

HEALTH AND WELLBEING BOARD 23RD MAY 2024

**REPORT OF LEICESTER, LEICESTERSHIRE, AND RUTLAND
INTEGRATED CARE BOARD**

**LLR ICB DRAFT PALLIATIVE AND END OF LIFE CARE STRATEGY
UPDATE 2023/24 – 2027/28**

Purpose of report

1. The purpose of this report is to inform the Health and Wellbeing Board (HWB) of the development and next steps of the Leicester, Leicestershire and Rutland (LLR) Integrated Care Board (ICB) draft Palliative and End of Life Care Strategy 2023/24 – 2027/28.

Recommendation

2. The HWB is requested to:
 - a. **RECEIVE** and **NOTE** the update on the development of the strategy and the next steps
 - b. Provide **COMMENTS** and **FEEDBACK** of the LLR ICB Palliative and End of Life Care Strategy 2023/24 – 2027/28

Policy Framework

3. The reforms within the Health and Care Act 2022 conferred new legal responsibilities on ICBs to commission high quality, safe palliative care services. The duty ensures 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.
4. NHS England issued Palliative and end of life care: Statutory guidance for ICBs in order to support ICBs with their duty to commission palliative care services within integrated care systems (ICSs).
5. NHS England expect all ICBs to produce and publish a Palliative and End of Life Care Strategy that sets out key priorities and actions that will guide and underpin delivery of these responsibilities. The LLR Integrated Care System has already identified dying well and end of life care as a key priority area.

Background

6. The LLR Health and Wellbeing Partnership (HWP) and the LLR ICB have both adopted the life course approach, from 'Best start in life' to 'Dying well' with a commitment to ensure patients have a personalised, comfortable, and supported end of life with personalised support for carers and families.
7. Our three upper-tier local authorities (also known as our Places); Leicester City Council, Leicestershire County Council and Rutland County Council; have also worked with partners to develop their respective Joint Health and Wellbeing Strategies (JHWSs) that focus on the specific challenges in each of their areas. All three strategies include a specific mention to the importance of dying well. Furthermore, all three places have recently updated their respective Joint Strategic Needs Assessments (JSNAs) in relation to end of life care.
8. The Ambitions for Palliative and End of Life Care: A national framework for local action was developed by a partnership of national organisations across the statutory and voluntary sectors. It sets out a nationally agreed vision to improve end of life care through partnership and collaborative action between organisations at local level. The framework is built upon six ambition areas each with a statement to describe the ambition in practice as detailed in figure 1 below. The ambitions and framework are recognised as the agreed national standard to ensure that everyone has the best possible experience of dying, death and bereavement. ICBs are statutorily required to undertake the self-assessment in order to identify progress and gaps against the six ambitions commitments.

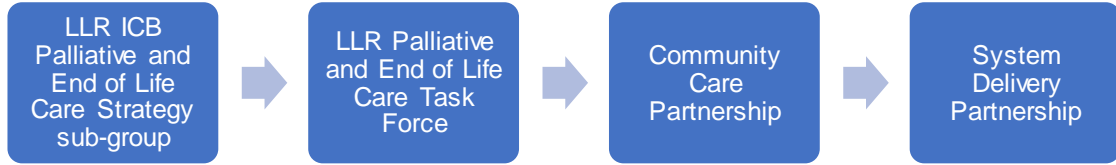


Figure 1- Ambitions for palliative and end of life care

9. The framework is a self-assessment toolkit that encourages local systems to undertake a deep dive reflective exercise to collectively determine their current level of delivery of services against ambitions. It identifies areas of strength and good practice and equally areas where greater focus and resources are needed to fully realise and deliver the ambition. The six ambitions also offer a purposeful structure on which a strategy can be developed.
10. A systemwide LLR Palliative and End of Life Care Task Force (reporting into the Community Care Partnership) was established post-pandemic to define, plan and deliver a longer-term end of life care pathway across the health and care system. The taskforce brings together system partners to collectively raise, discuss, troubleshoot issues and challenges, and realise opportunities impacting end of life care in LLR. The taskforce led on the self-assessment review and has a central role in delivering the strategy.

Progress to date

11. A sub-group of the taskforce was established to lead the development of the LLR ICB Palliative and End of Life Care Strategy.



12. The sub-group led the comprehensive review and analysis of three key inputs in order to determine the 10 strategic priorities that currently form the basis of the draft strategy:

Key inputs to determine strategic priorities:

- Findings and recommendations from JSNAs for end-of-life care
- Outputs of ambitions for palliative and end of life care self-assessment framework
- Existing insights and feedback from patients/public alongside direct input from frontline clinicians involved in palliative care.

13. The ten strategic priorities are detailed below in figure 2 along with an analysis of which of the six national ambitions they intersect with. The priorities have been endorsed by the LLR Palliative and End of Life Care Task Force, the Community Care Partnership, and the LLR HWP with clear synergies with a number of the pledges made in ICB 5 -year plan, specifically improving health equity, identifying the frailest on our community and wrap care and support around them and ensuring we deliver the right care, right time and the right place.

LLR PEOLC Priorities	Ambition 1 	Ambition 2 	Ambition 3 	Ambition 4 	Ambition 5 	Ambition 6 
1) Improve health equity in PEOLC service planning, provision and outcomes		✓	✓			
2) Map currently available PEOLC services across settings to identify gaps	✓	✓	✓	✓		
3) Improve service provision where gaps identified, including for: <ul style="list-style-type: none"> Bereavement support Anticipatory prescribing Social care offer 	✓	✓	✓	✓		
4) Improve systems for early identification of people at EoL	✓		✓	✓		
5) Improve advanced care planning	✓		✓	✓		
6) Improve record sharing and inter-operability of data systems across settings				✓		
7) Improve care transition between settings	✓	✓	✓	✓	✓	✓
8) Improve information, communication and engagement: <ul style="list-style-type: none"> support available; self-management; access and signposting; service offer; promoting discussion about death and dying; culturally appropriate information 	✓	✓	✓	✓	✓	✓
9) Provide a consistent and comprehensive training and resilience offer for staff, carers and volunteers (including recruitment), and monitor take-up across settings			✓		✓	✓
10) Improve family and carer support			✓		✓	✓

Figure 2 - LLR ICB Palliative and End of Life Care Strategic Priorities

14. Six LLR workstreams have been set up to support the implementation of key interventions for Year 1 (2024/25). Detailed in figure 3 is the draft delivery plan that will underpin the strategy with alignment to the priorities and ambitions. The workstreams have started to scope the actions and interventions needed to deliver the priorities, including funding and phasing.

Workstream	Key interventions for Year 1 (2024/25)	Priority alignment	Ambition alignment	Interdependencies with other PEOLC workstreams
Workstream 1: Service Provision Equity and Access in Palliative and End of Life Care (Y1A1_6)	<ol style="list-style-type: none"> Map current service provision and identify gaps in service, taking into consideration how services work together, are referred into and how they refer onwards. Develop a live service directory Create a set of recommendations for change and implementation from year 2. Undertake a health equity audit to examine how health determinants, access to services, and related outcomes are distributed across the population. Develop a set of recommendations based on findings to be implemented from Year 2 	Priority: 1,2,3,8,10	Ambition: 2,3,4,6	Y1A1 Y1A2 Y1A4 Y1A8
Workstream 2: Data review and standardisation Shared Care Record (Y1A2)	<ol style="list-style-type: none"> Review data sources. Develop a standardised data set that can be consistently shared with colleagues, as a data dashboard, to support service planning and delivery, improve equity of access and outcomes, as well as inform a PEOLC Outcomes Framework. Gain common understanding of current challenges relating to access of patient information and shared care records between settings / organisations, scoping interventions required from Year 2 onwards. 	Priority: 1,4,6,7	Ambition: 1,2,3,4,5	Y1A1
Workstream 3: Training and workforce development (Y1A3)	<ol style="list-style-type: none"> Review the training matrix, developed in 2022/23, develop and launch a training programme that meets the needs of the LLR workforce. Develop metrics that measure the impact of training, as well as the numbers trained. 	Priority: 4,5,7,8,9	Ambition: 1,2,3,4,5,6	Y1A5 Y1A6
Workstream 4: Improving ReSPECT and Advance Care Planning (Y1A4)	<ol style="list-style-type: none"> Review of the audit, current uptake and quality. Use findings and learning from other areas of the country to create a set of recommendations for improving this from Year 2. 	Priority: 5,6,7,8	Ambition: 1,2,3,4	Y1A5 Y1A6
Workstream 5: Communication, information & engagement (Y1A5)	<ol style="list-style-type: none"> Review of patient and professional information and engagement (platforms and language) to include family and carer support. Recommendations for implementation from year 2. 	Priority: 1,2,8,10	Ambition: 1,2,6	Y1A1 Y1A6
Workstream 6: Improving access to Anticipatory Medication in the community (Y1A7)	<ol style="list-style-type: none"> Pilot a new approach to AM in the community to include delivery to patient's home. Underpinning improvements are required around the authorisations process (underway), education and training (recognising dying / deterioration / symptom management), access to equipment (eg. Syringe drivers), formulary – routes and quantities. 	Priority: 1,3	Ambition: 1,2,3,4	

Figure 3 - LLR ICB Palliative and End of Life Care draft delivery plan

15. The system recently organised an event, '*a conversation on a different ending*',. Attendees shared their insights and views of death and dying, particularly the nuances of different cultures and the different beliefs, experiences and values of patients and their families. The learning will be used to inform the LLR strategy for end-of-life services.
16. Whilst the priorities have been endorsed further work is ongoing to refine and proceed to an engagement stage to help deliver the strategy. Accountability and delivery of the strategy will sit with the LLR Palliative and End of Life Care Task Force.

Stakeholder, Patient and Public Involvement

17. A draft strategy is presented to the HWB for comments and feedback. Once a complete draft strategy has been produced a comprehensive engagement exercise will be undertaken in Quarter 1 of 2024/25 to ensure the strategy resonates with system partners and key stakeholders including, Local Authorities, and Healthwatch. In addition, the ICB will also work with a range of organisations and groups to ensure it understands what matters most to people. This will include the Voluntary, Community and Social Enterprise sector, Patient Participation Groups, Public and Patient Involvement Assurance Group, Citizens' Panel and other patient and public groups.
18. Feedback will be used to refine the strategy prior to a final draft strategy being presented to the LLR ICB for endorsement and support during Quarter 1 of 2024/25.

Officer to contact

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Links

[NHSE England Palliative and end of life care: Statutory guidance for integrated care boards \(ICBs\)](#)

[Dying well – Priority LLR Health and Wellbeing Partnership](#)

[Leicester's Care, Health and Wellbeing Strategy 2022-2027 – Health Ageing](#)

[Leicestershire Joint Health and Wellbeing Strategy – Dying well](#)

[Rutland Health and Wellbeing Strategy - Ensuring people are well supported in the last phase of their lives](#)

[Leicester Joint Strategic Needs Assessment \(JSNA\) – End of life care](#)

[Leicestershire Joint Strategic Needs Assessment - End of Life Care and Support](#)

[Rutland Joint Strategic Needs Assessment - End of Life Care and Support](#)

[Ambitions for Palliative and End of Life Care: A national framework for local action](#)

Relevant Impact Assessments

Equality and Human Rights Implications

19. A key action within one of the workstreams is to carry out EIAs and QIAs across each organisation/service to incorporate into an overall equalities impact assessment.

Partnership Working and associated issues

20. Each workstream will take a partnership approach to assessing need, defining and agreeing priorities and agreeing actions to address these. Partnership working is at the core of these plans.

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