How Integrated Care Systems can improve the delivery of palliative and end-of-life care in the current landscape.

Next steps report

March 2024

Because no one should face death or grief alone

Introduction

In February 2024, Sue Ryder hosted a roundtable event at Portcullis House in Westminster, to explore how Integrated Care Systems (ICSs) approach the planning and delivery of palliative and end-of-life care (PEoLC). This is a report summarising the findings of that event.

1. Background

Following the establishment of ICSs in July 2022, Sue Ryder co-developed a set of recommendations for improved PEoLC.

Sue Ryder also commissioned a series of case studies to help bring some of these recommendations to life by showcasing how they are playing out in practice in developing ICSs.

In February 2024, Sue Ryder hosted a roundtable event at Portcullis House in Westminster to explore how ICSs approach the planning and delivery of PEoLC. The event was hosted by Rachael Maskell MP, member of the Health and Social Care Select Committee. It was attended by a range of representatives including regulators, commissioners, local government, providers, ICSs and other key stakeholders from the PEoLC sector, including Hospice UK and Marie Curie.

This session aims were to reflect on the last 12 months; examine the current situation for ICSs; and look forward, with a particular aim of identifying national and local enablers to improve PEoLC in the current health and social care landscape. Finally, attendees explored whether there are ways that the health and care sector can work better together to support PEoLC development.

This is a report of the roundtable event, prepared for Sue Ryder by independent consultant Lucy Nicholls, part of Better Decisions Together,.

2. Findings

General discussion is captured below, examining enablers, barriers, opportunities, questions to explore further, and concluding with potential next steps. An appendix summarises a SWOT analysis (strengths, weaknesses, opportunities and threats) for the PEoLC sector.

Comments have been themed according to the general stakeholder group to which they relate, to preserve confidentiality.

2.1 Enablers

This is a summary of the 'enablers' that were identified by attendees. In this context, an 'enabler' is something that is helping to progress improvements in PEoLC within ICSs.

	What enablers are helping progress PEoLC work?
Integrated Care Systems (ICSs)	• **Statutory duty:** has been helpful pushing the issue up the agenda within ICSs. • **Collaborative working:** bringing multiple hospice providers together as a collaborative has enabled work to move forwards. • **New PEoLC service models:** examples of new models that are working well in ICSs include 24/7 Single Point of Access (SPoA) hubs for everyone to access. Also, in-reach services, for example in A&E. • **Neighbourhood Teams**: PEoLC fits in well in community teams, in particular the neighbourhood team structure where PEoLC colleagues can work as part of a multi-disciplinary team (MDT). • **Smart working:** it's positive when duplication is avoided, for example, not setting up a PEoLC single point of access that is separate to the existing 111 service. • **Advance Care Planning (ACP):** can help avoid emergency care or admissions, and therefore reduce pressure on acute and emergency services. • **Business As Usual:** PEoLC should be considered 'business as usual'- a service that is needed for everyone, covering services from maternity to older adults – this perspective can help progress work in this area.

	What enablers are helping progress PEoLC work?
Voluntary, Community or Social Enterprise (VCSE) sector	• **Statutory duty:** has helped secure more engagement from ICSs around PEoLC work. • **Openness to engage with stakeholders:** where regulators/national teams are open and proactive at reaching out and engaging with VCSE partners: this has aided lines of communication. • **VCSE model:** VCSE sector can be more agile than statutory sector (for example, in developing flexible services at speed).
Regulators	• **Good practice examples:** for spreading ideas and understanding.
Local government	• **Health and Wellbeing Board:** retains a key role in setting priorities for health and social care at the local level - this is needs-led and not clinically-led.

2.2 Barriers

This is a summary of the 'barriers' that were identified by attendees. In this context, a 'barrier' is something that is preventing or hindering the progress of improvements in PEoLC within ICSs.

Note: the barrier of funding challenges and resourcing pressures applies across ICSs, VCSE sector and local government.

	What barriers are preventing progress?
Integrated Care Systems (ICSs)	• **ICSs are start-ups:** they are still learning and having to transform working relationships in a new culture which has moved from competition to collaboration; this is extremely challenging. Systems are still working out how Place and System work together. • **Lack of guidance:** ICSs and other stakeholders are lacking clear frameworks for what good looks like in PEoLC. • **Funding challenges-background is reductions in resource, capacity and services:** wider strategic priorities are taking up resources, system capacity is limited and services often inequitable (e.g. where one area provides a service five days a week and one area seven).

	What barriers are preventing progress?
	• **Difficulties undertaking population assessments:** data and knowledge/understanding is missing. • **Lack of Advance Care Plans (ACP):** low usage of ACP and poor communication between professionals are preventing people from dying in the place of their choosing and increasing emergency admissions. • **Lack of communication:** there's a lack of communication across the system regarding pathways for PEoLC (e.g. District Nurses/Specialist Palliative Care). • **Lack of awareness of hospice services:** across local systems, particularly Integrated Care Boards (ICBs). • **Unclear definitions:** of specialist/generalist, as well as a lack of understanding around how these cannot always be separated in delivery. • **Referral criteria:** providers clashing about referral criteria because of historic roles and funding arrangements. • **Governance:** can be a barrier to doing the right thing and collaborative working; working together was easier during emergency Covid measures because cross-sector working was prioritised over structures. • **National mapping challenge**: data platforms and solutions reinvented by each ICS causing significant inconsistency across areas. • **Transformation:** funding constraints creating an overreliance on the third sector to support the transformation needed for ICSs to reach their potential.
Voluntary, Community or Social Enterprise (VCSE) sector	• **Lack of clarity:** around models, definitions, contracts andreferral pathways. • **Funding challenges.** • **Lack of engagement:** partners across ICSs not engaging with VCSE sector. • **Workforce planning:** lack of system-wide thinking about workforce challenges means VCSE sector not included in planning, and that training and human resources are not being optimised. • **Voice:** PEoLC providers need a voice both as the VCSE sector but also an essential health care partner.

	What barriers are preventing progress?
Regulators	• **Priorities set by Secretary of State:** do not include end of life. • **Lack of national models:** makes it harder to identify what 'good' is – similarly a lack of consistency across data systems makes it hard to draw conclusions from the available data.
Local government	• **Funding pressures / section 114 (bankruptcy) risks:** local authorities are stripping back services so that other statutory services are taking up the majority of funding. • **Crisis focus:** tendency to review negatives (for example, looking at where crisis situations have occurred) and not evaluate positives (largely due to resource pressures).

2.3 Opportunities

This is a summary of the key opportunities where intervention could help each stakeholder group further progress PEoLC work.

Note: Resolving funding challenges applies across ICSs, VCSE sector and local government.

	What opportunities exist?
Integrated Care Systems (ICSs)	• **Provider collaboratives:** these make for easier commissioning, communication and contracting. • **Models that provide more for less:** with a background of financial restraint, any model that can evidence better outcomes for less resource is valuable. • **Input into Joint Forward Plans:** understanding from partners about how PEoLC can be embedded in Joint Forward Plans to help systems meet goals while improving delivery of PEoLC. • **Population needs:** better understanding of population need. • **Hospice offer**: clear messages shared about what hospice services offer. • **Clear definitions:** definition around specialist and generalist PEoLC and how these cross-over in practice. • **Governance:** clearly articulated models of governance to enable working across ICS system partners. • **Advance Care Planning (ACP) template:** build consistency in ACP used across ICSs (e.g. nationally) to support patients and outcome measures.
Voluntary, Community or Social Enterprises (VCSE) sector	• **Consistent guidance:** highlight how PEoLC should be modelled at an ICS level. • **Contractual clarity:** ICBs to provide more clarity around provider remits and responsibilities. • **Increase VCSE sector engagement:** across local and national systems.
Regulators	• **Good practice, models, and core components:** share examples with the Regulators.
Local government	• **Local peer reviews:** could benefit from understanding PEoLC and how they could review this.

	What opportunities exist?
	• **Health and Wellbeing Boards (HWBs):** improved understanding of PEoLC and local need could help elected members influence at a local level.
National influencers	• **Improving death literacy:** providing information to aid understanding of a good death, and how hospices help towards this. • **Health and Social Care Select Committee:** to re-review whether ICSs are meeting their aims now they've been in place for longer. • **Assisted dying debate**: to raise awareness of the need for good quality, equitable, PEoLC. • **Workforce planning:** improving approaches to workforce planning to include the whole health and care sector. • **Contextualising the potential of PEoLC:** building understanding of the role the PEoLC sector can have in improvements across the health and care system.

3. Conclusion

The roundtable event was attended by stakeholders who offered a broad range of local and national perspectives on PEoLC developments across different sectors in the emerging integrated health and social care landscape.

Key areas for improvement for advancing PEoLC within integrated care systems include:

Financial sustainability: Funding challenges and a lack of financial sustainability across all partners remains a key barrier. Honest conversations about resource constraints, competing strategic priorities, and workable models are needed. Balancing adequate resources for PEoLC, despite wider strategic pressures, is vital to ensure quality care provision.

Guidance and frameworks: There is a need for the development of clear guidance and frameworks to provide a roadmap for PEoLC within ICSs. This includes defining what constitutes 'good' PEoLC and establishing clear pathways for care delivery. Establishing standardised models, definitions, and evaluation metrics for PEoLC is important, while enabling ICSs to address local needs with local services. This would enable better comparison of outcomes and facilitate quality improvement efforts.

Collaboration and communication: Enhancing collaboration and communication among stakeholders is crucial to improve coordination and delivery of care between delivery partners.

Workforce planning: There's a need for system-wide thinking about health and care workforce challenges and this should include the PEoLC workforce, as well as how system-wide training opportunities and resources could be optimised across sectors.

Governance: Addressing governance issues and streamlining processes could help remove barriers to effective PEoLC delivery. This includes ensuring clarity around referral criteria, reducing conflicts among service providers, and enabling the development of new delivery models.

Improving awareness: Increasing awareness of hospice services and PEoLC options among healthcare professionals and the general public is necessary to improve 'death literacy' and understanding what constitutes a 'good death.'

The above areas offer key opportunities for PEoLC sector partners to come together and progress improvements in PEoLC.

Next steps: key questions

Stakeholders might want to consider the following key questions when developing plans for the next steps of working together:

1. Can we articulate a model of what good PEoLC provision looks like in an ICS?
2. Do we understand what PEoLC looks like in Neighbourhood Teams?
3. Can we solve the issues presented by the lack of definitions and understanding of specialist/generalist hospice care?
4. Do we have a good model for population needs analysis? And how can we support ICBs to implement this?
5. How can we best ensure that Joint Forward Plans reflect PEoLC needs?
6. How can we influence national and local workforce planning to include the needs of the PEoLC sector?
7. Are VCSE PEoLC providers open/willing to working together in a provider collaborative model?
8. How can we help equip local elected officials? How can we best influence Health and Wellbeing Boards?
9. Can we provide a framework for what a peer-led review of an ICS's approach to PeoLC might look like?
10. How can we improve death literacy?
11. Can we help build consistency in the use of Advance Care Planning to help meet people's needs and improve outcome measures that can be used across ICSs?
12. Are there opportunities to work with the Regulators to build their understanding of what a good approach to PeoLC would look like?
13. Can the sector work with the national Government to strengthen the Regulators' objectives on areas that impact the delivery of PEoLC, such as population needs assessment, workforce planning, and partnership working?

Appendix: SWOT Analysis

Analysis of the strengths, weaknesses, opportunities and threats for the PEOLC sector.

Strengths	Weaknesses
• Statutory duty now in place. • Innovative models emerging: 27/4 SPoA, In-reach in A&E. • PEoLC can be part of wider response solution to issues in health care system. • Hospices/VCSE sector are being commissioned with statutory duty but can be more flexible than statutory sector. • Some ICSs have been very good at engaging with PEoLC sector.	• ICS funding pressures driving counter-productive behaviour: focus on efficiencies/Urgent Care/cannot pump prime new models. • Lack of awareness and clarity in ICB/Ss about what hospice care can offer: What is specialist/generalist; an understanding of what good models looks like; data and records sharing poor. • ICS workforce plans do not routinely consider wider ICS staff e.g. hospices/VCSE sector. • Population assessment is proving difficult for ICSs. • Often reliant on individual leaders pushing PEoLC - some ICSs not engaging. • Locally, ambiguity/problems with providers gate-keeping roles (e.g. District Nurses/Specialist Palliative Care)/and referral criteria. • Pressures of doing the right thing vs risks appetite of getting the governance right. • Reliance on charitable sector to drive transformation.
Threats	**Opportunities**
• The background agenda in ICSs is one of reductions in central funding and reductions in capacity: ICSs are having to do more with less. • Upcoming election driving focus on Urgent Care/hospitals. • Hospices in some areas are facing potential closure due to lack of funding and in others, significant changes to model of delivery being considered.	• 2024 election (agendas/manifestos) and assisted suicide focus: chance for PEoLC sector to show potential for meeting wider system priorities; improve death literacy; uniform/robust data; highlight best practice. • Potential for integration of PEoLC in Neighbourhood Teams. • Lack of specificity around PEoLC means models of what hospice services are for the future can be developed: inputting into Joint Forward Plans; defining how specialist and generalist work together. • Collaborations of multiple providers, e.g. hospice collaboratives, likely to appeal to ICSs. • Influencing Health and Wellbeing Boards who set priorities at local level/Joint Strategic Needs Assessment. • Supporting the development of local government peer-led reviews: chance for basic guidance. • Workforce plans could integrate wider ICS partners such as hospices. • Shift in focus from acute/secondary to primary/community care. • New CQC inspection frameworks: focus on population health/partnerships/best practice - PEoLC can help to evidence that its meeting needs of under-served populations. • Appetite for broader agreement/mandate around Advance Care Planning models.

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