

Special Inquiry Committee on the Integration of Primary and Community Care

Sue Ryder response

April 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.

1. What are the main challenges facing primary and community health services?

- *What are the solutions within the current framework?*

The main challenge facing hospices, a key provider of community palliative and end-of-life care (PEoLC) services, is a lack of adequate statutory funding. Hospices receive around a third of the funding required to deliver PEoLC from the Government and are reliant on fundraising activities and voluntary donations to cover the remaining costs.

In England, demand for specialist palliative care is projected to rise by 55% in the next ten years.¹ This is due to a number of factors, including increased mortality rates and a growing desire by patients to die at home rather than hospital.

In 2021, Sue Ryder commissioned independent research to examine the cost of meeting growing demand for specialist palliative care services over the next decade.² The research found that, if government funding continues in line with its current model, hospices will be required to raise £597 million each year through fundraising. This is before accounting for inflationary increases since 2021.

¹ 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

² Ibid.

Without a government commitment to significantly increase levels of statutory funding to cover clinical costs for specialist palliative care services, there is a genuine and serious risk of services being withdrawn and patients and their families losing out on the specialist, holistic support that hospices offer within the community.

A commitment to fund 70% of total palliative care costs (in line with inflation) is the minimum required to ensure the sustainability of the hospice sector and these vital services in the medium-term.

- *What steps should be taken to improve support for the long-term management of complex conditions in the community, and respond to the needs of patients and communities?*

Palliative care is uniquely placed to follow patients throughout their journey from home to hospital to care home and so on. Palliative care teams can provide a link between hospital teams and primary care. They can monitor the services their patients access and act as a conduit for the patient. This approach must be learnt from and implemented across the health and care sector so care can become more integrated. This is increasingly happening, for example doctors from hospitals visit patients in care homes, but this integrated approach needs to be further embedded across the health and social care sector.

Hospices provide PEOLC to people with life-limiting conditions in a variety of settings, including in the community/at home. The proportion of people dying at home has been increasing for the last twenty years and this trend is set to continue.³ It is projected that by the 2030s more people will die at home than in hospitals and hospices.⁴

The Health and Care Act 2022 introduced a legal duty for Integrated Care Boards (ICBs) to commission palliative services which meet their population's needs.⁵ In theory, this should mean that palliative care provision will adapt over time to reflect the growing number of deaths at home.

However, ICBs can only commission the right services if there is a good understanding of PEOLC population health needs, which is not currently the case. Monitoring (including demographic monitoring) is not suitably carried out, leading to limited information on gaps in provision and inequalities in access to care.

³ The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care.

<https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-report.pdf>

⁴ Ibid.

⁵ 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/>

A recent King's Fund report on end-of-life care also found that commissioners were not making full use of available data or national resources for assessing local needs.⁶ Need was often understood based on levels of demand reported by providers for each service separately, making it difficult to build a complete picture or identify unmet need.

In order to improve understanding of population health needs, a national core dataset should be developed for PEO LC, specifying the data that ICSs, services and providers must collect and report. This would enable better planning and commissioning of appropriate services in the community.

Diversity data should be central to the development of a national core data set, to provide a full picture of PEO LC population health needs. Collection of diversity data is currently inconsistent across different healthcare providers and it is not always done well. This must be addressed in order to tackle the health inequalities which exist within PEO LC and ensure the commissioning of services which meet the diverse needs of different communities.

As well as increased statutory funding and the introduction of a core data set, continuous innovation is needed to deliver services which respond to the needs of patients in the community. The flexibility to think differently 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, improved outcomes or increase in access).

The current practice of short-term contracts is detrimental to innovation in hospice care 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 and often limited time and resources investing in developing solutions and evolving services for patients and communities. A lack of funding also inhibits innovation, with statutory funding covering just a third of running costs for palliative care services. **For continuous innovation to be truly possible investment must be made available through an innovation fund.**

An example of a successful piece of innovative work that responded to the needs of patients and communities is Sue Ryder's virtual wards pilot at Wheatfields and Duchess of Kent hospices. The aim of the pilot 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 inpatient admission. The virtual ward enabled patients to have complex symptom management, therapy reviews and psychosocial support in their place of choice, as well as avoiding unnecessary admissions to hospital or hospice.

As well as improved patient outcomes, the pilot has shown that virtual wards can help to manage the increasing demand on palliative care services and share limited staff resourcing

⁶ The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care. <https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-report.pdf>

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.

The model also relies upon the availability of skilled, multi-disciplinary staff, meaning that workforce shortages are a substantial barrier to the operation of virtual wards. This is just one example of how improving workforce planning and availability is vital in supporting the long-term management of complex conditions in the community and responding to the needs of patients and communities.

4. What are the implications of the Government's long-term workforce plan for the NHS on primary and community care staffing?

We welcome the Government's commitment to publish a comprehensive NHS workforce plan, including independently verified workforce forecasts, this year.⁷ The plan is an important step towards addressing the systemic workforce issues facing the health and care sector, including within primary and community care.

However, non-NHS providers, who play a critical role in the delivery of primary and community care, are also facing significant workforce challenges.

There has long been a workforce shortage within the hospice sector. Systemic problems in the health and care sector workforce are compounded by the lack of adequate statutory funding, which impacts the hospice sector's ability to ensure that pay remains in line with the NHS. UK hospices would need to raise an additional £120 million pounds a year to match the recently announced increased pay awards for NHS nurses and other staff.⁸ This in turn makes it more difficult and expensive to recruit and retain staff.

The hospice sector is a key part of the healthcare system, delivering vital palliative and end-of-life care services that the NHS would otherwise have to provide. In 2020/21, hospices supported an estimated 300,000 people in the UK, including people at the end of life, families, carers and bereaved relatives.⁹ Demand for specialist palliative care is projected to rise by 55% in the next ten years,¹⁰ however workforce shortages undermine the hospice sector's ability to extend care to meet this growing demand.

⁷ HM Treasury (2022), Autumn Statement.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1118417/CCS1022065440-001_SECURE_HMT_Autumn_Statement_November_2022_Web_accessible_1_.pdf

⁸ UK hospices 'face funding crisis and need extra £120m to pay staff' | ITV News

⁹ Hospice UK and Nuffield Trust (2022), Support at the end of life: The role of hospice services across the UK. <https://www.nuffieldtrust.org.uk/sites/default/files/2022-06/hospice-services-web-1-.pdf>

¹⁰ 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

The Government must plan for the workforce as a whole system across health and social care, including for charitable providers of essential services. Workforce plans must consider all parts of the system as equal players to prevent unintended consequences for vital services that sit outside of the core NHS structure, but are key to the delivery of primary and community care.

It needs to be ensured there is a robust and fit for purpose pipeline of trainees across all disciplines - including nursing, medical, allied health professionals and carers. This is critical for the short, medium and long term.

In order to achieve this, we encourage the Government to look at the following areas:

- Review the reasons stated for staff leaving the sector and include steps to make changes to prevent future leavers in a whole system workforce plan.
- Review why healthcare university students are dropping out and take relevant steps to reduce the dropout rate.
- Conduct research as to why people are not choosing health and social care roles as career options and commit to addressing these issues.
- Review processes to ensure all health and social care roles on the list of those that can be employed from another country can be done so efficiently and affordably.
- Focus current recruitment efforts on return to nursing applicants and staff who have retired or are due to retire.

8. To what extent could improved access to out of hours and 24/7 services contribute to alleviating pressures on the health system?

People with palliative or end-of-life care needs must be able to access 24/7 care to support pain and symptom management. This can in turn alleviate pressures on the health system, in particular emergency services.

The importance of 24/7 PEOLC services has been recognised by NHS England. [The Palliative and End of Life Care: Statutory guidance for integrated care boards](#) outlines the need for ICBs to *“engage in defining how their services will operate population needs 24/7”*.

NHS England also published ‘24/7 Care and Specialist Advice for Palliative and End of Life Care: Commissioner’s good practice guide’ in March 2023. This guidance highlights the importance of integrated care and states that 24/7 PEOLC must be *“coordinated with other care teams who have contact with the person e.g., community nursing, district nursing and personal assistants”*.

However, many people with palliative or end-of-life care needs are unable to access 24/7 support. Marie Curie research from 2022 found:¹¹

- 27% of areas in the UK have no designated line for out of hours palliative and end-of-life care and 42% only had partial coverage.
- 25% of areas had a pharmacy open all night that was able to dispense palliative medicines and 68% of areas only had partial availability of healthcare professionals who can administer palliative medicines at night.
- 52% of areas had only partial or no access to equipment out of hours.

The report highlights the high frequency of visits to emergency departments for people at the end-of-life and that out of hours visits to emergency departments increase more than in hours visits in the last months of life.¹² This indicates that better provision of 24/7 PEOLC services in community settings would alleviate pressures on emergency departments.

ICBs must ensure they address these shortcomings in 24/7 PEOLC when planning and commissioning services for their local populations. However, current guidance on planning and commissioning for 24/7 PEOLC is inadequate. More detailed guidance must be produced to better equip ICBs to plan and commission these services, which will help to alleviate the chronic pressures on emergency services.

9. To what extent have Integrated Care Systems (ICs) been able to deliver the aims they were set up to achieve?

- *To what extent are they sufficiently equipped to support the delivery of local priorities relating to better prevention and early intervention?*
- *To what extent has primary and community care relied on the voluntary sector, and how appropriate has the balance been?*

Delivering legal duty to commission palliative care

The Health and Care Act 2022 introduced a legal duty for ICBs to commission palliative and end-of-life care services which meet the needs of their local populations. This is a key aim that they must achieve.

To support ICBs with this duty, NHS England has published statutory guidance and an accompanying handbook which provides practical advice and resources. However, these resources contain little direction and advice on approaches to assessing PEOLC population health needs. Given the well-evidenced health inequalities that exist within PEOLC, we

¹¹ Marie Curie (2022), The Better End of Life Report 2022. <https://www.mariecurie.org.uk/policy/better-end-of-life-2022>

¹² Ibid.

believe that this must be incorporated into the guidance to enable ICBs to meet their statutory duty.

Statutory guidance also lacks detail on how the quality of PEOLC services will be ensured, 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. Improved guidance will better equip ICBs to deliver their statutory duty to commission palliative care services.

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 approach and through the publication of Integrated Care Strategies.

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. This concern is heightened by the current climate in which the focus is strongly on prevention and treatment. Prevention and treatment are of utmost importance and we welcome the Hewitt Review's recommendations with regards to these areas. However, the value of a good death should not be overlooked because it does not fit neatly into the box of 'preventing illness'. With the demand for palliative care expected to grow by 55% in the coming decade, ICSs must consider the positive impact palliative and end of life care can have for patients and their families and, as outlined above, the ability of the PEOLC sector to follow patients' journeys and facilitate integration across services. PEOLC prevents unnecessary pressures on other parts of the system and can ensure people get the right symptom management at the right time.

ICSs provide an opportunity to transform our health and care system, the inclusion of palliative and end-of-life care is core to their success and the delivery of appropriate care for their populations. This must continue to be recognised as the focus on prevention increases.

Reliance on voluntary sector to provide PEOLC and the need to improve funding for the sector

The voluntary sector is heavily relied upon to deliver PEOLC, including in the community. In 2020/21, hospices supported an estimated 300,000 people in the UK, including people at the end of life, families, carers and bereaved relatives.¹³ The voluntary sector is able to provide high-quality holistic care at the end of life. Sue Ryder's research found that 82% of people who have had a loved one die in a hospice due to a terminal illness felt their needs

¹³ Hospice UK and Nuffield Trust (2022), Support at the end of life: The role of hospice services across the UK. <https://www.nuffieldtrust.org.uk/sites/default/files/2022-06/hospice-services-web-1-.pdf>

were met. In comparison, of those who had a loved one die in a hospital, only 33% of people said their death was dignified and just 22% said the care was positive.¹⁴

As we have highlighted throughout this response, despite its critical role in the provision of PEOLC, the voluntary hospice sector remains substantially underfunded. Without a government commitment to significantly increase levels of statutory funding to cover clinical costs for palliative care services, there is a genuine and serious risk of services being withdrawn and patients and their families losing out on the specialist, holistic support that hospices offer. The collapse of the independent hospice sector would be disastrous, with the NHS forced to take on the extra demand.

A commitment to fund 70% of total palliative care costs (in line with inflation) is the minimum required to ensure the sustainability of the hospice sector and vital PEOLC services in the medium-term. The alternative is likely to be hospice closures, resulting in the overstretched NHS having to provide end-of-life care services at an additional cost of £484 million each year for the Government, before accounting for inflationary costs since 2021.¹⁵ The voluntary hospice sector must also be considered as an equal player in decision-making around PEOLC. Hospices provide a significant proportion of PEOLC services and have vital expertise on how to deliver this care. This must be recognised when making both local and national decisions around PEOLC and the care that is needed for the community.

11. In what way could the existing infrastructure be enhanced to improve the use of health technologies, and what are the possible benefits for patients?

- *What are the main barriers to increasing the sharing of information and data across different health services?*

Existing infrastructure

Technology allows healthcare professionals to connect with and learn from others in the healthcare system, which can benefit patients. Project ECHO is an existing technology that can be learnt from and can improve patient care. ECHO stands for 'Extension of Community Healthcare Outcomes' and is an internationally recognised online learning and support methodology. It enables and supports knowledge sharing between health and social care professionals. For example, there is a Palliative, End of life care and Dementia ECHO network which brings together practitioners keen to build their skills and confidence in caring for those affected by dementia at the end of life. This ability to share specialist knowledge and best practice via technology is hugely beneficial and should be learnt from and expanded to

¹⁴ Sue Ryder 2022

¹⁵ 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

give everyone across the health and social care system the opportunity to connect with and learn from others in their field online.

Technology should be used to equip patients and their friends/ families to manage their health. An example of good practice in this area is the Informed Guide produced by Hospice in the Weald. This provides clear written guidance and videos on personal care that equip people to care for their loved ones at the end of life. Many rely on family and friends at end of life to provide care so it is so important that people feel equipped to do so. Currently many people do not feel confident, often due to a reluctance to have these conversations and to think about providing care before they are in a position where they have to do so. Online guides are an easy and accessible way for people to build up their confidence and develop vital knowledge on caring for their loved ones.

Barriers

There are a number of barriers to increasing the sharing of information and data across different health service, these include:

- Data security, maintaining confidentiality of personal data if identifiable and obtaining consent if data is to be used for a different purpose than it was collected for.
- IT systems can be incompatible across (and within) organisations.
- Data may have been collected using different definitions and in a different format. It can be time-consuming to get the data into a standard format for sharing and may involve IT skills that organisations don't have.
- Some are reluctant to share what they see as their data.

A first step to overcoming these barriers to increasing the sharing of information and data would be to develop a national core data set for PEO LC. This should specify the data that services and providers must collect and report to the ICS, enabling better planning of services to meet local needs, facilitating greater integration and supporting both providers and central bodies to compare information and better understand the national picture.

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 PEO LC 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.

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.

Contact details: Nina Huszarik, Policy Manager, nina.huszarik@sueryder.org