Independent Expert Panel evaluation into the state of palliative care in England
Sue Ryder

April 2025

Introduction

At Sue Ryder, we want to work with the Government to fix the current challenges in palliative and end-of-life care (PEoLC) and create a new ecosystem which supports people to live and die well. Life expectancy is much higher now than when the NHS and the hospice movement started. We have a rapidly growing, ageing population and not only are people living longer, they acquire comorbidities along the way. That is why we need radical approaches to meet the needs of people at the end of life.

Our five-point plan to help build a new ecosystem for PEoLC includes:

1. Greater specialist PEoLC provision in hospitals through the introduction of Sue Ryder Alongside suites.
2. Shifting care into the community through the increase of hospice at home services and virtual wards.
3. Ensuring existing hospices are an active part of neighbourhood health infrastructure, utilising the services to effectively improve support.
4. An improved national digital PEoLC support offer shaped by experts, providing people with the right tools to plan effectively for their future and share their wishes with everyone involved in their care.
5. Equipping healthcare professionals to have conversations about death and dying through better education and training.

These proposals, detailed throughout our submission, aim to improve outcomes for patients, tackle inequalities and reduce pressure on the NHS.

1. FOCUS AREA COMMISSIONING OF PALLIATIVE AND END OF LIFE CARE (PEoLC) IN ENGLAND

To what extent have ICBs been able to successfully rollout the provision of PEoLC?

Prior to the introduction of the Health and Care Act 2022, provision of PEoLC was patchy and funding for providers insufficient. We had hoped that the introduction of the statutory requirement for Integrated Care Boards (ICBs) to commission PEoLC in the Act would rectify this, as well as address disparities in access.

However, there has been little to no improvement in these areas over the last three years. The situation is now arguably worse as existing challenges have been exacerbated by external factors, such as increases in the cost of living, cuts to ICB funding and NHS pay increases.

As a first step, commissioning guidance should provide greater direction on population health needs assessments and set out a baseline level of provision for core PEoLC services. The baseline level of

provision should address the components we have raised in our PEoLC ecosystem (outlined in the introduction) and ensure services are available in hospital settings, in people's homes and in IPUs.

Have ICBs been able to commission PEoLC that meets demand?
ICBs are not adequately commissioning PEoLC for their populations. As many as one in four people in the UK die without the care and support they need at the end of life[1] and 43% of deaths occur in hospital[2], despite the fact that most people in the UK want to die at home.[3]

What's more, the hospice population is still disproportionately White, of higher social economic status and middle-aged.[4] Work is being done across the sector to reduce inequity, with individual hospices taking a proactive approach to address disparities and widen access to care. However, preventing variation in access to and experience of PEoLC must also be a priority at ICB level.

The Government should commit to strengthening the accountability on ICBs to deliver PEoLC in line with their statutory duty and to ensure guarantees on the minimum levels and types of service that should be expected. This should include changing the way they've traditionally commissioned PEoLC in order to meet more needs.

To what extent are 24/7 Specialist level palliative care (SLPC) services funded?
There are concerning gaps in the funding of 24/7 specialist level palliative care. For example, Marie Curie's Better End of Life 2022 research found that only 27% of areas surveyed had a designated out-of-hours telephone line for patients with PEoLC needs and their informal carers.[5] This is despite a National Institute for Health and Care Excellence (NICE) recommendation that a designated telephone line should be available for people with palliative and end-of-life care needs 24/7.[6]

Gaps in 24/7 provision are not limited to PEoLC services delivered by non-NHS providers. The National Audit of Care at the End of Life (NACEL) has found that only 60% of hospitals meet the current standard to have face-to-face specialist palliative care advice available for eight hours a day, seven days a week.[7] ICBs must ensure they deliver across five areas of the new eco-system for PEoLC (outlined in the introduction) as this would guarantee 24/7 availability of specialist PEoLC.

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[1] ONS (2018), 2016-based National Population projections, 2016-2041 projections and based on the Palliative Care Funding Review, July 2011. English data
[2] Nuffield Trust (2024), What primary and community services do people who die at home receive? https://www.nuffieldtrust.org.uk/news-item/what-primary-and-community-services-do-people-who-die-at-home-receive
[3] Marie Curie (2024). Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401b_padd_briefing_final.pdf#:~:text=Most%20people%20in%20the%20UK,their%20preferred%20place%20of%20death.&text=Being%20free%20from%20pain%20and,days%20(38%25)%20of%20life
[4] Tobin J, Rogers A, Winterburn I, et al. BMJ Supportive & Palliative Care 2022;12:142–151. https://arc-eoe.nihr.ac.uk/sites/default/files/uploads/files/Hospice%20care%20access%20inequalities%20a%20systematic%20review%20and%20narrative%20synthesis_2.pdf
[5] Marie Curie (2022), Better End of Life 2022. https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2022/better-end-of-life-report-2022.pdf
[6] National Institute for Health and Care Excellence. End of life care for adults: Quality standard [QS13], https://www.nice.org.uk/guidance/qs13
[7] National Audit of Care at the End of Life (2023), Fourth round of the audit (2022/23): England and Wales. https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2023/NACEL%202022%20Summary%20Report%20-%20Final.pdf

Is the commissioning of PEoLC sufficiently funded?

On average, hospices receive a third of the funding required to deliver their vital services from the Government and are reliant on fundraising activities and voluntary donations to cover the remaining costs.

For the most part, hospice contracts are short-term which can lead to uncertainty and is detrimental to innovation in hospice care as providers must frequently focus their efforts on the next round of commissioning. When contracts are longer-term they often don't commit to providing inflationary increases over time. Any extra funding that is provided to address shortfalls is often given in the form of non-recurrent grants, which can help with short-term cash flow, but does not sustain services in the longer-term.

At the same time, hospices are also not being commissioned on a level playing field with NHS services. Evidence submitted to the APPG on Hospice and End of Life Care revealed that 28% of ICBs provided annual increases to hospice contracts that were below increases offered to NHS services in their area and 5% gave no uplift at all.[8] Annual increases to hospice contracts also often fail to reflect the reality of delivery costs. In the last year, Sue Ryder's staffing costs have increased by approximately 7% as a result of changes to the National Living Wage, while the annual Government funding we receive has only increased by 1%. This funding model is unsustainable, leaving hospices under constant financial pressure. Instead of expanding care to meet growing need, many hospices are being forced to withdraw or reduce services to stay afloat. Last year, one in five hospices warned of service cuts, and 300 beds have been taken out of commission.[9]

There needs to be a reset to fully realise the benefits of the hospice sector and make sure people get the PEoLC they need right now and in the challenging years ahead. We believe a new ecosystem for PEoLC will help to achieve this. Our proposals, which include commissioning in line with NHS rates, will create a fairer and more reliable funding model. However, there is also a need for parts of the hospice sector to move towards more sustainable delivery models in order to deliver high-quality care that meets demand and is cost-effective.

How could funding and resource be channelled differently to improve the commissioning process for PEoLC?

At Sue Ryder, we want to work with the Government to create a new ecosystem for PEoLC to improve outcomes for patients, tackle inequalities and reduce pressure on the wider health and care system.

[8] APPG on Hospice and End of Life Care (2024), Government funding for hospices. https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2024-02/APPG%20Report%20-%20Government%20funding%20for%20Hospices%20HUK.pdf?VersionId=0l8T4jC5V2C0zRKQLFs9ClZ5QZ5xEiOs

[9] https://www.theguardian.com/society/2025/mar/24/hospices-in-retreat-funding-crisis-squeezing-uk-palliative-care-providers (last accessed 28.03.2025)

Our PEoLC ecosystem involves Sue Ryder Alongside suites being created on hospital sites. In our model, patients who are expected to be in the last year of life would be transferred to a Sue Ryder Alongside suite from ambulances, A&E and other wards within the hospital.

Once in our care, we can put packages in place to discharge people back to the community, helping to contribute to the Government's vision and, crucially, helping people live the rest of their lives to the fullest, and in the place they most want to be – home. In the current system, there are considerable delays and challenges when discharging patients nearing the end of life from hospital.

For people who are at the end of life and cannot be discharged, Sue Ryder Alongside suites provide the "home for home" setting that people so greatly value from our hospices but all on the same grounds as the hospital. This gives families the space they need and gives the patient the compassionate care that hospices do so well.

Each Alongside suite has the potential to care for hundreds of patients every year, rapidly freeing up bed space within the wider acute setting. The bed capacity of Alongside suites could be scaled up or down dependent on need within the acute setting and the landscape of existing services in the area that can support admissions prevention and discharge.

We propose that Alongside suites are co-funded by the charitable sector and by the NHS on a tariff basis, creating a more sustainable way for both government and hospices to deliver this care. By splitting the cost of this model down the middle – 50:50 – the hospice sector would see a dramatic improvement to the Government income it currently receives. This model does not require additional Government funding. Instead, our proposed funding mechanism is the redirection of some of the existing funding spent on PEoLC within Trusts to pay for Alongside suites on a currency/tariff basis. This ensures that money follows the patient – Alongside suites will take patients directly out of the acute setting.

While this does represent a considerable shift in the approach to PEoLC commissioning, Alongside suites will deliver substantial value for money for the NHS. Our model would provide dying people admitted to hospital with the expert, compassionate care that families value so much from hospices. It would be a more cost-effective use of available funds and would instantly free up beds in our stretched and crowded hospitals. Not to mention, the model would realise wider savings in the system through the early identification of need for bereavement interventions.

Sue Ryder's vision for a future PEoLC ecosystem also involves shifting care into the community through the increase of hospice at home services and virtual wards. Thousands of patients who need clinical support at the end of life could be supported by community hospice services rather than hospitals. However, gaps in community care, particularly out of hours, mean that currently many don't get the right care at home. With appropriate investment, PEoLC expertise and services can be embedded where they have the most impact. This will increase the numbers of people who can be cared for by community hospice services, supporting the NHS 10-Year Health Plan ambition to shift care from hospital into the community.

The model would be co-funded by the NHS, with 50% of delivery costs being recovered for the hospice sector by the provision of contracts in line with NHS tariffs based on currencies for equivalent NHS care. We recommend that consideration should be given to the use of Fast Track Continuing Healthcare (CHC) monies to fund the expansion of hospice at home provision. This is not about new money but about efficient use of existing budgets.

Increasing the provision of PEoLC in the community will bring a significant return on investment for the NHS, with 50% of delivery costs being met by the hospice sector. At the same time, this model of care will help people stay out of acute settings, reach wider communities, improve PEoLC outcomes for patients and drive-up standards in community care delivery.

Specialist hospice inpatient care continues to be an essential component of the community PEoLC delivery model and should be funded through a combination of charitable income and statutory funding, in line with NHS tariffs. However, specialist hospice inpatient care must be complemented with other approaches if we are to ensure everyone has access to appropriate care when needed.

Existing hospices are an active part of neighbourhood health infrastructure and must be part of the neighbourhood health approach to ensure people at the end of life get integrated care at the right time.

Is commissioning guidance sufficiently robust to ensure ICBs develop relevant commissioning strategies to meet the needs of its local population? Do ICBs have sufficient guidance and data to determine what is 'appropriate' under s3(1) of the Act?

Commissioning guidance requires further development if it is to be fit for purpose in supporting ICBs with their statutory duty. The current version of the guidance is too ambiguous about what constitutes 'appropriate' provision of palliative care, as per the Health and Care Act 2022, and the actions ICBs must take to commission palliative care services in line with this.

In particular, commissioning guidance lacks specificity around approaches to population health needs assessment and addressing of health inequalities, as well as expectations regarding minimum standards of service provision. For example, it states that commissioners should, "pay particular attention to access to specialist palliative care services" and "ensure access to out of hours services".[10] This leaves the guidance open to interpretation, risks potential for substandard provision and creates a situation where ICBs can deprioritise PEoLC in favour of other areas, without repercussions.

Guidance should provide greater direction on population health needs assessments and set out a baseline level of provision for core PEoLC services, with enough flexibility to allow for local circumstances. Guidance on population health needs assessments should support ICBs to commission care that addresses shared needs across underserved population groups, making care more inclusive for all.

[10] NHS England (2021), Palliative and end of life care: Statutory guidance for integrated care boards (ICBs). https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf

These changes would not only better equip ICBs to meet their statutory duty, but it would also enable greater accountability. At present, failure to define 'appropriate' provision of palliative care services allows ICBs to set their own parameters, which in turn restricts the ability to hold them to account for not delivering on their statutory duty.

To what extent are inequities of access, service delivery and inequality of palliative care outcomes considered by commissioners of PEoLC?

Almost three years after the introduction of the Health and Care Act 2022, persistent inequities remain within PEoLC. This is not because Integrated Care Systems (ICSs) fail to recognise the importance of addressing inequities - when surveyed in 2023, tackling inequalities ranked as the primary ambition ICB leaders would like to have achieved in five years' time.[11] Instead, many ICBs do not feel confident in their ability to tackle inequalities.[12]

Marie Curie's 2023 survey exploring how ICSs are responding to the Health and Care Act found that only a minority (35%) of ICB respondents felt they significantly or fully understood their PEoLC population health needs. It is therefore unsurprising that ICSs do not feel equipped to tackle inequalities - an understanding of PEoLC population health needs is integral to preventing variation in access, service delivery and inequality of outcomes.

Sue Ryder Alongside suites would significantly improve efforts to address health inequalities at end of life due to the diversity of patients in acute settings. While this is not the only action that needs to be taken to address inequalities, it is an efficient way to address inequalities at the source. The hospice population is still disproportionately White, of higher social economic status and middle-aged.[13] In contrast, 43% of White people who died between 2019 and 2021 died in a hospital setting, compared to 59% of Asian/Asian British people and 52% of Black /African /Caribbean /Black British people who died.[14] As well as addressing inequitable access to inpatient PEoLC, Alongside suites would help to address inequities in community care as the model would increase referrals from acute services to community PEoLC. As well as Alongside suites, each of the five points of the PEoLC ecosystem (outlined in the introduction) must be implemented to ensure all the right care options are available, that staff are better at identifying PEoLC needs and that all communities are more open to discussing death and dying.

How are underserved or vulnerable patient groups considered in the commissioning of PEoLC?

Many people who are approaching the end of their life do not get the support they need, with certain population groups finding it harder to access appropriate services and experiencing lower standards of care. There is still a lot of work to be done at a commissioning level to address this.

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[11] NHS Confederation (2024). Putting money where our mouth is? Exploring health inequalities funding across systems. https://www.nhsconfed.org/system/files/2024-04/Putting-money-where-mouth-is-health-inequalities-funding.pdf
[12] Ibid.
[13] Tobin J, Rogers A, Winterburn I, et al. BMJ Supportive & Palliative Care 2022;12:142–151. https://arc-eoe.nihr.ac.uk/sites/default/files/uploads/files/Hospice%20care%20access%20inequalities%20a%20systematic%20review%20and%20narrative%20synthesis_2.pdf
[14] ONS (2022), Number of deaths by ethnicity, place of death, region and age: England, 2011 to 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/14716numberofdeathsbyethnicityplaceofdeathregionandageengland2011to2021

Research from Sue Ryder and the University of Birmingham[15] has identified a range of common needs across underserved population groups which must be met to facilitate equitable access, experience and outcomes. Such needs include compassionate and culturally sensitive end-of-life care, health literacy in palliative and hospice care, and appropriate access to primary care. Any approach to tackling inequity should therefore seek to address these shared needs, making care more inclusive for all.

Efforts to tackle inequity, however, must go further than the provision of inclusive services. Our research has found that socio-economic inequalities such as low economic status, social exclusion and low health literacy increase a person's likelihood of experiencing inequity in PEoLC.[16] A collaborative, whole-system approach which tackles the wider determinants of health is therefore crucial to reducing variation in access to services and quality of care.

Going forward, ICBs should:

- Ensure all commissioned care addresses shared needs across population groups who experience inequity in PEoLC.
- Seek to measure and address the shared vulnerabilities that increase a person's likelihood of experiencing inequity in PEoLC.

To what extent are available tools, such as ICB dashboards, used to monitor inequalities in outcomes and the commissioning of services to reduce these inequalities?

Each ICB uses data differently and none have been able to collect and use data to adequately address the needs and inequalities that exist. Sharing good practice and providing improved guidance around how to better use the data available to ICBs are key steps in addressing this.

Is the provision of PEoLC impacted by geography, i.e. where a person in need of this care lives?

It is widely recognised that PEoLC provision is inconsistent across the UK. The previous Health and Social Care Committee put forward that, "The UK has long been a world leader in palliative and end of life care, but access to and provision of palliative and end of life care is patchy. The UK must ensure universal coverage of palliative and end of life care services, including hospice at home".[17]

Geography is a significant determinant of PEoLC provision. Last year, the APPG on Hospice and End of Life Care reported that not only is there variation in the amount of funding hospices receive from ICBs, but also what types of services are funded. This inequity in funding creates a 'postcode lottery' in the PEoLC services populations can access.[18] Charitable hospices are the main providers of specialist PEoLC

[15] Sue Ryder (2024), Inequity in palliative and end-of-life care and bereavement support: An umbrella review. https://media.sueryder.org/documents/Inequity-in-palliative-andend-of-life-care-and-bereavement-support-an-umbrella-review.pdf

[16] Sue Ryder (2024), Inequity in palliative and end-of-life care and bereavement support: An umbrella review. https://media.sueryder.org/documents/Inequity-in-palliative-andend-of-life-care-and-bereavement-support-an-umbrella-review.pdf

[17] House of Commons Health and Social Care Committee (2024), Assisted Dying/Assisted Suicide. https://committees.parliament.uk/publications/43582/documents/216484/default/

[18] APPG on Hospice and End of Life Care (2024), Government funding for hospices. https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2024-02/APPG%20Report%20-%20Government%20funding%20for%20Hospices%20HUK.pdf?VersionId=0l8T4jC5V2C0zRKQLFs9ClZ5QZ5xEiOs

and, unless statutory funding is made more consistent and enables better models of care, this variation will only continue.

In addition to this, a 2024 evidence review found that geography was a structural determinant of inequity in access to PEoLC.[19] This is partly as a result of access issues, such as being in rural and remote areas, poor infrastructure, limited transport options and long travel times.

Even with more equal statutory funding, PEoLC provision will remain inconsistent due to the current hospice funding model. Evidence to the APPG on Hospice and End of Life Care emphasised how the reliance on donations deepens socio-economic inequalities, with communities in the most economically deprived areas least likely to be able to donate to their local hospice. As a result, their local hospice may have a lower income than hospices in more affluent areas and its community may have poorer access to services.[20]

How is experience of care measured? And to what extent does this support continuous improvement?

Where people die in acute, community or mental health hospitals, the National Audit of Care at the End of Life (NACEL) monitors standards related to the quality of the end-of-life care provided.

In other settings, it is not as straightforward or consistent. A 2023 King's Fund[21] report on commissioning quality end-of-life care at home found that commissioners lacked information about individuals' and carers' experiences of end-of-life care. As more care is shifted into the community, improving ways of measuring care experience must be prioritised.

Individual hospices will measure experience of care in different ways and reporting requirements will vary by ICB. More consistency around valuable measures would support improvement. This should account for the range of hospice services provided, included within community settings. As providers of hospice at home services, hospices should be involved in the improvement of how care experiences are measured in community settings.

What data is there on the effectiveness of current commissioning on PEoLC?

The publication of Five-Year Joint Forward Plans presents a significant opportunity for ICBs to set out how they are meeting, or plan to meet, their duty to commission PEoLC as well as measuring whether ICBs are commissioning effectively.

There is no standardised template or guidance for ICBs to follow around Joint Forward Plans – the guidance *'sets out a flexible framework for JFPs to build on existing system and place strategies and plans, in line with the principle of subsidiarity'.*

[19] Sue Ryder (2024), Inequity in palliative and end-of-life care and bereavement support: An umbrella review. https://media.sueryder.org/documents/Inequity-in-palliative-andend-of-life-care-and-bereavement-support-an-umbrella-review.pdf
[20] Ibid.
[21] The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care. https://assets.kingsfund.org.uk/f/256914/x/ba501077d3/dying_well_at_home_2023.pdf

We understand the reasoning for a flexible approach for ICBs to determine the scope, development and structure of their JFP but without a clear expectation or stated legal requirement for ICBs to include plans on PEoLC commissioning and service delivery within these plans it's harder to hold them to account for those PEoLC services which they are now legally obliged to provide.

Data on how to measure effectiveness of commissioning is lacking, this is a significant gap in ICB and provider knowledge and needs to be rectified. A good starting point to address this would be to ensure each area holds a PEoLC register and that data on patients' touchpoints with healthcare services is being collected.

2. DELIVERY OF PEoLC IN ENGLAND

To what extent are existing systems able to enable advance care planning (ACP) for individuals approaching the end of their life?

Despite the benefits to both patients and the healthcare system, Sue Ryder polling found that almost nine out of ten people in the UK have not written an advance care plan (ACP).[22]

Where ACPs are in place, they aren't always shared across the system. In the case of hospital deaths, an ACP may be in place but not shared with the GP record, or if it is shared via an electronic letter then it may not be coded in the GP system.[23] Additional 2024 research found that while digital systems supported the documentation of ACPs, they were less helpful in sharing them. Care homes, ambulance teams and some hospital teams were the least likely to have access to electronic ACPs and needed to find other ways to share this information.[24]

Patients should be able to add and amend digital versions of their ACP and other important documentation as part of their patient passport/digital record. This should be attached to their NHS ID and would allow better understanding of the patient's needs.

These care plans should be consistent across the country with standardised data elements. They should have patient-owned inputs, and healthcare professionals should ensure that people own their own plans and can access them. Sue Ryder can play an expert role in shaping these services and ensuring the data and practice standards role model good practice in providing personalised services using individuals' care plans.

If digital patient records could be shared across relevant partners working in an integrated way as part of Neighbourhood Health Centres then it would be possible to see a reduction in emergency admissions and improvements in patient outcomes. The Government should support technology innovations that dovetail with improvements being made to NHS digital systems to improve public and professional engagement with documenting health and care wishes, making engagement more accessible and helping to break down taboos around planning for the end of life.

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[22] Attitudes to palliative care research conducted by Censuswide and commissioned by Sue Ryder, March 2024

[23] https://www.nuffieldtrust.org.uk/news-item/what-end-of-life-care-do-people-who-die-in-a-care-home-receive-and-how-has-this-changed-over-time (last accessed 28.03.2025)

[24] https://compassionindying.org.uk/blog-post/digital-approaches-advance-care-planning/ (last accessed 28.03.2025)

What impact does advance care planning have on service providers delivering, and individuals receiving PEoLC?

Evidence shows that having an ACP has strong associations with lower rates of hospital death, improved quality of care and a reduction in the frequency of avoidable emergency admissions in the last months of life.[25] Improved advance care planning also has the potential to reduce overtreatment at the end of life, which leads to higher resource utilisation, decreased quality of life, and increased cost.[26]

Is the delivery of PEoLC impacted by geography, i.e. where a person in need of this care lives?

Research from Sue Ryder and the University of Birmingham has identified several shared vulnerabilities across different population groups that increase a person's likelihood of experiencing inequity in PEoLC.[27] One of the structural vulnerabilities identified was 'geographical and structural impediments'. The research found that access issues, such as poor infrastructure, limited transport options and long travel times, can make it harder to access PEoLC services.

This aligns with wider findings that people living in remote or rural areas are one of the groups who remain underrepresented among those receiving hospice care.[28] While access issues can impact people across the country, the centralisation of specialist health services in urban areas can introduce structural inequalities which disproportionately impacts rural communities.[29]

There are particular challenges facing the health and care workforce in remote and rural areas which impact the delivery of community-based PEoLC. This includes recruitment issues, ensuring sustainable workforce models and rotas, out-of-hours cover, lone working and access to support and skills development.[30]

Is there safe, quick and effective co-ordination and communication between acute and community services to enable effective, informed and personalised care, including transfers of care?

Everyday thousands of patients unnecessarily remain in hospital. The latest NHS England data shows that, on 23 March 2025, 12,980 patients remained in hospital despite no longer meeting the criteria to

[25] Macmillan Cancer Support (2018), Missed Opportunities: Advance Care Planning Report. https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf
[26] Goswami P. Advance Care Planning and End-Of-Life Communications: Practical Tips for Oncology Advanced Practitioners. J Adv Pract Oncol. 2021 Jan-Feb;12(1):89-95. doi: 10.6004/jadpro.2021.12.1.7. Epub 2021 Jan 1. PMID: 33552664; PMCID: PMC7844190.
[27] Sue Ryder (2024), Inequity in palliative and end-of-life care and bereavement support: An umbrella review. https://media.sueryder.org/documents/Inequity-in-palliative-andend-of-life-care-and-bereavement-support-an-umbrella-review.pdf
[28] Hospice UK (2021), Equality in hospice and end of life care: challenges and change. https://hospiceuk-files-prod.s3.eu-west-2.amazonaws.com/s3fs-public/2021-10/Equality%20in%20hospice%20and%20end%20of%20life%20care%20-%20May%202021_0.pdf
[29] Ibid.
[30] Ibid.

reside.[31] Many of these patients will be in the last year of life as this group makes up a third of all inpatients.[32] There are many reasons for delays to discharge – including challenges transferring people into appropriate care settings.

The solutions we have proposed as part of the future PEoLC ecosystem would support better coordination of PEoLC provision between acute and community services. For example, Alongside suites will be in a better position to facilitate efficient transfer to community settings through their links with and knowledge of local hospice services. This is much needed – 8% of people referred to a Sue Ryder IPU between September 2023-October 2024 died before admission, indicating admissions are being left too late.

3. SHIFTING TO COMMUNITY

Is there enough capacity in the workforce across sectors to enable the shift towards community for PEoLC? What role will General Practice play in the shift of PEoLC into the community?

High-quality PEoLC in the community is reliant on the availability of a range of healthcare services, including district nursing, GPs and community pharmacy. The delivery of these services must be considered alongside any increase in community PEoLC and capacity must be increased. In a recent Sue Ryder survey of acute healthcare professionals, respondents said that an increased availability of district nurses and community PEoLC teams would help to avoid emergency admissions for PEoLC patients. Primary healthcare professionals said that more PEoLC professionals, including nurses, doctors, and consultants, dedicated to home-based services could support people to stay in the community while receiving PEoLC, and in turn minimise emergency admissions.

The upcoming refresh of the NHS Workforce Plan must recognise the need for a workforce that can support the shift of PEoLC into the community. It must also recognise charitable PEoLC providers who are a key part of the health and social care system a play a vital role in shifting care into the community.

To what extent will current funding and funding models enable the shift to community for PEoLC?

The hospice sector is well placed to facilitate a shift into the community, in 2022/23, 18% of hospices' total service activity was delivered in an (in-patient unit) IPU and 55% of hospices' total activity was delivered at the person's place of residence.[33] 80% of the care Sue Ryder provides is in people's homes.

However, current funding models are a barrier to shifting to community based PEoLC. It currently costs £1.8 billion each year to run the hospices in the UK and less than £0.5 billion of this comes from the

[31] NHS England Urgent and Emergency Care Daily Situation Reports 2024-25. https://www.england.nhs.uk/statistics/statistical-work-areas/uec-sitrep/urgent-and-emergency-care-daily-situation-reports-2024-25/?utm_campaign=1914384_NHS%20still%20under%20immense%20pressure%20despite%20drop%20in%20flu%20levels&utm_medium=email&utm_source=NHS%20Confederation&dm_i=6OI9,155GX,3M1K22,5B6CE,1

[32] Pring A, Westwood J, Bowtell N*, et al* 51 Emergency hospital admissions near the end of life *BMJ Supportive & Palliative Care* 2024;**14:**A20-A21.

[33] Hospice UK (2025), https://www.hospiceuk.org/about-us/key-facts-about-hospice-care#content-menu-21317

Government.[34] Demand for PEoLC is rising, in part due to an ageing population, and hospices are fundraising to their full capacity. This makes it challenging for the hospice sector to keep up with rising demand and develop new models of care to ensure people get the right care at the right time.

Changing the way hospice services are funded so funding reflects what is paid for NHS care and introducing Government support for a move to a more efficient model of care delivery would mean that hospices could do more to support the shift to the community. There is also the potential for CHC funding to be used more efficiently to support this shift. This would allow hospices to care many more people nearing the end of life, help people stay out of hospital and improve patient outcomes. At Sue Ryder funding in this way would allow us to double the care we deliver over the next five years.

To what extent has there been consultation with relevant stakeholders on shifting PEoLC to the community?

The Government has carried out some engagement with stakeholders around the NHS 10-Year Health Plan (10YHP). There are core issues that need to be addressed in the 10YHP to make a shift to the community possible, including: addressing the number of people dying in hospital and ensuring effective routes back out into the community; ensuring workforce planning for the PEoLC workforce and improving knowledge among primary care professionals of PEoLC to help them identify when a patient is in need of a community referral to a hospice service.

If these core issues aren't addressed in the 10YHP then further consultation will be needed on how this shift is going to be made possible.

What role does advance care planning play in facilitating delivery of care at the right place and right time?

Advance care planning is essential in ensuring people can get the right care at the right time, as outlined above. It can help people to understand what care options are available to them and can support earlier PEoLC intervention. There are a number of misconceptions around PEoLC and a lack of knowledge of the care options available to people at the end of life, including the option to be cared for at home. Having early conversations about people's choices can help to address these misconceptions and allow people to better advocate for the type of care they want, which is often care in the community.

The benefit of advance care planning in improving care in the community is recognised by healthcare professionals. In recent polling by Sue Ryder (currently unpublished), primary care health professionals identified inadequate advance care planning as a key reason why individuals are unable to receive treatment or support within the community.

Low uptake of advance care planning is partly down to the fact that many healthcare staff feel unprepared for initiating conversations around the subject, particularly when death and dying remain

[34] Ibid.

taboo topics.[35] There must be improved PEoLC training for healthcare professionals so they feel better equipped to undertake advance care planning with patients.

To what extent will a shift to community impact on ICBs' capacity to commission good quality care?

Good care in the community does exist, for example 80% of Sue Ryder's care is already delivered there.

This response has outlined the issues around ICBs measuring the needs of their populations and the quality of care that's being provided. The key steps to addressing these issues are:

- ICBs must better understand their population's PEoLC needs.
- ICBs must work with providers of PEoLC services to improve data collection around needs and outcomes.
- The Government must increases accountability on ICBs to provide in line with their statutory duty in the Health and Care Act.
- ICBs should be encouraged to think differently about commissioning and move from a block bed grant model to model that provides funding based on NHS tariffs for equivalent care.

Is there sufficient co-ordination and communication between hospitals and the community, and are there any specific issues, e.g. the prescription of pain relief in the community, to enable this shift without impacting on quality of care?

Co-ordination and communication between hospitals and the community needs to be improved. One key area that must be improved is referrals. People are being referred too late to PEoLC services, for example 8% of people referred to a Sue Ryder IPU between September 2023-October 2024 died before admission, indicating referrals are being left too late. There are similar issues with late referrals into community care. Healthcare staff must be trained in PEoLC, including the PEoLC available in their area so they can effectively refer to community support where appropriate. Sue Ryder's Alongside suites (as outlined above) will help to increase referrals from A&E and other hospital wards to community settings for palliative patients as patients in hospital who do not need inpatient care would be referred by the Alongside team into community services.

Palliative care should be included in care provided by Neighbourhood Health Centres, this will help to improve communication with community services, ensure services are used as effectively and efficiently as possible, and better integrate care. The Voluntary, Community, Faith and Social Enterprise Sector (VCFSE) hospice sector must be a part of designing an effective approach to neighbourhood health and is uniquely placed in this space to help form neighbourhood health teams. Upcoming plans such as the 10YHP shouldn't overlook VCFSE engagement and involvement in neighbourhood health design if the NHS wants to capitalise on the value the hospice sector can bring to tackling the challenges in the current health and care landscape.

[35] Macmillan (2018), Missed Opportunities. Advance Care Planning Report https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf

What are the major barriers that may impact the shift to community for PEoLC?

Funding models and workforce capacity are the major barriers to shifting to community care, as outlined above.

What impact might this policy have on equity of outcomes for different patient groups, including vulnerable and underserved groups?

A 2023 King's Fund[36] report on commissioning quality PEoLC at home found that commissioners were aware there were likely to be inequalities and unmet need in their local area, but without better use of information they could not gauge the extent of these gaps or develop plans to address them. They also found commissioners had limited ability to assure the quality of care for people who die at home. They were not making full use of available data or national resources for assessing local needs and were not monitoring quality across health and social care. This is particularly concerning in the context of the rising number of deaths at home. The proportion of people dying at their usual place of residence has increased from 35% in 2004 to 50% in 2022,[37] and this trend is set to continue.

This King's Fund research demonstrates that if care is to be moved into the community in a way that benefits everyone, work must be done to better understand and address inequalities, including through engagement with patients, families and carers. ICBs should measure and address inequality in order to meet the PEoLC needs of their populations, with a focus on working with local government to address shared vulnerabilities that put people at higher risk of missing out on appropriate care.

A gap analysis of every area must be carried out to identify where populations are at higher risk of missing out on care and to identify where PEoLC provision is inadequate. This must be followed by the implementation of a plan to address any identified deficiencies and to ensure a sufficient range of services are available to meet the population's needs.

Additonally, 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 must include collecting demographic data as this is key to an ICS understanding its PEoLC population health needs and in turn acting in line with their statutory duty to address these needs. Currently collation of this information is inconsistent across the system and providers.

[36] The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care. https://assets.kingsfund.org.uk/f/256914/x/ba501077d3/dying_well_at_home_2023.pdf

[37] Nuffield Trust (2024), End of life care. https://www.nuffieldtrust.org.uk/resource/end-of-life-care#:~:text=The%20proportion%20of%20people%20%20dying%20at%20their%20usual%20place%20of,)%20to%2043%25%20in%202022

Does the current system support individuals living and dying well and in a place of their choice, whether in the community, or at home? How might this change under the shift to community? To what extent does a focus on shifting to community appropriately address the needs of those receiving PEoLC?

The current system does not support people to die in their place of choice. 43% of deaths occur in hospital[38] but just 6% of people want to die in hospital and the majority want to die at home.[39] Therefore shifting care out of hospitals and into the community will go a long way in helping people die in their place of choice. However, without action to address the barriers we have set out, this shift will not be achievable.

To what extent does a focus on shifting to community appropriately address the needs of providers of PEoLC?

A shift to community can allow charitable providers of PEoLC to provide care in a more efficient way. IPU beds are costly and while IPU provision is necessary, moving people into the community where possible is more cost effective and will allow the sector to meet more people's needs. Providers are here to ensure all people's needs are met and so a mixed model approach is necessary, but a significant increase in community care will be good for both provider and patient.

Hospices have high running costs for things such as heating, building upkeep and catering. These are all costs that are not incurred when a patient is cared for in the home. The average cost of a Sue Ryder IPU bed is £870 per day and in 2022, the average cost of an NHS inpatient palliative care bed (19 years and over) was £349 per day,[40] when accounting for inflation, this would now be closer to £385. Therefore, while IPU care remains essential for some patients, and IPUs can be part of community provision and a way of seeing patients earlier in their prognosis for symptom management; care should be provided in the community where possible. This allows for more efficient care to be provided for more people. This care is also often better for the patient and in line with their wishes.

How are/ will inequities of access, service delivery and inequality of outcomes be addressed in this shift?

A shift to community can help to address inequities of access. The hospice population is still disproportionately White, of higher social economic status and middle-aged.[41] In contrast, 43% of White people who died between 2019 and 2021 died in a hospital setting, compared to 59% of Asian/Asian

[38] Nuffield Trust (2024), What primary and community services do people who die at home receive? What primary and community services do people who die at home receive? | Nuffield Trust

[39] Marie Curie (2024), Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401b_padd_briefing_final.pdf#:~:text=Most%20people%20in%20the%20UK,their%20preferred%20place%20of%20death.&text=Being%20free%20from%20pain%20and,days%20(38%25)%20of%20life

[40] Jones, K. Weatherly H., Birch, S., Castelli, A., Chalkley, M., Dargan, A., Forder, J., Gao, M., Hinde, S., Markham, S. Ogunleye, D. Premji, S., Roland, D. (2022) Unit Costs of Health and Social Care 2022 Manual. https://www.pssru.ac.uk/pub/uc/uc2022/Unit_Costs_of_Health_and_Social_Care_2022.pdf

[41] Tobin J, Rogers A, Winterburn I, et al. BMJ Supportive & Palliative Care 2022;12:142–151. https://arc-eoe.nihr.ac.uk/sites/default/files/uploads/files/Hospice%20care%20access%20inequalities%20a%20systematic%20review%20and%20narrative%20synthesis_2.pdf

British people and 52% of Black /African /Caribbean /Black British people who died.[42] Ensuring hospitals are effectively referring to community PEoLC can address inequalities in PEoLC as people in hospital will be identified and referred into community setting that they may not have accessed otherwise.

While work is ongoing to address inequities in hospice care we do know that some people still do not feel comfortable in hospices and may be worried about things such as their religious and spiritual needs not being met and that they won't be able to have all their family to visit whenever they would like. Caring for people at home means that they are comfortable and in their own surroundings, this can encourage people who may be reluctant to go to a hospice to access PEoLC and get the high-quality care they need.

However, as outlined above, more needs to be done to understand and address inequities in community PEoLC to ensure this shift can reduce and not worsen inequities.

4. WORKFORCE, EDUCATION AND SKILLS

Under current models and systems of staffing, to what extent is 24/7 availability of a healthcare professional achievable?

Staff shortages are reducing the availability of 24/7 PEoLC. Research from 2022 found that there are significant gaps in out of hours PEoLC, for example in 78% of the areas surveyed nursing services were not consistently available to dying people overnight at home.[43] It recognised that district nurses and community nursing teams play a vital role in providing out of hours care and found that huge pressures on this workforce limit the care that can be provided.

Funding models and workforce planning will have to improve to ensure 24/7 availability of PEoLC.

Do current funding models support an effective PEoLC workforce across sectors?

Systemic problems affecting the wider health and care sector workforce are compounded by the lack of adequate statutory funding, which impacts on the hospice sector's ability to keep pace with NHS pay. To put the challenges the sector faces into perspective, UK hospices would have had to raise an additional £66 million pounds to match the increased pay for NHS staff announced in July 2024.[44] Our current Government funding falls significantly short of covering our staffing costs, much less supporting necessary pay increases. For example, in 2024 Sue Ryder's palliative staffing costs were 170% of the total income we received.

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[42] ONS (2022), Number of deaths by ethnicity, place of death, region and age: England, 2011 to 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/14716numberofdeathsbyethnicityplaceofdeathregionandageengland2011to2021

[43] Sophie Pask, Joanna M Davies, Ahmed Mohamed, Javiera Leniz, Rachel L Chambers, Philippa McFarlane, Anna E Bone, Stephen Barclay, Irene J Higginson, Katherine E Sleeman and Fliss E M Murtagh, (2022). Better End of Life 2022. https://www.hull.ac.uk/work-with-us/more/media-centre/news/2022/new-research-from-hull-york-medical-school-drives-advances-in-end-of-life-care

[44] https://www.hospiceuk.org/latest-from-hospice-uk/nhs-pay-rise-response (last accessed 28.03.2025)

The Government must include all providers of essential health services within their upcoming refreshed workforce plan, including charitable PEoLC providers. This is an important next step towards addressing the systemic workforce issues facing the health and care sector.

Healthcare services all employ staff from the same pool, so plans to address issues in the workforce must not focus on one part of a system and not another. Without supporting the components necessary to support a pipeline of professionals in PEoLC, the Government will find it difficult to realise the positive potential that hospice services can have for the health and care system, particularly with the ambition to shift more PEoLC into the community.

Are current training and development opportunities for staff in this sector able to address any issues of retention?

There are improvements that can be made to improve development and training opportunities. It is important for staff who are training to experience rotation within different services, working alongside different disciplines. Sue Ryder would welcome the development and implementation of a system where, for example, training rotations for nursing degrees could be experienced across the whole health and care system, including NHS Trusts and other charitable health organisations.

Training and development is important, as is the reward of working with PEoLC patients, but ultimately pay must remain competitive to adequately address issues of retention.

To what extent does current available training support non-specialist health and social care professionals to deliver holistic needs assessments for patients with PEoLC needs, and their carers/families? To what degree is the current framework of workforce education and skills appropriate to deliver care in different care settings?

In order to ensure the effective flow of patients in their last year of life, from A&E and other hospital wards into an appropriate palliative setting, all healthcare staff must feel well-equipped and educated to have the relevant conversations. A lack of mandatory PEoLC training modules means that many staff are not well equipped. A lack of staff training and confidence also contributes to low uptake of holistic needs assessments. End of life and death are still taboo topics which can make staff reluctant to discuss PEoLC needs.

To address this, we plan to develop a Sue Ryder International Academy for Palliative Care, capitalising on our expertise in end-of-life care and bereavement to ensure that the extensive network of professionals and organisations that impact people's experiences of death, dying and grief are equipped to address an important part of the PEoLC ecosystem – understanding and talking about death and grief.

Our presence in local communities through touchpoints like our online bereavement community (the largest in the UK) and our network of almost 400 shops (with a footfall of 7 million people each year) means that we're ideally situated as an anchor institution to support a neighbourhood health approach. We will utilise these hubs to signpost people and their families to information and support within their communities and break down taboos around death and dying.

In addition to this, we need to ensure there is a robust and fit for purpose pipeline of trainees across all disciplines -including nursing, medical, allied health professionals and carers. We need to see an increase in the number of university courses/places across all roles in health and social care, and

support for universities to recruit to healthcare programmes. As well as diversification of the routes into all healthcare professions, and programmes for career development for specific roles; for example, nursing assistant to registered nurse, physiotherapist assistant practitioner to physiotherapist. These career development opportunities should be available across the country and have the required financial support attached, particularly for mature students who cannot access Student Finance. We would also welcome a review of Health Education England's application for additional funding support for some Healthcare Apprenticeships widened to include non-NHS organisations (such as our hospices).

To what extent is the PEoLC workforce trained to assess and meet the needs of all communities?

What is known about the PEoLC needs and experiences of different communities is constantly evolving, and this is an area of research that has progressed significantly in recent years.[45] Training and education must evolve as our understanding does.

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[45] Sue Ryder (2024), Inequity in palliative and end-of-life care and bereavement support: An umbrella review. https://media.sueryder.org/documents/Inequity-in-palliative-andend-of-life-care-and-bereavement-support-an-umbrella-review.pdf