

Hewitt review call for evidence: Sue Ryder response **January 2023**

About Sue Ryder

Sue Ryder supports people through the most difficult times of their lives. For almost 70 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can.

We take the time to understand what's important to people and give them choice and control over their care. This might be providing care for someone at the end of their life, in our hospices or at home. Or helping someone manage their grief when they've lost a loved one. Or providing specialist care, rehabilitation or support to someone with a neurological condition.

We want to provide more care for more people when it really matters. We see a future where our palliative and neurological care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

Section One: Empowering Local Leaders

Question 1: Please share examples from the health and care system, where local leaders and organisations have created transformational change to improve people's lives.

This can include the way services have been provided or how organisations work with residents and can be from a neighbourhood, place or system level.

Sue Ryder's virtual ward model pilot

- There is a drive towards virtual wards within the NHS, with all Integrated Care Systems (ICSs) being asked to extend or introduce virtual ward models.¹ Supporting information for ICS leads states that, "In doing so, additional 'bed' capacity could be created as a result of efficient and productive use of resource and management of patients".²
- There is considerable value in adopting virtual wards in a palliative care setting, as demonstrated by a recent Sue Ryder pilot.
- The palliative care sector is facing rising demand for its services. Sue Ryder projects that the number of people in receipt of palliative care will rise from 240,000 in 2018/19 to 379,000 by 2030/31.³ At the same time as demand is increasing,

¹ NHS England and NHS Improvement (2022). Supporting information for ICS leads: Enablers for Success: virtual wards including hospital at home.

<https://www.england.nhs.uk/publication/enablers-for-success-virtual-wards/>

² Ibid.

³ Sue Ryder (2021). Modelling demand and costs for palliative care services in England.

https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf

community palliative care has evolved in intensity and complexity, with more desire from patients to stay at home.

- In response to these emerging trends Sue Ryder piloted a virtual ward model for six months at our Wheatfields Hospice in Leeds. The aim was to provide a responsive, enhanced multi-disciplinary specialist palliative care service to manage complex and acute needs in the community, for patients felt to be at high risk of in-patient admission.
- The virtual ward has enabled patients to have complex symptom management, therapy reviews and psychosocial support in the place of their choice, helping to support their preferred place of care and death, as well as avoiding unnecessary admissions to hospital or hospice.
- As well as improved patient outcomes, the Sue Ryder Wheatfields Hospice pilot has shown that virtual wards can help to manage the increasing demand on palliative care services and share limited staff resourcing effectively. However, the efficiency of the model relies on collaboration across providers. Whilst a virtual ward can be delivered by a single provider, we believe it is more effective when hospice providers and NHS community teams work together.

Sue Ryder's Nurse-Managed Bed service

- In 2018 Sue Ryder introduced a Nurse-Managed Bed (NMB) service at our Wheatfields Hospice in Leeds, with the Integrated Care Board (ICB) currently commissioning 3-4 Nurse-Managed Beds. The aim of the service is to provide nurse-led care for patients at the end-of-life who do not have specialist palliative care needs.
- The objectives of the NMB service are to:
 - Support non-complex patients whose preferred place of death is hospice.
 - Reduce hospital deaths by supporting patients' preferred place of death in hospice.
 - Support hospital avoidance and hospital discharge for non-complex patients at the end-of-life.
 - Increase in-patient unit (IPU) capacity to admit patients for end-of-life care.
 - Enable medical teams to support more complex patients in the IPU.
 - Provide an equitable service across the city of Leeds.
- In order to evaluate the appropriateness of the patients admitted to the service, a retrospective audit was undertaken. The audit reviewed 45 patients referred to the hospice by the community nursing team or teaching hospitals over a six-month period.
- Overall the audit revealed that the majority of patients referred were appropriate to be managed by the NMB service. The number of patients referred continues to increase as primary and secondary care services become more aware of access to the Nurse-Managed Beds, as it is seen as a valuable resource.
- Sue Ryder has been in discussion with other commissioners about providing a similar service in their ICSs for several months. However, progress has been hampered due to slow decision-making processes. Future reforms must look at removing barriers to enable efficient decision-making, so that local populations can benefit from innovative and valuable services at the earliest opportunity.

Question 2: Do you have examples where policy frameworks, policies and support mechanisms have enabled local leaders, and in particular, ICSs to achieve their goals?

Question 3: Do you have examples where policy frameworks, policies, and support mechanisms made it difficult for local leaders, and in particular, ICSs to achieve their goals?

This can include local, regional or national examples.

- The Health and Care Act 2022 introduced a legal duty for ICBs to commission palliative care services which meet their population's needs.⁴
- NHS England has published materials to support ICBs to achieve this duty, including statutory guidance⁵ and an accompanying handbook which provides practical advice and resources on implementing quality palliative and end-of-life care (PEoLC).⁶
- Whilst it is positive that these resources have been produced, they require further development. There is little direction and advice on approaches to assessing PEoLC population health needs. Given the well-evidenced health inequalities that exist within PEoLC, we believe that this must be incorporated into the guidance to enable ICBs to meet their statutory duty.
- There is an additional concern around how the quality of PEoLC services will be ensured. Statutory guidance lacks detail in this area, allowing for local interpretation and creating potential for substandard provision. Guidance should set out a baseline level of service provision that needs to be in place for ICBs to deliver on their responsibilities, without being prescriptive about how this is achieved.
- It is also currently unclear how ICBs will be held accountable for adhering to the new statutory duty. We hope that this will become less ambiguous as the CQC continues to develop and introduce their new regulatory approach⁷ and through the publication of Integrated Care Strategies.
- ICSs face many competing priorities due to national targets, statutory duties and responding to local health population needs. Although there is a statutory duty around the commissioning of PEoLC services, we are concerned that the limited detail around service provision and lack of clarity on accountability will mean that other areas are prioritised and PEoLC will not get the attention it needs.
- A whole system approach to workforce planning is also needed if ICSs are to achieve their goals and statutory duties. In order for safe, high-quality care to be provided, each ICS should develop a workforce strategy that covers their entire health and care workforce, not just NHS teams. Closer integrated working between the NHS and ICS providers, such as sharing of workforce plans/data, is also essential. The healthcare workforce is limited and coordinated planning is required to ensure services are safe and can meet the needs of patients.

⁴ NHS England (2022). Palliative and end of life care: Statutory guidance for integrated care boards (ICBs).

<https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

⁵ Ibid.

⁶ https://future.nhs.uk/EOLC_Practitioners/view?objectId=38207120 (last accessed 06.01.23)

⁷ <https://www.cqc.org.uk/news/our-revised-plan-and-approach-transformation> (last accessed 06.01.23)

Question 4: What do you think would be needed for ICSs and the organisations and partnerships within them to increase innovation and go further and faster in pursuing their goals?

- Continuous innovation is needed to deliver care better.
- ICSs should be afforded the permission to research, test and learn. The flexibility to think differently, innovate and trial new models or approaches is vital to understanding whether current ways of working are the right ones, and identifying changes that can deliver benefits (such as cost savings or improved outcomes).
- This should not, however, be exclusive to the NHS. ICSs must ensure that the resources to facilitate innovation are accessible to all health and care providers within their footprint.
- Regulators and other bodies should not be punitive where such research does not result in the desired outcome. Instead, it should be seen as an opportunity to share important learning with other ICSs.
- It should be noted that, whilst it is imperative that ICSs consider and test different ways of working, certain essential services must always be delivered. For palliative and end-of life-care, an example of such a service would be 24/7 access to a specialist palliative care professional advice line.
- Nevertheless, it is not enough to simply give ICSs and organisations within them the permission to innovate. For innovation to be truly possible investment must be made available through an innovation fund. Statutory funding currently covers around a third of running costs for PEOLC providers and the remainder is raised via fundraising. This funding should be spent on essential services for patients. To foster greater innovation, ICSs should collaborate with PEOLC providers who are already contributing significant value to the system, which will further enhance care for patients.
- There must also be greater security for health and care providers. The current practice of short-term contracts is detrimental to innovation as providers must frequently focus their efforts on the next round of commissioning. Increasing the length of contracts would enable providers to spend their valuable, often limited time and resources investing in developing solutions and evolving services for the local population. Short contracts also hamper innovation because there is no guarantee that providers will deliver their service from one year to the next, which could discourage them from investing resources to seek improvements.

Question 5: What policy frameworks, regulations or support mechanisms do you think could best support the active involvement of partners in integrated care systems?

Examples of partners include adult social care providers, children's social care services and voluntary, community and social enterprise (VCSE) organisations. This can include local, regional or national suggestions.

- The integration agenda, embodied by the creation of ICSs, should encourage a shift away from an imbalance of power between partners 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 VCSE sector should be represented on every ICB. Progress in this area should be monitored and a mandate introduced if VCSE representation is commonly missing. Any mandate should ensure that the VCSE sector plays a meaningful, rather than tokenistic, role.
- The PEO LC sector should work with NHS England 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 PEO LC sector, consideration must be given as to how the quality and equality of collaboration can be ensured. This could be through the development of a framework or introduction of a regulatory responsibility.
- 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 PEO LC VCSE sector within the system. Sufficient opportunity for the PEO LC 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.
- As a minimum, each ICS should establish a PEO LC Collaborative, underpinned by a governance framework, that brings together representatives from the local sector and ensures equity across all providers.

Section Two: National targets and accountability

Question 6: What recommendations would you give national bodies setting national targets or priorities in identifying which issues to include and which to leave to local or system level decision-making?

- We can only answer this question in the context of PEO LC.
- Central targets can be consistent with local autonomy, so long as the correct balance is struck between the two.
- Central targets can play an important role in preventing inconsistent service provision. Sue Ryder's recent research, *A Better Route Through Grief*, found that there are significant disparities in the availability of bereavement services across the country - creating a patchwork of support.⁸ In some areas, therefore, a lack of central targets may only serve to worsen disparities in service provision across different ICSs.
- It is also important to maintain central targets that enable the identification and monitoring of national population health needs, for the purposes of future planning.
- National bodies must consider both of the above points when identifying which issues to include in national targets and priorities.
- It is important to note that certain population groups are more likely to face barriers in access to PEO LC and to experience lower standards of care. There is no national, one-size fits all solution to this. Health inequalities vary by ICS based on their unique population demographics and other characteristics such as rurality. It is therefore

⁸ Sue Ryder (2022), *A better route through grief: Support for people facing grief across the UK*. <https://www.sueryder.org/sites/default/files/2022-06/A%20better%20route%20through%20grief%20report.pdf>

imperative that each ICS has the autonomy to identify and meet the PEOLC needs of its local population.

Question 7: What mechanisms outside of national targets could be used to support performance improvement?

Examples could include peer support, peer review, shared learning and publication of data at a local level. Please provide any examples of existing successful or unsuccessful mechanisms.

- For PEOLC, a national core dataset should be agreed and published at ICS level to create a transparent system and enable the identification of good or poor performance. We expand further on this point in response to question nine.
- It is essential that proactive sharing of learnings is something that is expected of and practised by all ICSs going forward. Knowledge sharing should be in place to support all ICSs, but could particularly benefit those who are underperforming.
- For this to work in reality, processes and structures that facilitate shared learning must be established. We would suggest that a shared library/platform which allows ICSs to share and access learnings is created (e.g. improved use of the FutureNHS platform).
- We acknowledge that, in order for this to be effective, it is not enough just to provide a platform for the exchange of information. A culture of sharing best practice must be fostered and the right incentives considered at both national and ICS level to encourage ICSs to impart advice and knowledge.
- Consideration must be given as to how providers working within the same sector and ICS footprint share best practice. Whilst this may occur naturally in some circumstances, support is needed for this to happen effectively on a wider scale.
- Sharing best practice and encouraging the fostering of this as a way of working should be championed by NHS England and Improvement, and should be brought to life for different parts of the sector by their networks and leads. For example, in palliative care this would be through the Ambitions Partnership and in Neurological care this would be led by the National Clinical Directors for Neuroscience. These groups/individuals should take responsibility for the sharing of good practice with the Department of Health and Social Care/NHS England and Improvement and ensure case studies are regularly updated at a national level and are available as part of core strategic planning and commissioning guidance.

Section Three: Data and transparency

Question 8: Do you have any examples, at a neighbourhood, place or system level, of innovative uses of data or digital services?

Please refer to examples that improve outcomes for populations and the quality, safety, transparency or experience of services for people; or that increase the productivity and efficiency of services.

- N/A

Question 9: How could the collection of data from ICSs, including ICBs and partner

organisations, such as trusts, be streamlined and what collections and standards should be set nationally?

- A national core data set should be developed for PEOLC, specifying the data that services and providers must collect and report to the ICS. This would enable better planning of services to meet local needs, facilitate greater integration and support both providers and central bodies to compare information and better understand the national picture.
- Diversity data is key to an ICS understanding its PEOLC population health needs and in turn, meeting its statutory duty regarding the commissioning of palliative care services. However, collation of this information is currently inconsistent across different providers and it is not always done well. Diversity data must therefore be central to the development of a national core data set for PEOLC.
- A national core data set would also ease the reporting burden of central targets for providers. Currently each ICS has different key performance indicators for PEOLC providers to report to each month. This is time-consuming and resource intensive as it means that IT systems cannot be configured to capture all of the required data and integrate with ICS systems. A core data set that is consistent across ICSs would enable providers to put systems in place to efficiently capture and input information.
- Further, we believe that central data on national targets should be more widely and openly shared with providers.

Question 10: What standards and support should be provided by national bodies to support effective data use and digital services?

- As outlined in response to question nine, national standards for the collation and reporting of PEOLC data should be developed and implemented. This must be accompanied by supporting guidance for PEOLC providers.
- Small providers should be further supported to make the changes required where needed. For example, the availability of grants to update reporting systems and the sharing/provision of resources from the ICS where technical expertise or additional capacity is required to implement the necessary changes.

Section Four: System oversight

Question 11: What do you think are the most important things for NHS England, the CQC and DHSC to monitor, to allow them to identify performance or capability issues and variation within an ICS that requires support?

- We can only comment in the context of PEOLC.
- As outlined in response to questions two and three, we believe that statutory guidance regarding an ICB's duty to commission palliative care services should be further developed so that it sets out the baseline level of service provision required. This baseline should have key performance indicators attached to it which ICSs must report on, enabling easy identification of performance or capability issues.
- The quality of ICS collaboration should also be assessed, based on evidence of integrated working. For example, assessing how well providers collaborate to reduce harm in a given ICS.

- **Commissioning to meet local need.** The Health and Care Act 2022 introduced a legal requirement for ICBs to commission palliative care services which meet the needs of those for whom it has responsibility.⁹
- It is right that ICSs are granted the flexibility to determine how they measure local population health needs. However, there must be oversight to ensure that the approach is adequate, and fully considers the needs of different population groups within the ICS footprint. For example, ICSs should be able to demonstrate to regulatory bodies that appropriate engagement with providers, communities and health professionals has taken place.
- In the longer-term, we would like to see national guidance developed further to better support ICSs to understand local PEOLC need.

Question 12: What type of support, regulation and intervention do you think would be most appropriate for ICSs or other organisations that are experiencing performance or capability issues?

- A centralised process of support should immediately be implemented for ICSs identified as experiencing performance or capability issues.
- This process should recognise that each ICS will face unique challenges and therefore solutions to remedy the failure will need to be locally focused. The inclusion of statutory duties within integrated care strategies will prove integral to this, supporting both parties to identify the cause of the issue and where changes are required.
- Further, transparency around an ICS's failure to meet statutory obligations and progress against actions being taken to rectify this is absolutely necessary for accountability.

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⁹ NHS England (2022). Palliative and end of life care: Statutory guidance for integrated care boards (ICBs).
<https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>