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# Palliative and End of Life Care

## Statutory Guidance for Integrated Care Boards (ICBs)

20 July 2022

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## Background and introduction

There are wide reaching reforms within the Health and Care Act 2022, including the legal foundations for ICBs. An amendment has also meant that ‘palliative care services’ is included in the section which specifies that ICBs have a legal responsibility to commission health services that meet their population needs. This section describes a list of health services that ICBs must arrange as appropriate, including palliative care services.

Integrated Care Systems (ICSs) have a key role to play in ensuring that people with palliative and end of life care (PEoLC) needs can access and receive high quality personalised care and support and there is a duty for ICBs to commission palliative care services within ICSs - this guidance has been developed by NHS England to support that duty. The guidance is statutory and ICBs must have regard to it. It also contains links to resources and good practice for ICSs when planning locally and working collaboratively with local partners.

In addition to ICBs, this guidance will also be of relevance and interest to: patients, carers and the public; NHS providers, commissioners and professionals within health and social care services; local authorities; and voluntary, community and social enterprise (VCSE) organisations.

Technical guidance and resources will be published by September 2022 that will supplement this. Elements of this guidance may be made available sooner.

## Defining palliative care

Palliative care<sup>1</sup> 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.

## Existing frameworks for delivery

Co-produced by 34 organisations, the [Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026](#) provides a framework for each ICS to

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<sup>1</sup> <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

evaluate commissioning and delivery of their palliative and end of life services. This builds upon the [NHS Long Term Plan](#) commitments for palliative and end of life care, including increasing identification for people likely to be in their last 12 months of life and those people being offered personalised care and support planning, alongside ensuring workforce training supports this<sup>2</sup>.

In addition, the NHS England Palliative and End of Life Care National Delivery Plan 2022–2025 (see p9) sets out a three-year trajectory for PEOLC, focusing on improving access, quality and sustainability. Alongside this, NHS England is developing core metrics that will support colleagues in monitoring the impact of the National Delivery Plan for PEOLC.

## The legal requirement on ICBs

The core responsibility for commissioners is to commission high quality safe services that are tailored to the needs of the individual. The Health and Care Act 2022 states a legal duty on ICBs to commission palliative care services under s3(1) NHS Act 2006 (as amended):

**(1) *An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—***

***(h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service***

The duty 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.

All organisations who provide palliative and end of life care should understand and ensure that they comply with their other legal duties and professional obligations. This includes addressing health inequalities for PEOLC, by improving equity of access to services and reducing inequity of outcomes and experience. This will be done by utilising population health management approaches to identifying

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<sup>2</sup> <https://www.personalisedcareinstitute.org.uk/>

underserved populations. [Further resources on addressing inequalities in PEOLC can be found on the NHS England website.](#)

## Key considerations to meet ICB legal duties

- People with palliative and end of life care needs should be supported by a whole system approach. This means that care and support should be provided by the right professional, at the right time. This includes access to out of hours palliative and end of life care.
- People's palliative and end of life care needs, and complexity of their needs, will fluctuate throughout their journey, and this means that a flexible model of care is required. No single provider can provide for all needs and people will require access to a wide variety of non-specialist palliative care delivered by primary, community, acute and urgent care services, as well as specialist-level palliative care services to enable the system to provide personalised care to the person.
- The consideration of commissioned palliative and end of life care services applies to people of all ages. There are important differences between adults and children's palliative and end of life needs, including at the transition between childhood and adulthood, which must be taken into account in the commissioning and design of services.
- ICBs should have a clear vision of how the package of services they commission locally deliver against the Ambitions Framework and should actively seek out commissioning resources to achieve this.
- There must be sufficient workforce in place across all settings, with the knowledge to deliver the care required. Regard should be given to supporting general clinicians to build knowledge, skills and confidence to deliver high quality, personalised PEOLC, supported by specialist palliative care clinicians and services where appropriate.

To realise this duty, ICB commissioners should:

- action an Ambitions for Palliative and End of Life Care self-assessment, to identify progress and gaps against the six Ambitions commitments (involving people with lived experience)
- develop and implement a PEOLC service specification that aligns closely with the national PEOLC service specifications (these will be published by 1 September 2022).
- specify clearly what needs to be in place to deliver high quality end of life care for their populations.

- work to ensure that there is sufficient provision of care service providers available to deliver this, paying particular attention to access to specialist palliative care services, hospice beds, bereavement services, pharmacy services, equipment, spiritual care (as part of mental health and wellbeing support) and access to information.
- ensure access to general medical and nursing services, out of hours services and rapid response to maintain continuity of care, thereby supporting the patient's preferences and choice.
- Complete an Equalities and Health inequalities impact assessment and action plan focused on PEOLC

There is currently variation locally in access to high quality, personalised palliative and end of life care services. ICSs have a responsibility to ensure action is taken to improve equity of access and outcomes for PEOLC, specifically for underserved populations (see above).

### Core components for commissioning PEOLC services

Every ICB should commission PEOLC services that meet people's needs, aligning to the commitments within the [Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026](#). The framework sets out what high quality palliative and end of life care looks like, and the building blocks to implement this locally.

There are a number of core components for ICBs to consider regarding their duty to commission PEOLC services which are set out in the Ambitions Framework and expanded on below.

The Ambitions Framework (p7) sets out what is needed across the whole system for good palliative and end of life care, and includes a focus on families, carers and staff. It has system-wide consensus as was co-developed by 34 organisations.

The NHS England Delivery Plan (p10) sets out, at a high level, the NHS England approach to improving PEOLC and what should be implemented locally

## Case study

### **Integrated Care System (ICS) - Nottinghamshire**

Nottingham integrated care system has used the Ambitions Framework to understand the current delivery of PEOLC across the ICS footprint. They undertook a self-assessment using the Framework to inform the ICS strategy; they have found the self-assessment tool beneficial for service development.

A collaborative of local hospices, community trusts, primary care providers and the acute trust came together to form a partnership and work collaboratively to deliver palliative and end of life services. The collaborative worked to define an integrated care model and secured funding against the new patient journey from local commissioners.

Key services delivered across the integrated patient journey include:

- A single point of referral to provide triage, assessment and coordination of care needs
- Hospice at Home services and community hospice beds
- Hospital inreach and outreach by specialist palliative nurses
- Day hospice
- Bereavement services and carer support services

The Ambitions Framework is used for guiding principles in commissioning processes and local policy, for service design and quality improvement, and for education and training as has been included as part of the Nottinghamshire ICS five-year transformation plan.

## Ambitions for Palliative and End of Life Care – Framework Foundations

Ambition 1	Ambition 2	Ambition 3	Ambition 4	Ambition 5	Ambition 6
Each person is seen as an individual	Each person gets fair access to care	Maximising comfort and wellbeing	Care is coordinated	All staff are prepared to care	Each community is prepared to help
Ambitions Foundations	What this means?				Useful resources
<b>Personalised care and support planning</b>	People’s planned and delivered care is focused around what matters most to them and there is earlier identification of people in the last year of life to ensure timely conversations about holistic needs. ICBs should consider: <ul style="list-style-type: none"> <li>• Alignment of care registers across primary and secondary care, to ensure timely PCSP</li> <li>• Test and develop identification tools, e.g. EARLY, to support identification of people in last year of life.</li> </ul>				<a href="https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/">https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/</a>  <a href="https://www.personalisedcareinstitute.org.uk/resources-2/">https://www.personalisedcareinstitute.org.uk/resources-2/</a>
<b>Shared care records</b>	Key information about the individual’s needs and priorities shared digitally through Shared Care Records enables more effective and efficient care. ICBs should consider: <ul style="list-style-type: none"> <li>• Full implementation of EPaCCs</li> <li>• Adopting the refreshed Information standard locally</li> </ul>				<a href="http://theprsb.org">Palliative and End of Life Care – PRSB (theprsb.org)</a>
<b>Evidence and information</b>	Driving up quality and availability of PEOLC services which are responsive to people’s needs and choices is a key role for commissioning. ICBs should consider: <ul style="list-style-type: none"> <li>• accurate and up to date information to help the commissioning, delivery and improvement of services.</li> </ul>				ICS Data packs (pdf by OHID on FutureNHS)  <a href="#">End of Life Care Fingertips</a>

<b>Involving, supporting and caring for those important to the person</b>	<p>Commissioning good PEOLC care should include giving care and support to those important to the dying person, including (pre)/ bereavement care. ICBs should consider:</p> <ul style="list-style-type: none"> <li>identifying, assessing and supporting care givers and those important of the dying person</li> </ul>	<p><a href="#">QoF QI Identifying, assessing and support carers module</a></p>
<b>Education and training</b>	<p>High quality PEOLC requires multi-disciplinary teams to work collaboratively across health and care, including VCSE partners. ICBs should consider:</p> <ul style="list-style-type: none"> <li>adequate workforce with appropriate skill-mix, and high quality education, training and professional development</li> <li>better care for people as well as improving the wellbeing and resilience of workforce</li> <li>incorporating the requirements for a PEOLC workforce within their wider workforce plan for the system</li> <li>ongoing recruitment and retention of PEOLC workforce.</li> </ul>	<p><a href="#">Health Education England, e-ELCA</a></p> <p><a href="#">RCGP End of Life Care Quality Improvement modules</a></p> <p><a href="#">Personalised Care Institute for free e learning and quality assured training providers</a>  <a href="https://www.personalisedcareinstitute.org.uk/">https://www.personalisedcareinstitute.org.uk/</a></p>
<b>24/7 access</b>	<p>All commissioners have to engage in defining how their services will operate population needs 24/7. ICBs should consider:</p> <ul style="list-style-type: none"> <li>implementing the 24/7 Service specification</li> <li>access to medicines.</li> </ul>	<p>This shall be part of technical guidance</p>
<b>Co-design</b>	<p>The needs and wants of the public, patients and communities should be central to the commissioning process and delivery of PEOLC on a reoccurring basis. ICBs should consider:</p> <ul style="list-style-type: none"> <li>involvement of lived experience/ patient voice at key meeting and development of local PEOLC strategies.</li> </ul>	<p><a href="#">NHS E Strategic Coproduction</a></p>
<b>Leadership</b>	<p>ICS leaders have an important role in creating the conditions necessary for the commissioning of integrated and high-quality personalised palliative and end of life care. ICSs should consider:</p> <ul style="list-style-type: none"> <li>setting up PEOLC ICB board, that has a dotted reporting line into the PEOLC Strategic Clinical Networks</li> </ul>	<p><a href="#">NHS E PEOLC pages</a></p>

	<ul style="list-style-type: none"> <li>• embedding clinical leadership and peer leadership (lived experience) throughout ICS, ICP and place-based approaches</li> <li>• embedding PEO LC as part of wider ICS strategic plans.</li> </ul>	
<b>Integration</b>	<p>An integrated approach to commissioning PEO LC will support high quality PEO LC. ICDs should consider:</p> <ul style="list-style-type: none"> <li>• working collectively with colleagues across health, social care, local government and the VCSE sector to develop systems and commission services which put the person at the centre of the care they receive</li> <li>• identifying funding to support the provision of PEO LC from budgets across health and care services to support joint commissioning and joined up patient journey.</li> </ul>	<a href="#">LGA - End of Life Care Guide for Councils</a>

### NHS England National Delivery Plan

Priority	Action	Delivery Asks of ICS/ICB
<b>Improving Sustainability</b>	<b>People are identified as likely to be in the last 12 months of life and are offered PCSP</b>	<ul style="list-style-type: none"> <li>• Palliative care registers across primary and secondary care in place, for timely PCSP</li> <li>• Identification tools implemented to increase identification of people in last year of life</li> <li>• Full implementation of EPaCCs</li> </ul>
	<b>Staff, patients and carers can access the care and advice they need, whatever time of day</b>	<ul style="list-style-type: none"> <li>• All patients with PEO LC needs, including those not yet listed on palliative care registers, can access the appropriate advice and signposting supported by a SPOC</li> <li>• Collaborative working to achieve seamless transition between care settings</li> </ul>

	<b>Equitable access to PEOLC for all, focussing on locally identified under-served populations.</b>	<ul style="list-style-type: none"> <li>Evidence how plans and actions address priority underserved populations</li> <li>Equalities and Health inequalities impact assessment and action plan focused on PEOLC and EARLY/risk stratification extractions</li> </ul>
<b>Improving Quality</b>	<b>High quality PEOLC for all, irrespective of condition or diagnosis</b>	<ul style="list-style-type: none"> <li>Collaborate with system-level networks, e.g. CYP, dementia, frailty, cancer to ensure high quality personalised PEOLC for all, across all settings</li> </ul>
	<b>A confident workforce with the knowledge, skills and capability to deliver high quality PEOLC</b>	<ul style="list-style-type: none"> <li>Roll out training for staff in terms of personalised PEOLC, including PCSP, e.g. QoF Qi training, E-eLCA and Personalised Care Institute <sup>3</sup></li> </ul>
	<b>High quality PEOLC across all system</b>	<ul style="list-style-type: none"> <li>Adopt QI Methodology for PEOLC, at system level engage with local quality and improvement leads, in both acute and community settings, to ensure an outstanding CQC rating is achieved consistently across the ICS</li> </ul>
<b>Improving Sustainability</b>	<b>PEoLC is sustainably commissioned</b>	<ul style="list-style-type: none"> <li>ICB Plans have PEOLC as a strategic priority <ul style="list-style-type: none"> <li>PEoLC service specification, contracting arrangements against investment framework and data collection methodologies</li> </ul> </li> <li>Sustainability of CYP PEOLC through CYP match funding and CYP hospice grant</li> </ul>
	<b>The PEOLC workforce is fit for purpose, now and in the future</b>	<ul style="list-style-type: none"> <li>Future workforce evidenced in all ICB generic workforce plans</li> <li>Implementable specialist palliative care workforce plan, progress in implementing that plan and utilising the regional mapping tool</li> </ul>
	<b>Personalised and community approaches are fundamental to improving PEOLC experience</b>	<ul style="list-style-type: none"> <li>Personalised and community centred approaches across ICS, place and PCNs</li> </ul>
<p><b><u>Ambitions Outcomes</u></b></p> <p><i>Everyone person is seen as an individual</i></p> <p><i>Each person gets fair access to care</i></p> <p><i>Maximising comfort and wellbeing</i></p> <p><i>Care is coordinated</i></p> <p><i>All staff are prepared to care</i></p> <p><i>Each community is prepared to help</i></p>		

### Glossary

Electronic Palliative Care Coordination Systems	EPaCCs	<p>Electronic Palliative Care Coordination Systems (EPaCCS) is a means to capture and share information from people’s discussions about their care. The aim of this is to ensure that any professional involved in that person’s care has access to the most up to date information, including any changes to their preferences and wishes and personalised care and support plans.</p> <p><a href="https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/for-professionals/electronic-palliative-care-coordinating-systems-epaccs/">https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/for-professionals/electronic-palliative-care-coordinating-systems-epaccs/</a></p>
Personalised care and support planning	PCSP	<p>Personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation. This process recognises the person’s skills and strengths, as well as their experiences and the things that matter the most to them. It addresses the things that aren’t working in the person’s life and identifies outcomes and actions to resolve these. Personalised care and support planning is key for people receiving health and social care services.</p> <p><a href="https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/">https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/</a></p> <p>Personalised care and support plans may be regarded as a wide umbrella that encompass not only the care and support planning for the here and now (as described above) but also personalised planning for future care (advance care planning).</p> <p><a href="https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/">https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/</a></p>
Shared Care Records	SCR	<p>Shared Care Records (SCR) are an electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care.</p> <p><a href="https://digital.nhs.uk/services/summary-care-records-scr">https://digital.nhs.uk/services/summary-care-records-scr</a></p>

## Further resources

The list below highlights some of the supporting and technical guidance which support this Statutory Guidance – this includes both existing and newly developed resources.

This list is not exhaustive and the full and most up to date library of resources, can be accessed on the [PEoLC Network](#) on Future NHS.

### **Commissioning and Contracting**

- PEO LC service specification for adults and children
- PEO LC service specification self-assessment
- PEO LC Funding Guidance
- PEO LC Commissioning and Investment Framework
- 24/7 PEO LC Guidance
- Together For Short Lives Resources from CYP in Systems

### **National Policy**

- Ambitions Framework
- Ambitions Framework self-assessment tool
- NICE '[End of Life Care for adults](#)'
- [End of life care for infants, children and young people with life limiting conditions: planning and management.](#)

### **Data and Intelligence**

- OHID data packs
- PHE Fingertips

### **Other**

- Universal Principles for Advance Care Planning
- Virtual Wards guidance
- Chaplaincy Guidance

## Keep up to date

- There is a PEOLC Strategic Clinical Network (SCN) across each of the seven NHS England regions that support Integrated Care Boards in the delivery of high quality, personalised PEOLC, for whole population, across all settings.
- Free to attend monthly PEOLC webinars focusing on a range of topics. [Register on our events landing page to secure your place.](#) Previous webinar slides are available on Future NHS in the [PEOLC webinar library.](#)
- Future NHS Palliative and End of Life Care Network - contact [england.palliativeandendoflife@nhs.net](mailto:england.palliativeandendoflife@nhs.net) to request an invite to join.
- Regular emailed bulletin updates - to be added to the distribution list, email [england.palliativeandendoflife@nhs.net](mailto:england.palliativeandendoflife@nhs.net)
- National NHS England PEOLC web pages - <https://www.england.nhs.uk/eolc/>
- @Pers\_Care Twitter account for regular updates – using #EoLC
- A dedicated mailbox for all queries relating to PEOLC – [england.palliativeandendoflife@nhs.net](mailto:england.palliativeandendoflife@nhs.net)

*This statutory guidance is issued by NHS England for integrated care boards in relation to commissioning palliative and end of life care services, under **s14Z51 of NHS Act 2006** (as amended):*

- *NHS England must publish guidance for integrated care boards on the discharge of their functions.*
- *Each integrated care board must have regard to guidance under this section*

*In publishing this guidance NHS England has had regard to its equality duties under the Equality Act 2010 and the NHS Act 2006 (as amended by the Health and Care Act 2022) and in using this guidance each ICB must also have regard to its equality duties.*

*This guidance will be reviewed and updated, as appropriate.*

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