
- Increase in the number of patients where consent to share ACP has been ticked, allowing visibility across LSC ShCR.
- Percentage/number increase who had a CPR discussion/decision recorded.

6.3 Outcomes to be monitored via self-declaration & EMIS reporting

- Self-declaration of EARLY Identification Toolkit having been run every 6 months (twice in the contract year), identified cohort list clinically validated.
- Average across LSC of 1% of the total patient population to be identified as having PEoLC needs and added to the practice palliative care register. While recognising the demographics of each practice population are variable, this target is aspirational and, in some practices, the expectation would be to significantly achieve above 1%.
- Minimum of 60% of all patients on the PEoLC register to have a personalised ACP in place, that documents:
    - Preferred Place of care

  - Preferred Place of death
  - DNA CPR discussion having been offered – outcome to be documented and shared accordingly
- Self-declaration of 4 MDT meetings, with dates and one set of redacted minutes including anonymized outcomes and actions, lessons learned and improvement plans.
- GP Practices are required to audit data held about their registered patients on EMIS at appropriate intervals and to data cleanse as appropriate to ensure it is accurate and up to date.
- Record the actual Place of Death for deceased patients.

6.4 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions	X
Domain 3	Helping people to recover from episodes of ill-health or following injury	X
Domain 4	Ensuring people have a positive experience of care	X
Domain 5	Treating and caring for people in a safe environment and protecting them from avoidable harm	X

6.5 Local defined patient outcomes

- Improve the overall quality of care for people in the last phases of life.
- Enable patients in last phase of life to die in a place of their choice, if clinically appropriate.
- Support families and carers to be clear on the patient's wishes including treatment.
- Support healthcare professionals to deliver care in accordance with the patient's wishes.

6.6 Reporting

Reporting via:

1. Data Quality searches (see technical guidance) and
2. The LSC EoL Primary care System report in Aristotle

Once practices complete the LSC EPaCCS template this information feeds the LSC EoL Primary Care System report, which practices can access in Aristotle to check progress at a practice and PCN level.

7. Training

The Midlands and Lancashire CSU Data Quality Team will provide training on how to use the LSC EPaCCS template and how to access the EARLY Toolkit and run the tool.

An **educational package to support early identification** of people likely to be in their last year of life is available and has been developed by colleagues in the PEoLC Clinical

Networks in the Northwest. The masterclass consists of 4 videos, produced by the End-of-Life Partnership in association with the Clinical Networks and can be used as standalone instructional videos, as part of a study day:

The videos are:

1. Why identification of patients nearing End of Life is important
2. How we can identify patients nearing End of Life
3. How can we approach care planning for patients nearing End of Life?
4. How we can approach care planning for patients nearing End of Life with difficulties in capacity and consideration around information sharing

The EARLY Toolkit, and supportive resources, can be accessed via this link https://www.cheshire-epaige.nhs.uk/knowledge-base/category/primary-care/early-tool-primary-care/

Supporting advance care planning discussions - A resource for health care providers: This resource has been designed for use by health care providers working within the NHS, but the site has open access and is accessible to all. Members of the public, including individuals wishing to plan their future care, and their families, friends or carers may also find aspects of the resource helpful for understanding what is involved in advance care planning https://www.acpsupport.co.uk/

What Matters Conversation – A short film based on 50 interviews conducted during the COVID pandemic across the UK in 2020. It highlights the importance of what matters conversations in the delivery of effective patient care from the perspective of professionals and gives examples from clinical practice of how this approach can be incorporated into busy daily practice. This film is to encourage thought and discussion and will be useful for general education and small group work with a wide range of clinical and social work practitioners.
https://www.whatmattersconversations.org/

My Wishes

My Wishes provides a range of online tools that generate both legally and non-legally binding forms. Once completed, documents can be downloaded, printed, emailed and shared with loved ones, healthcare professionals and funeral directors. It is important to note My Wishes does not replace or form part of any elements of an advanced care plan.
www.MyWishes.co.uk