

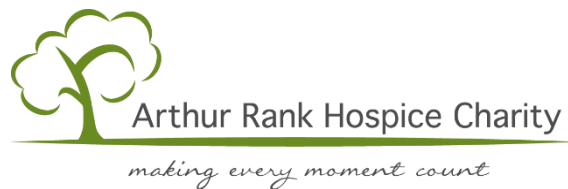


Enablers for end-of-life care

Key recommendations for commissioning and delivering better end-of-life care within Integrated Care Systems

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Introduction

In early 2022 Sue Ryder commissioned Traverse to support the development of a set of shared recommendations that would enable better end-of-life care within the context of the national transition to Integrated Care Systems (ICSs).

Traverse conducted interviews with sector leaders and facilitated a workshop bringing together palliative and end-of-life care (PEoLC) and voluntary, community social enterprise (VCSE) sector stakeholders in order to understand key opportunities and challenges associated with the transition. Traverse then worked with the group to develop recommendations based around the key themes/enablers discussed; setting out solutions to address these challenges.

With the introduction of ICSs in July 2022 and the release of [guidance](#) for Integrated Care Boards (ICBs) on their statutory responsibilities for delivery of PEoLC services, this piece of work is important to further improve how the ICS system can work in practice. Technical guidance and resources are due to be published by September 2022 that will supplement the guidance released on 20 July 2022 - at the time of writing this document the technical guidance has not yet been published.

This document provides a summary of the key opportunities, challenges, and suggested recommendations for each of the four themes/enablers that were discussed during the workshop:

- Funding & commissioning
- Workforce, retention & pay. Education & training
- Collaboration within the system
- Health inequalities, cultural awareness & minority groups

We would like to thank all who contributed to the workshop that formed the basis of this document, and to everyone who helped finalise this document, namely:

- Katharine House Hospice;
- Hospice UK;
- Arthur Rank Hospice Charity;
- Forest Holme Hospice;
- Cransley Hospice Trust;
- Keech Hospice;
- The Kirkwood Hospice;
- Macmillan Cancer Support;
- Willen Hospice;
- And others.

Overarching enablers/recommendations:

The below are points that were raised multiple times throughout discussion on the four main themes and are considered key for the commissioning of appropriate end-of-life care, they included:

- **Patient centred care:** The introduction of ICSs should remove any disjointed care patients receive. The care patients and their families receive should be easily navigated and seamless - no matter where or who the service is commissioned by.
- **Longer term planning:** Creating a shared understanding and assessment of population needs should enable strategic whole system workforce planning, provider service development, and commissioning on a sustainable basis as well as to reduce health inequalities.
- **Partnerships and governance:** The PEOLC sector should work with NHS England (NHSE) to provide further guidance/examples on how to develop and maintain well-functioning collaboration at ICS level. Although we would expect ICSs to be proactive in working with the PEOLC sector, consideration should be given to how the quality and equality of collaboration can be ensured. This is especially important when an ICS has not yet taken a proactive role in fostering joint initiatives or created a formal 'space' for the PEOLC VCSE sector within the system. Sufficient opportunity for the PEOLC VCSE sector to become established formal partners within the ICS needs to be given and should not all fall to the VCSE sector to create.
- **Data:** Each ICS should centralise the data collected within their systems in order to support an ICS-wide understanding of PEOLC needs and improve the knowledge that innovations and service adaptations are built on.
 - Improved ICS level data can be shared nationally to facilitate a consistent national data set which is underpinned by a drive to use common recording systems across all ICSs.
- **Importance and impact of PEOLC organisations:** VCSE organisations deliver a large percentage of frontline PEOLC services that are essential for meeting population health needs and for capacity within the health system. The PEOLC sector must work together to demonstrate the importance of the services they deliver within each area. This should include efforts to improve collective impact measurement, recognising that outcomes are harder to measure at the end of life, and establish monitoring and evaluation practices.
- **Sustainability of funding:** Government funding for the VCSE PEOLC sector is often much lower than the total expenditure needed to deliver the care. The Government should work with ICSs to ensure funding is set at a more sustainable level for charitable health providers and that commissioned services keep pace with rising costs. Real term reductions to funding impact the sector's ability to improve and extend care and meet more people's needs.

Key theme 1: Funding & commissioning

Key opportunities

- In the long term, a better system-wide understanding of population needs (obtained through improved data collection and sharing) would help facilitate shared agreement on and provide clarity around what constitutes core, specialist and enhanced PEOLC services for different “Places” and communities. In the short term an ICS wide population health needs assessment should be carried out to provide information to support PEOLC provision planning at both ICS and Place levels. Both of these will in turn support sustainable commissioning.
- The transition to ICSs offers an opportunity to create a landscape that supports different-sized providers and allows the PEOLC sector to speak with one collective voice, preventing smaller providers from getting left behind. This streamlined approach could also facilitate more effective ways of working with commissioners to meet the varied needs of patients in appropriate settings.
- There are opportunities for the wider-ICS to explore different outcome-based approaches to tackle health inequalities and meet the needs of the populations across their footprints. The use of social investment models could help to achieve this.

“To offer a collective voice and flexibility - allows us to innovate and give solutions which offers us VCSE organisations a unique and useful position at the table”

Key challenges

- There is a national shortfall in funding needed for the health and care sector to meet population health needs. The sustainability of PEOLC funding and how it is distributed across sectors and geographies needs national and local attention.
- Some ICSs have been involved in NHS integration programmes for longer and are more mature when it comes to identifying key leaders, partnerships and collaborations between organisations within the ICS. This has caused differences in the pace of ICS development, creating inconsistencies. There are concerns that this will impact on the equity of funding and commissioning opportunities across England, as newly imposed deadlines approach for a draft Integrated Care Strategy by December 2022, which some ICSs may feel less equipped to produce collaboratively.
- Without the right governance framework in place across ICSs:

- The move from Clinical Commissioning Group (CCG) commissioning to ICS commissioning, where there is more than one Place, could continue to create inconsistencies in the way PEOLC needs are met across the ICS footprint.
- The voices of some providers could be drowned out or ignored, which could impact their access to funding opportunities and stifle innovation.
- PEOLC provision needs to be flexible to provide personalised care for patients when and how they need it. This is especially important when supporting patients with more complex needs. However, there is currently no common definition of what constitutes core or specialist PEOLC services. Consequently, this creates inconsistencies in service provision across ICSs and the country which brings challenges around funding and resourcing.

"We are reminded of the tight financial envelope...the desire to spread thinner won't serve the needs of those more complex patients"

Suggested recommendations

- Each ICS should provide their position on how they intend to meet their statutory duties for end-of-life care within their Integrated Care Strategy and implementation plan. These plans should be measurable and specific (underpinned by a population health needs assessment) and should provide transparency on how these duties will be delivered for patients. Providers should try to align outcomes data to the measures set out by ICSs in order to help the ICS track its strategic progress and to improve accountability.
 - The PEOLC sector should develop clear national outcome measures and use these to create a local narrative around 'impact achieved' and 'impact to generate' to aid conversations with commissioners and support ICSs to meet their aims.
- The PEOLC sector and ICSs must reach a joint agreement on the level and shape of PEOLC population need. The PEOLC sector will use these agreed assessments to present proposals on how best to meet population requirements in order to help the ICS and commissioners meet their aims.
 - As a first step, the PEOLC sector must work with NHSE to agree on an appropriate baseline of population health measures to aid the ICS's initial assessments. This will need to be reviewed over time as palliative and end-of-life care data collection improves.
- More detailed guidance around what constitutes core, specialist and enhanced care should be created to ensure improvements in commissioning to meet different levels of need. This guidance should be created collaboratively with the PEOLC sector and NHSE in order to aid ICSs.

- ICS leadership and commissioners should create appropriate levels of engagement with PEOC sector collaboratives to ensure it is not the loudest, largest or those with the best links or relationships who are favoured.

"If we can demonstrate impact it could lead into commissioning conversations about improving quality of life"

Key theme 2: Workforce: retention & pay, education & training

Key opportunities

- Whilst workforce challenges are a nationwide issue, the move to ICSs provide an opportunity to address workforce challenges by using flexible and innovative solutions such as:
 - Pooling staff across localities to support capacity crunches and to change the way we approach and recognise the workforce. This could allow staff to apply their skills across more than one organisation and create a system that increases equality between health care professionals employed by the NHS and VCSE sector and ensure availability of staff to enable joined up care.
 - Using remote technologies such as virtual consultancy provision could offer opportunities for people to work from anywhere in the country, which could meet resourcing needs.
- There is an opportunity for more attention to be placed on the workforce needs of VCSE PEoLC health care providers as ICS leaders review the workforce requirements necessary to meet the needs of their population.
- The move towards greater integration within each ICS could be key for improving training, where it is vital to have rotation within different services in line with multi-disciplinary team working. For example, increasing the availability of training rotations for nursing degrees across the whole health and care system, including NHS Trusts and other charitable health organisations.

"There's something about how we share resources. You might be employed by one system but that shouldn't stop you from working across others"

Key challenges

- There is not currently a national picture of the existing PEoLC workforce which means that the understanding of workforce requirements is limited.
- Funding for PEoLC does not keep pace with rising costs, impacting recruitment, training, and retention.
- There are not enough existing staff or new recruits coming into the PEoLC sector. The reasons behind this are largely known, such as a difficulty for the VCSE sector to keep pace with NHS pay, and fewer opportunities for progression in

independent organisations. These reasons are compounded by wider shortages across the health and care workforce.

- The inability for the VCSE sector to keep pace with NHS pay also has an effect on the development of both in-reach and out-reach roles which span the local health and care system.
- The root of many workforce issues are beyond the remit of ICSs, such as the funding available nationally for health care service, as well as the number of university training places available.

"One of the biggest problems is that we do not have a comprehensive picture of the workforce...having that data and insight into where the gaps are, you can then start planning and finding solutions"

Suggested recommendations

- Every ICSs current workforce strategy should specifically include their PEO LC-health and care workforce, with input from providers, stakeholders and professionals.
- This strategy should:
 - be developed in line with projected population demand across all vital health services (not just NHS and social care) and be reviewed periodically;
 - identify what the gaps in capacity are across each "Place" within the ICS footprint and work collaboratively and innovatively to find solutions;
 - be adopted by regulators as a key indicator of the actions necessary to ensure the ongoing quality and safety of patient care;
 - set out measures to increase recruitment from local communities (both long and short term); and
 - consider the potential for factors to impact the workforce in the future such as, the use of technology, grading/pay and conditions.
- The PEO LC sector, as part of its work as a collaborative, should proactively identify workforce gaps and potential solutions, which will feed into the ICS workforce strategy (as per the recommendation above).
- To support each ICS with the creation of their workforce strategies, the PEO LC sector should work with the Department of Health and Social Care (DHSC) and NHSE to help develop further guidance for creating a localised PEO LC workforce strategy.

Key theme 3: Collaboration within the System

Key opportunities

- The integration agenda, embodied by the creation of ICSs, should encourage a shift away from an imbalance of power between partners (NHS/Local Authorities/VCSE) and towards genuine collaboration. This would see the NHS, Local Authorities and wider ICS partners 'creating space' in their current practices, ensuring sufficient opportunity for the VCSE sector to establish its position in the ICS, and for the PEO LC VCSE sector to take a more prominent role and its value and expertise be recognised.
- The move towards further integration across services should create the opportunity to collaborate more effectively with different partners within the ICS to deliver more holistic palliative and end-of-life care.
- Historically, relationships have been central to commissioning. However, commissioning decisions should be based on what different services are able to offer as opposed to which organisations have the stronger relationships or connections with decision-makers. The move to ICSs creates an opportunity for the VCSE sector to develop a framework for collaboration between the sector and the ICS which would enable continued relationships regardless of changes in personnel.

"This is a great opportunity to come together and share ideas and make sure the voluntary sector has a voice"

Key challenges

- The shift to ICSs from CCGs has created a lot of change, with new roles being created and appointed in a short period of time. It is key to get clarity on where and who with the responsibilities now sit so that collaborations between the PEO LC sector and the ICS can be established before the sector loses the initial opportunity to inform or influence ICS plans focusing on PEO LC.
- PEO LC Collaboratives could become problematic if there is no clarity or equitable process from the ICS when approaching their aim to identify a 'lead PEO LC provider'. The lead provider model will shift the balance of power between providers, impacting commissioning, innovation and the provision of services. The process to identify and embed a lead model needs to be transparent and inclusive. Further guidance is needed to ensure this happens, as otherwise this will

likely favour providers who have the most resources at their disposal or have the right relationships that will enable them to secure lead roles.

- Fractured relationships between providers, that can stem from the necessity to compete for a very limited pool of funding, could hinder engagement and credibility with the ICS, resulting in poorer outcomes for patients.

Suggested recommendations

- Each ICS should establish a PEO LC Collaborative which:
 - brings together representatives from the local PEO LC sector. This would allow the sector to work better together and offer a joined-up voice; and
 - is underpinned by a governance framework which facilitates accountable and transparent leadership, equity across all providers involved, and details the responsibilities of members.
- Further guidance should be created by NHSE to ensure an equitable process when identifying a 'lead PEO LC provider' within each ICS, and to enable this role to work well alongside the wider PEO LC Collaborative.
- There is a dedicated PEO LC lead for each ICS who, among other things, is responsible for driving sector engagement and collaboration at a local level.
- The sector should collaborate to show how important voluntary PEO LC organisations are in meeting the ICS's aims and generating local impact. This could increase opportunities to influence and shape the way the system designs, commissions and delivers services for the future.

"The government as a whole has recognised that the VCSE has been an important part of the support service over the pandemic. We need to push that and take the opportunity to make sure that we are recognised as a professional body in the health and social care environment as a whole"

Key theme 4: Health inequalities, cultural awareness, & minority groups

Key opportunities

- The move to ICSs and the introduction of a system-wide focus on meeting population health needs should encourage all ICS partners to work together to minimise health inequalities.
- The focus on population health creates an opportunity for patient voices to play a more central role in the creation of care models, including in the co-production of solutions.
- There is an opportunity for greater exchange of best practice and lessons learned around tackling health inequalities, at both a national and local level. This would help different systems to understand how to better reach and deliver for different communities and places, which could encourage better stewardship of resources. Whilst this could aid base level understanding of different needs, tackling health inequalities must take place alongside the co-production of solutions at a local level, rather than instead of.

Key challenges

- In order for ICBs to fulfil the new legal duty to commission palliative care services that meet the requirements of the people for whom it has responsibility, ICSs must first understand their population health needs and determine the actions needed to sustainably meet this need.
- ICSs will have a focus on making improvements around health inequalities. However, despite the reality that the majority of individuals will at some point need palliative and end-of-life care, health inequalities within PEOLC may not be at the forefront of every ICS's planning. A push for the ICS to increase focus on this as an important area to minimise health inequalities could be challenging to secure due to a lack of impactful outcome measures in end-of-life.
- The PEOLC workforce often does not reflect the diversity of the communities and places they work within, and multiple factors impact this. ICSs do not hold ultimate responsibility for all factors that impact this, such as deciding the number/location of training places and providing national initiatives to encourage people into the workforce. However, ICSs can develop interventions within workforce strategies to improve levels of diversity and representation.

- There is a risk that providers working within the same ICS will duplicate efforts to address local health inequalities because of a failure to share learning across the system. This does not only waste resources but could contribute to communities disengaging if they are consulted repeatedly and by different providers about the same issue.

Suggested recommendations

- The VCSE has a strong track record of being a trusted pillar of the communities they serve and often has strong links into population groups that are at greater risk of health inequality. ICSs should work with the VCSE sector to understand the needs of their communities and work with PEO LC providers to reduce health inequalities.
- Every ICS should aim for a workforce which better reflects the communities they serve. Equality, diversity and inclusion should feature within every ICS's workforce strategy, setting out how they plan to improve representation.
- The development of an ICS collaboration framework should include an exchange between the ICS and the PEO LC VCSE sector of their plans for tackling health inequalities. This would avoid duplication, promote areas for collaboration, enable better use of resources, and ultimately improve services for patients.
- As more information becomes available on the PEO LC needs of different communities and Places, ICSs should consider these against their current and projected population demographics.

"We must be inspirational as at the heart of our care is personalisation - built around individuals and communities"

Conclusion

The transition to ICSs will create opportunities as well as challenges for the PEO LC sector around the key themes set out within this document, as the sector helps to fulfil the cornerstones of the ICS legislation, which are to:

1. Improve outcomes in population health and healthcare.
2. Tackle inequalities in outcomes, experience, and access.
3. Enhance productivity and value for money.
4. Help the NHS support broader social and economic development.

This document highlights the views and solutions put forward by a cross section of the PEO LC sector that we hope can become the starting point for a wider conversation around how ICS structures can improve the vision for the future of PEO LC across England and ensure more people can get the care they need.

The need and enthusiasm from within the sector for the discussion that led to the creation of this document is reflected in the desire to contribute and the quality of insights provided. We hope to use this momentum to work collaboratively with NHS England and the Government to help bring the recommendations identified to fruition.

The contributors to this document are committed to working collaboratively with the wider PEO LC sector to continue this conversation and to ensure all voices are heard.



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