NHS
Lancashire and South Cumbria
Integrated Care Board

FAQs for Palliative & End of Life Care

Q: If the criteria for the searches only brings up the 1% predicted, this would be a manageable LES, if the criteria for the searches is too broad, this would end up including inappropriate patients. How will this work in practice?
A: The EARLY tool will on average pull through 1% or slightly more of the practice population that are not already on the practice palliative care register. As the tool is run more regularly the numbers that are expected to be flagged will reduce.
Q: Why is early identification important in palliative and end of life care?
A: Early identification of patients who may be in the last 12 months of their life is important because this gives people the opportunity to be involved in planning for their future care. This could include thinking about the type of care they would like or would not like, where they would like to be cared for, who should be involved in their care and can help with planning for loved ones.
Q: What is the EARLY Toolkit?
A: EARLY is an acronym for **E**arly Identification, **A**dvance care Planning, **R**ecord, **L**ook again and **Y**ou can continually improve. The tool was developed in the North West in collaboration with colleagues in NE London. It works within GP electronic patient records to help identify people who are likely to be in their last year of life. The purpose of this toolkit is to support colleagues in Primary Care settings in the early identification of people who may be in their last year of life who may benefit from an opportunity to discuss a Personalised Care Support Plan (PCSP), which can be shared on EMIS.
Q: Why is the EARLY Toolkit & resources located on the Cheshire EPAIGE?
A: The Cheshire EPAIGE (Electronic Proactive Assessment and Information Guide for End-of-Life Care) is where you will access the EARLY Toolkit and available resources. 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. 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.**
Q: How can EARLY support PCNs and the wider system?
A: It can help support identification in all disease areas and focus on discrete disease areas. Once the search tool has identified patients, the list is subdivided into disease areas such as cancer, heart failure, COPD etc so practices can focus on one area at a time.
Q: Why is clinical validation a critical and essential step?
A: The search tool: - Is highly dependent on coding so may under or over identify - Will pick up metastatic cancers – but these may be stable e.g. breast and bone metastasis – so may not be appropriate to pursue end of life discussions - May also pick up end stage renal disease where people are on transplant waiting list - Will pick up those prescribed high doses of opiates where indication is not palliative care

Therefore, the list requires validation by a clinician to ensure that each patient is appropriate for a personalised care and support planning discussion.
Q: Why is the 'consent to share' box so important on the ACP template?
A: To ensure the completed ACP, and patient's preferences and what matters to them, are visible across LSC via the Shared Care Record (ShCR formally LPRES) practices MUST tick the 'consent to share box' within EMIS. If this box is NOT ticked the completed ACP 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/ACP pulled through from the EMIS record – for example preferred place of care/death.
Q: ACPs can only work if they are done by all. At the moment, despite it being mandated by NHSE for Acute Trusts, they are not done. There needs to be an element of sign up and ICB surveillance if they are not done by Trusts and Community Staff. It will not work if Primary Care are expected to be the only ones done. What is being done about this?
A: There is work underway across the whole ICB system to review Advance Care Planning processes and the way that these are undertaken and shared. Once this work is underway the palliative and end of life care team will ensure that General Practice and wider primary care are kept up to date.
Q: Could you confirm the exact criteria patients must meet to be counted towards the 1% population target for the PEoLC register?
A: Patients with a code that adds them to the gold standards framework, that would have been your QOF list.
Q: If a patient has had an end-of-life discussion and has their *Preferred Place of Care (PPC)* and *Preferred Place of Death (PPD)* recorded but is subsequently registered elsewhere (e.g. admitted to a nursing home under another GP practice), would they still be counted towards our practice's target?
A: The target is an ongoing one, and will be evolving constantly, as patients are added to the register and leave as they reach end of life. It is aspirational in terms of what is expected for each practice and we recognise that not all practices will reach this level, however some practices far exceed the 1% level already and should be aiming for significantly higher given their practice population. The Early tool will help practices to get closer to their target level and we will not be penalising practices for not achieving 1%, however would like the tool run regularly to try and maintain the register at the optimum level to ensure patients are receiving a high level of care towards the end of their life.
Q: If a discussion around PPC and PPD is conducted, but the patient is not yet ready to make a final decision, does this still meet the requirement for having a personalised Advance Care Plan (ACP) and is counted towards our practice's target?
A: There are codes for having had the conversation in the epaccs template, all of this work and discussion should be recorded and coded as much as possible to form the current ACP. Any further discussions and decisions should be added to the LSC EPaCCS/ACP template as they happen so

that it is a live 'document' and reflects the current situation. As long as the conversations are documented and coded as much as possible that forms an ACP and will count towards the target.
Q: If a patient is on the PEoLC register but either declines the discussion or it is clinically inappropriate at the time, is there an exemption code or alternative process we should follow to ensure this is appropriately recorded?
A: On the LSC EPaCCS/ACP template there are codes for declined to discuss, not appropriate etc.
Q: In situations where a patient lacks capacity to consent to data sharing and to participate in ACP discussions, would documenting their inclusion on the PEoLC register along with the statement that they lack capacity be sufficient for them to be counted towards the target?
A: There is a code on the consent box for 'in best interests' sharing of information, this should be included and a decision made to share in best interests by the person completing the template where that is the right thing to do, so that any discussions had are visible to other providers. Sharing the template information only shares a small number of codes and information and not the whole shared care record.
Q: The contract specifies a data extraction date of 31/03/2026. Will the assessment be based solely on the data captured as of that date, or will compliance be monitored throughout the reporting year?
A: We are monitoring monthly throughout the year the information that is currently on aristotle, and comparing it as practices progress through the year. The practice register, and completion of ACPs will vary through the year as patients are added and go on to die, the team recognise this is a dynamic register and will monitor accordingly.
Q: Considering that the PEoLC register is dynamic, would patients who were appropriately included on the register, had an ACP in place, and later died or moved away before 31/03/2026 still be counted?
A: There is no intention at present to look back at people who have moved or died, however as we are monitoring throughout the year any end of year concerns can be taken into account.
Q: How can Practices monitor improvement and ensure adherence to the requirements of the LES?
A: In the first year, practices are encouraged to achieve an aspirational goal of registering 1% of their patients on the end-of-life care register. Additionally, 60% of those on the register should have an advanced care plan that specifies their preferred place of care, preferred place of death, and whether a DNACPR is in place. A search is available and can be found in the ML DQ Search package within the ACTIVITY folder. There is a report labelled xACP Key Items Recorded that you can use to identify which key item each patient is missing.
Q: What education/training is available for staff to support with the PEoLC LES such as Advance Care Planning?
A: 1. **End of Life Care for all (e-ELCA) website** End-of-life Care For All (e-ELCA) - elearning for healthcare The End-of-life Care for All (e-ELCA) programme is an e-learning library which provides resources to enhance the training and education of the health and social care workforce so that well-

informed high-quality care can be delivered by confident and competent staff and volunteers to support people wherever they happen to be.
There are over 180 interactive sessions grouped into 9 modules, and you can select the resource that is most suitable for your role.

2. The ACP Support website https://www.acpsupport.co.uk/
This resource has been designed for health care providers (clinical and non-clinical health care staff) to increase awareness and understanding of advance care planning and will also support communication and shared decision making. Whatever your current level of involvement in advance care planning, this training will give you a valuable overview of the components of the process. It will also give you tips for supporting individuals with what can be difficult and sensitive conversations about their future care.

The aim of this resource is to provide training in advance care planning that:

- Is practical and digestible, delivered across bite-sized units
- Builds on your existing knowledge, skills and competencies
- Can be shared with other members of staff in your organisation
- Will help you to identify good timing for advance care planning discussions, or when an individual is indicating that they would like to discuss these issues
- Depending on your role, will help equip you to have advance care planning discussions, or guide you in directing individuals to further support with advance care planning

3. EARLY Identification Masterclass videos
This is a set of four videos that introduce the concepts around the benefits of early identification of patients, how we may be able to improve identification, why advance care planning is important and an introduction to information sharing and mental capacity:

- Identification 1 - https://www.youtube.com/watch?v=VBe5uboUUuw
- Identification 2 - https://youtu.be/NwdfG3jSZDg
- Advance Care Planning - https://youtu.be/E2imT3pabBo
- Capacity and Information Sharing - https://youtu.be/kydlQrbyId0

4. Local Hospice
All hospice's offer education programmes, which you may be able to access by contacting your local hospice:

- St Johns & St Marys Hospices - North Lancashire & Morecambe Bay
- Trinity Hospice - Blackpool, Fylde & Wyre
- St Catherines Hospice - Central Lancashire
- Queenscourt Hospice - West Lancashire
- East Lancashire Hospice - Blackburn, Darwen, Hyndburn & Ribble Valley
- Pendleside Hospice – Burnley & Pendle
- Rossendale Hospice – Rossendale

Q: What other tools are available to patients that can provide further information on preparing Wills, Advance Care Planning and Funeral wishes?

A: My Wishes is a free-to-use platform is now available to all Lancashire and South Cumbria (LSC) residents. It is a public health intervention empowering people in their own homes to make plans for their future health and social care wishes. Upon completion forms can be downloaded, printed

and shared. This document can be shared with the person's GP, loved ones and anyone involved with their care. When someone in LSC creates an account and enters a postcode within our region they have access to the Lancashire and South Cumbria (LSC) version of the MyWishes. If a LSC postcode is not available to use when registering for an account the individual will be directed to the generic MyWishes platform where their future end of life care planning can still be documented. MyWishes: Free Will Writing, Digital Legacy, Advance Care Plan & Funeral Software There is also a printable leaflet available for GP's and patients. Please see the End of Life supporting documents section, for printable leaflets which you may find useful.
Q: EARLY Identification Tool – When reviewing the patients, is there a particular template we need to complete?
A: At the moment the use of the tool is not being monitored by the ICB. In the specification, it states - self-declaration of EARLY Identification Toolkit having been run every 6 months (twice in the contract year), identified cohort list clinically validated. Any changes as a result of patients being reviewed would be reflected in the Palliative Care register and once patients are on the Palliative Care Register the ML LSC EPaCCS (Palliative & End of Life) Template should be used. At the moment, there is no code to remove patients from the lists, but this is being discussed further by the EARLY team. A practice suggested a code that they have added to the report to indicate for themselves who have been reviewed and this is something the DQ team will take a look at.
Q: EPaCCS Template – it would be useful to be able to add a date next to the Advance Care Plan so that it matches if we have received from another provider, g.g. palliative nurses?
A: This has been added and will be in the roll out of v1.4
Q: Requirement to have minutes of the meetings for MDTs? How are we meant to provide those?
A: The specification states - self-declaration of 4 MDT meetings, with dates and one set of redacted minutes including anonymized outcomes and actions, lessons learned and improvement plans. The encouragement is to ensure that the ML LSC EPaCCS template is completed for each patient discussed at an MDT.
Q: What is the link for the My Wishes website?
A: LSC Integrated Care Board :: MyWishes