# Commissioning independent hospices in England

## a guide to sustainability

**February 2025**

# About Hospice UK

Hospice care eases the physical and emotional pain of death and dying. Letting people focus on living, right until the end. But too many people miss out on this essential care. Hospice UK fights for hospice care for all who need it, for now and forever.

# Acknowledgements

NHS England asked **Hospice UK** to help compile some guidance for Integrated Care Boards (ICBs) about how to commission and contract independent hospices. This document brings together known planning guidance and recommended outcome measures; and adds Hospice UK's descriptions of both what services hospices can provide and how hospice finances work.

These elements and much of the guidance around commissioning, engagement and good practice examples are useful and relevant across the four nations. The national frameworks for contracting and funding, however, are NHS England specific. Such frameworks do not yet exist in the other nations but are variously being worked up.

This document was compiled by colleagues in Hospice UK and NHS Norfolk and Waveney ICB in February 2025. It is now one of **four documents** designed by Hospice UK as commissioning support for hospices and commissioners locally and at national level.

# How to cite this document

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# Disclaimer

# Contents

# Elements for hospice sustainability

**Hospices are part of the health and care system that provides palliative and end of life care in the community: in people's homes and in specialist inpatient units. This guide is written specifically for commissioners of services from independent hospices which sit outside any NHS provider model. There are three key elements for commissioners and hospices to work together for hospice sustainability:**

1. System recognition of palliative and end of life care as a transformation opportunity
2. Integrated Care Boards (ICBs) understanding and contracting hospices strategically and sustainably
3. Hospices providing and evidencing care consistently and collaboratively

# What is Palliative and End of Life Care (PEoLC)?

## Palliative Care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (**WHO definition**).

## End of Life Care (EoLC)

End of life care is defined for adults (aged 18 and over) who are approaching the end of their life. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and carers (**NICE quality standard**). For children and young people, the trajectory of illness may be much longer and last year of life is not useful terminology.

## Specialist Palliative Care (SPC)

Specialist palliative care services are for people (all ages) living with more complex and/or long-term conditions which are life-limiting or life-threatening. The main components are:

- in-depth specialist knowledge (specialist consultant and specialist nursing services as a minimum) to undertake assessment and management of physical, psychological and spiritual needs to reduce symptoms, suffering and distress
- supporting analysis of complex clinical decision-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment
- providing specialist advice and support to the wider care team who are providing direct core level palliative care to the person. (This is the **NHS England service specification** description of the specialist health services to be commissioned)

# What are hospices?

**Hospices are dedicated places and multi-disciplinary teams of staff and volunteers that provide palliative and end of life care. Hospice care supports holistic, quality of life at any stage in a person's life-limiting condition from diagnosis to end of life, and continues to support family and carers in bereavement. Diagnoses range from cancer to respiratory, neurological to dementia, are increasingly complex, multi-morbid and with increasing frailty in the adult population.**

There are 160 independent hospice providers across England. These hospices deliver care in the community: in a person's place of usual residence, outpatient clinics, hospice inpatient units and in other community settings. They are operationally independent and contract their own staff and volunteers. NHS trusts may also employ specialist palliative care teams, some in inpatient wards, some in community visiting teams. Some NHS trusts have dedicated palliative care wards and some support stand-alone NHS hospice sites. These are operationally delivered within the NHS.

There are 126 hospices providing services for adults only, 22 for children only, and 12 for all ages. These include two national charities: Marie Curie and Sue Ryder who operate across multiple hospice and community service sites. Other independent hospices, particularly the children's hospices, also operate out of multiple sites though more geographically contiguous.

These independent hospices are not provided within the NHS. They are individually run charities with governance responsibilities to the Charity Commission. However, part of their charitable purpose and their service provision is clinical, often specialist, health care. Therefore, they are also regulated by the **Care Quality Commission (CQC)**.

Referrals to hospice care are often made by healthcare professionals working in the NHS. The care patients and families receive is free at the point of use. But hospices are only part-funded through commissioning arrangements with Integrated Care Boards (ICB). The majority of their income comes from income generation and fundraising.

Although part of the voluntary sector, because of the healthcare nature of the services they provide, hospices are key system and neighbourhood partners alongside primary care, social care and NHS trust providers.

# How do hospice finances work?

## Charity governance

Hospices are almost always formed as a charitable company, so they need to comply with charity legislation plus any laws applicable to a standard company.

Good governance ensures that hospices are managed in a transparent, accountable, and efficient manner, aligning with both their charitable objectives and the quality expectations of their stakeholders. The Charity Governance Code provides guidance on expected governance standards.

## Governance structures and responsibilities

- **Board of trustees** – holds overall accountability for the organisation and is responsible for strategic direction and financial oversight. This includes ensuring the hospice operates in accordance with its charitable purposes, complies with legal and regulatory requirements, and maintains high standards of financial management and service delivery. Trustees are volunteers, with a role similar to non-executive directors in other organisations.
- **Senior management** – is responsible for day-to-day operations. These include implementing Board policies, managing staff, overseeing finances and ensuring that services meet quality standards. Management are paid employees.
- **Trading subsidiaries** – most hospices operate a wholly-owned trading subsidiary which exists to raise funds typically through retail and community lotteries. The profits from this are donated to the parent charity.

## Hospice annual report and financial statements

Hospices are required to publish an annual report and financial statements within nine months of their year-end. All but the smallest hospices are required to obtain an independent audit report. Anything but an unqualified audit report would normally be a matter of significant concern.

The annual report is a narrative report outlining the purpose of the charity, how it is structured, and its key activities and outcomes. It also states the reserves policy.

The financial statements comprise:

1. **Statement of income and expenditure** – shows changes in a hospice's financial position over the year. Income and expenditure relating to different funds are shown in different columns. As well as changes such as investment values.
2. **Balance sheet** – presents a snapshot of a hospice's finances at its year-end date. Assets such as the value of buildings, investments, cash and debtors are offset by liabilities such as amounts owed to suppliers. Hospice net assets are shown for each fund type.
3. **Cashflow statement** – shows changes in a hospice's cashflow over the year. Declining cashflow can be an early sign of financial distress. Smaller hospices may not be required to publish a cashflow statement.
4. **Notes to the accounts** – these explain the accounting policies used to prepare the financial statements and break down the key numbers into more detail.

## Different types of funds

Under charity accounting rules, hospices must separate income and expenditure into different funds:

1. **Unrestricted general funds** – donations or grants without any specific conditions attached. Hospices can allocate these funds according to their strategic priorities and operational needs, allowing for greater flexibility in responding to emerging challenges or opportunities.
2. **Designated funds** – similarly hospices are free to use these funds as they see fit. The trustees decide to set them aside for a specific purpose such as the purchase of a building or a future project.
3. **Restricted funds** – donations or grants with specific conditions or purposes set by the donor or funding body. Hospices are legally obliged to spend these funds in line with the wishes of the donor.
4. **Endowed funds** – a specific form of restricted fund where the principal amount is held in perpetuity and the income generated through investment is used by the hospice. These funds are intended to provide longer-term financial stability and ongoing support for particular initiatives.

## Reserves policy

A robust reserves policy is a key component of financial sustainability for hospices. Reserves act as a financial buffer that helps the organisation manage unexpected expenses, funding shortfalls or economic downturns without compromising patient care. An understanding of how reserves are managed is crucial to evaluating financial resilience.

- **Financial stability** – reserves set aside are sufficient funds to meet unforeseen challenges.
- **Risk mitigation** – reserves help mitigate risks associated with the inherent volatility of charitable income.
- **Target reserve level** – there is a clear reserves target often expressed as a percentage of annual expenditure. This target is based on a realistic assessment of the organisation's financial needs and risks.
- **Review and monitoring** – there is continuous monitoring of the reserves against the target level, regular reporting to Board and regular review of the target level itself.

## Income streams

Hospices typically generate income from several sources:

1. Charitable donations and fundraising – from individual donors, community fundraising events, grants and corporate sponsorship. This income stream is inherently variable.
2. Legacies – from wills. This is a major but very unpredictable source of income. Overdependence on them is a major risk factor for hospice sustainability.
3. Statutory funding – from the NHS or government bodies. This should be in service contracts but much still comes in the form of grants. This income stream requires negotiation with the funding bodies and is usually for specific services.
4. Retail – through charity shops on high streets and online selling mostly donated goods.
5. Community lotteries – from participants. This tends to be a more regular but smaller income stream.

## Expenditure overview

Hospice expenditure can be broadly categorised as:

1. Wages and salaries – operational staff including clinical, administrative, managerial and income generation roles. This represents, on average, 70% of hospice costs.
2. Other fixed costs – for example: rent, utilities, insurance, technology and maintenance costs.
3. Variable costs – for example: fundraising expenses, catering, costs directly related to patient care, and training and development.

# What to consider with hospice finances

Understanding the root causes of any financial distress is essential for identifying early warning signs and implementing effective interventions.

## Understand external root causes

- **Economic downturns** – individuals and corporations may reduce discretionary spending on donations.
- **Donor fatigue** – repeated appeals can lead to donor fatigue and a decline in contributions.
- **Short-term statutory funding** – lack of long-term and sufficient statutory funding arrangements does not cover the full cost of services and leads to financial uncertainty.
- **Rising operational costs** – increases in staffing costs, utility charges, inflation or other expenditure may not be matched by increases in income. This also affects the net yield from fundraising.
- **Staffing challenges** – inadequate staffing levels or reliance on expensive temporary staffing solutions may exacerbate financial pressures.

## Assure internal governance and management

- **Lack of financial oversight** – insufficient financial monitoring or delayed responses to variances may allow problems to escalate.
- **Inadequate risk manageme**nt – failure to plan for contingencies or unforeseen events can leave hospices vulnerable to financial shocks.
- **Inadequate financial planning** – poor forecasting or reactive financial management can leave hospices unprepared for shortfalls.
- **Communication breakdown** – lack of effective communication between hospice management, the Board and external stakeholders can result in misunderstandings and delayed corrective actions.

## Recognise early warning signs

- **Reserves levels** – reserves lower than the target level are a key indicator of financial crisis. Realistic plans need to be in place to address this.
- **Recurrent deficits** – deficits in any one year may be manageable but recurrent deficits over several years are not sustainable.
- **Budget variances** – persistent overspending or frequent budget revisions signal underlying affordability issues.
- **Cash flow problems** – cash shortages will affect the ability to deliver day-to-day operations.
- **Staff turnover** – high turnover may signal financial or operational instability.
- **Maintenance delays** – not carrying out maintenance or upgrades is the result of budgetary constraints.
- **Service reductions** – cuts or delays in expansion are the last resort result of budgetary constraints.

# What does good contracting look like?

## Commissioning guidance

NHSE's PEoLC team commissioning guidance[1] is for ICBs to deliver against the statutory guidance. It includes specific reference to funding and contracting with the independent hospice sector. The guidance states that ICBs, along with Local Authorities, are responsible for funding core and specialist palliative care.

1. **Commissioning and Investment Framework:** categorises PEoLC services into core generalist palliative care, specialist palliative care and enhanced. Service components and funding flows are included for each.
2. **Funding and Contracting Approaches:** advocates for a 'blended payment' approach to contracting, this is now called 'aligned payment and incentive (API)' in the NHS Payment Scheme. There is a phased approach to implementation which references many of the same elements set out here.

## Commissioner Requested Services (CRS)

ICBs can designate hospice care services as commissioner requested services with the protection of the continuity of services provisions of the NHS provider licence. This requires more robust governance of both providers and commissioners to ensure essential services for the population do not fail.

## Contracting documents

There are national PEoLC service specifications for both children and young people, and adults.

The NHS Payment Scheme expects ICBs to use the NHS standard contract and to follow the same core payment principles and use the same four payment mechanisms with all service providers.

## Strategic contracting agreements

Current issues with contracting agreements:

1. The NHS standard contract is not in use everywhere, many agreements are still in the form of grants or service level agreements.
2. Funding levels are set annually and often non-recurrent.
3. No national unit price or guide price for SPC (specialist palliative care) on which to base either fixed or variable payments.

Proposed contracting agreements:

1. The NHS standard contract is used for hospice core and specialist services.
2. Five-year contracting cycle to allow strategic planning of service delivery.
3. Contract risk sharing agreements and / or payment limits for over and under performance against predicted activity and / or performance outcomes.

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[1] NHS England. Commissioning and investment framework for palliative and end of life care. 2022.

4. Contract variations for:
    a. Annual cost uplift factor (CUF), including for Agenda for Change and medical pay awards
    b. Increase / decrease in service requirements, based on local population need and system provider mapping

## Community services currencies

NHSE is rolling out the use of **community currencies**, including for adult 'last year of life' (LYoL), and children and young people's end of life support. These currencies have been proposed since the 2011 **Palliative Care Funding Review** and **developed and tested** since 2016.

In line with other NHS currencies, they create units of activity that can then be priced and their costs monitored across service providers. Unlike other currencies, diagnoses and procedures do not relate to the palliative care resources needed to deliver care. Therefore, the units within the palliative care currency are instead built on patient casemix segmentation that takes account of complexity of need and care.

Both adult and children's currencies use palliative Phase of Illness. Adult's also uses the Australia-modified Karnofsky Performance Scale.

## SPC complexity

Complexity is signified by internationally verified **patient centred (reported) outcome measures** (PCOMs or PROMs). At the start of each new episode of patient care, in whichever setting, and when there is a change in phase of illness, note is made of the patient's:

1. **Palliative Phase of Illness:** stable, unstable, deteriorating, dying, deceased (all age)
2. **Australia-modified Karnofsky Performance Scale (AKPS):** clinician-observed performance status (adult only)
3. **Integrated Palliative Care Outcome Scale (IPOS):** patient-reported severity of symptoms and concerns (adult only)

The **Children's Palliative Care Outcome Scale (CPOS)** is being launched for use with this age group.

## Casemix

The **C-CHANGE research programme** concluded in 2023. It evidences the casemix classification for adults and demonstrates its correlation with relative and reported day costs in hospital and hospice settings. The C-CHANGE framework for measuring complexity of patient care requires further information, such as sex and living alone status, as well as Phase of Illness, AKPS and IPOS.

## Unit prices and cost

Although complexity, casemix and currencies allow for comparative and relative resourcing of PEoLC, there is still no nationally agreed pricing model to turn it into unit prices. The C-CHANGE report does quantify the day costs for different care settings.

As alternative costing mechanisms, some ICBs are using indicative activity costs (price per unit, price per day) to calculate the full cost of current hospice service activity and estimate the current statutory funding gap. Other ICBs are just looking at the gap between what hospices currently spend in their charitable expenditure and current levels of statutory funding. These equate to the figures from Hospice UK used in the **Nuffield Trust report on public expenditure in the last year of life**.

These methods are the best estimate baselines the system currently has. However, a sustainable and fair funding model needs the currencies to take account of complexity of care and the API funding approach to respond to patient need.

## Statutory funding streams

There are no dedicated national statutory funding streams for PEoLC. Services are paid for from ICB budgets. The only exception is the children's hospice grant, which was a national funding pot, and is now delegated but ringfenced to ICBs and likely confirmed but renamed to 2026.

ICBs can work with hospices to optimise the shift from hospital to community for those requiring palliative care as well as those at the end of life. Evidence in Appendix A shows the efficacy of PEoLC, including but not constrained to SPC, along the whole patient pathway in delivering better quality care and avoiding unnecessary admissions to hospital.

ICBs can consider how to incentivise more integrated care in the community by looking at partnerships and funding streams such as:

- fast-track continuing healthcare for adults and continuing care for children and young people (all age continuing care) – options to use these funding pots differently including in the form of personal health budgets
- Better Care Fund – mostly now committed but options for provider partnerships for keeping people at home
- **Service Development Fund** – now mostly un-ringfenced so options for use in shifting care to the community
- **funding for Neighbourhoods** – hospices are key partners with primary care in PEoLC elements of neighbourhood delivery so these partnerships should be incentivised
- **funding from NHS trusts** – to shift care from hospital into the community, funding also has to flow from hospital into the community either through ICB contracting or via provider partnerships and sub-contracting

## National data collections

NHS community services data is currently collected via the national community services data set (CSDS). Hospices have varying levels of engagement with this collection. Hospice UK participated in the consultation for the replacement Faster Data Flows (FDF) to inform a more relevant, as well as automated, hospice reported data set. Given the underlying data required for the currencies, FDF should ensure the data set includes Phase of Illness and AKPS, as per the Resolve proof of concept Outcomes Registry collection.

ICBs should support hospices to enable full participation in meaningful data collections. ICB data collections for contract reporting and system dashboards should feed into and not duplicate the data collation into new regional secure data environments and onwards to NHSE.

Hospices should also be part of the national cost collection (PLICS) to inform the assessment of any currency model based payments.

# What does good hospice engagement look like?

In return for good ICB contracting of core and specialist services, hospices bring wider value as system partners:

- **Funding** – whilst the current funding model is unbalanced and therefore unsustainable, hospices are charities which will always bring additional money into the health and care system
- **Prevention** – in the context of PEoLC this means supporting patients from diagnosis through advance care planning to living well, hospices have the time and skills to support GPs with this
- **Neighbourhoods** – in the context of the NHS, all hospice services are community services and hospices are local organisations which can work closely with GPs and other local partners in neighbourhood environments
- **Patient and family voice** – hospices are embedded in, and connected with, local communities who can advise and feedback on their experiences
- **PEoLC expertise** – hospice clinicians and senior managers can lead and inform ICB PEoLC strategic governance groups, clinical networks or take on responsible officer roles
- **SPC training** – hospice clinicians and educators run training and support programmes for health and care colleagues from care homes to primary care
- **Volunteers** – 95,000 volunteers across the UK help provide the care and the environment that hospices offer patients and families
- **Flexibility and innovation** – as non-NHS providers, hospices are charities run by Boards of trustees with agile leadership structures, as such they are more able to adapt and innovate their services in line with local need

## Collaborations

For ICB contracting and for system and neighbourhood engagement, it is preferable that the hospices in any given area present as a united voice, offer service equity across a population and function within trusted relationships.

Hospice collaboratives have proven to be the best way to achieve this and mirror other provider alliances within the system.

There are ten hospice collaborations already in existence at ICS level, with additional pockets of place level collaboration.

Examples of the most established hospice collaboratives are:

- Greater Manchester Hospices Provider Collaborative
- West Yorkshire Hospice Collaborative
- Sussex Hospices Collaboration

For system delivery, as well as working together, hospices are forming provider alliances with other providers.

Examples of a PEoLC alliance and a voluntary sector alliance are:

- **Mid-Nottinghamshire End of Life Care Together Alliance**
- **Third Sector Together (3ST) North West London**

Collaborations bring the benefits of:

- negotiating with one voice with the ICB – potential for collaborative contracting models
- economies of scale – potential for shared back office and staffing models
- standardisation of data – potential for inclusion in ICB data dashboards

Collaborations take time and are built on trusted relationships and shared purpose. The governance structures evolve to underpin the resulting activities. Actual hospice mergers may or may not be the answer to improved hospice governance and better patient care.

Examples of hospice mergers are:

- **Birmingham Hospice**
- **Southern Hospice Group**

Hospices can also transfer either into or out of full NHS provision. **Bassetlaw Hospice** is transitioning from the NHS into charity provision. Whereas, **Katharine House** hospice in Oxfordshire transitioned into NHS provision but supported by charity fundraising including the hospice building.

## Data

For patient care, ICB contracting and national visibility, hospices need to collect, collate, share, report and use data based on standard operational definitions.

NHSE still references the **palliative care coordination information standard** from 2015 that specifies the core content to be held in electronic palliative care co-ordination systems (EPaCCS).

In 2023, the Professional Record Standards Body (PRSB) produced the **palliative and end of life care standard** to ensure consistent information is collected and shared and to support **advance care planning**.

Hospice UK carries out annual surveys to collate **hospice activity and workforce data** to inform national and local understanding of the sector.

However, patient level data informing either ICB dashboards or NHSE collections is neither consistent nor widespread. As above, ICBs and NHSE need to include hospice data in a relevant and appropriate way to inform system planning and national pricing.

Examples of ICBs tracking some PEoLC and hospice data across their systems are:

- **North West London**
- **Greater Manchester**
- **Suffolk and North East Essex**

# How do you plan for need?

## NCPC population needs assessment methodology

In 2004, Tebbit wrote 'Population-based needs assessment for palliative care: a manual for cancer networks'[2]. It remains the underpinning methodology for assessing the palliative care needs of a population using:

1. incidence of deaths, ratio of annual deaths per 100,000 population
2. prevalence of disease / symptoms
3. key characteristics of the population
4. indices of deprivation

Then planning, consulting on and benchmarking the required volume of services[3]. The guidance provides worked-up examples of figures and workforce for specialist palliative care inpatient, community, outpatient and hospital support services.

## PopNAT population needs assessment tool

**PopNAT** is Hospice UK's population needs assessment tool, kept relevant and up to date by **Gavurin**. It collates the national population, health and demographic data across all four nations. The data is PEoLC specific for understanding service reach and planning. It is analysed into dashboards at ICB geography, hospice catchment area and middle super output area (MSOA).

## NICE guidance

**NICE guideline (NG142)** sets out 12 recommendations for organising and delivering end of life care services for adults. It is supported by the **NICE quality standard (QS13)**.

**NICE guideline (NG61)** sets out 5 recommendations for planning and management of end of life and palliative care for infants, children and young people (aged 0 to 17 years) with life-limiting conditions. It is supported by the **NICE quality standard (QS160)**.

General principles include: identifying those at end of life or who would benefit from palliative care; advance care planning; multidisciplinary holistic care and care coordination; assessing and managing symptoms; support for carers and families including bereavement; 24/7 services.

## EAPC specialist palliative care service recommendations

In 2022, the European Association for Palliative Care (EAPC) published its **revised recommendations on standards and norms for palliative care provision** in Europe. These include the recommended core elements of a specialist palliative care service.

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[2] Tebbit P. Population-based needs assessment for palliative care: a manual for cancer networks. London: National Council for Hospice and Specialist Palliative Care Services; 2004

[3] The advice is based on sources which include 'national averages and the work undertaken by the Sheffield School of Health and Related Research (ScHARR) for the report on Modelling the costs of specialist palliative care.'

Inpatients:

1. at least one specialist palliative care inpatient unit per healthcare service area
2. 80-100 palliative care and hospice beds per 1,000,000 population (one bed per 10,000-12,500 population)
3. 8-12 bedded inpatient units
4. at least one multidisciplinary team per 250 hospital beds
5. 1.2 nurses per bed
6. 24 hour access within 30 minutes to a doctor specialised in palliative care

Home visiting:

1. one home palliative care team per 100,000 population
2. 4-5 whole time equivalent professionals comprising nurses, specialised doctors, social workers and administrative staff
3. 24 hour access

Outpatients (day hospice):

1. day hospice centre with at least four places
2. two health or care workers present during opening hours comprising at least one palliative care professional as well as access to physiotherapists, social workers, spiritual care workers
3. direct access to a doctor

## Wales specialist palliative care staffing formula

In 2009, Baroness Finlay developed a **staffing formula to meet adult specialist palliative care needs** across Wales. There are four underlying principles:

1. 24/7 support to generalist services
2. fairness of access for those facing end of life
3. support for patients' preferred place of care
4. evidence-based care

Domains covered by one whole time equivalent (WTE) palliative care specialist:

1. one bed per 15,000 population
2. one WTE palliative care consultant (supported by minimum one other doctor) per 300,000 population or 20 hospice beds
3. one WTE advanced nurse practitioner (leading a multidisciplinary team) per 50,000 population or 7.5 hospice beds

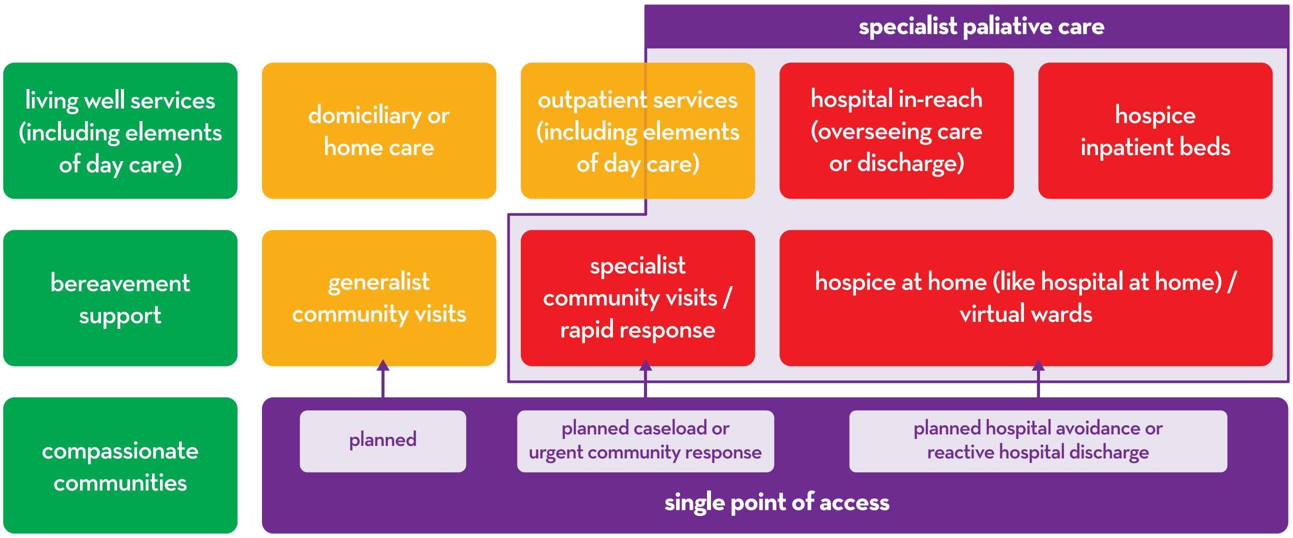
# What services can hospices provide?

As independent, community-based organisations, hospices have evolved to provide for the needs of their populations. The terminology used for their service provision is not consistent and not all palliative care services are either specialist or healthcare. Hospice care meets the physical, emotional, psychological, social and spiritual needs of patients and families.

Hospice UK has attempted to group hospice services into models of care delivery described by acuity of need and urgency of response. This categorisation helps to align hospice services with **NHSE's core components of community health services**.

## Hospice service models

**by acuity (green, amber, red) and urgency (planned, reactive)**



Devised by Annette Alcock and Anita Hayes, Hospice UK, 2025.

ICBs can map, plan and then commission hospices in-line with population need and gaps in service provision across their area. Not all hospices currently provide all these services, but the full PEoLC offer should exist from a coordinated group of providers in every ICB area.

Services delivering both professional and carer advice, specialist rapid response, domiciliary-type care at home, access to medicine and to transport should exist throughout the ICB area and be available 24 hours a day.

## Green pathways

Living well services – support patients and families from the point of diagnosis with rehabilitative approaches and wellbeing strategies. Services include complementary therapies, support groups, play, counselling and pre- and post-bereavement support. Respite care is a lifeline for families of children with life-limiting conditions. **Advance care planning** with patients and **carer support assessments** are vital for care to be delivered around individual wishes.

**Compassionate communities** – is a philosophy of holistic care and embraces the power of communities to support patients and families. Hospices work with their communities in this way to widen support systems and better tailor equitable services.

## Amber pathways

Outpatient / day care – where patients are able, hospices offer outpatient clinics and day services for ongoing symptom management, therapies and access to clinical interventions such as blood tests and infusion therapies.

Community visits / domiciliary care – this is an area where different hospices have different team make ups and referral criteria. The team is always multi-disciplinary with various levels of specialism. Teams look after a case-load of patients at home over a particular period of time. Many hospices provide this care from voluntary funds and fill gaps in service provision. Increasingly, hospices are providing some of these services with **fast-track continuing healthcare funding** (CHC-FT) and some are also now registered as domiciliary care service providers. However, others refer to this service as **hospice at home**, meaning mostly 'home care' style support to patients and families.

## Red pathways

Rapid response community visits – specialist palliative care clinicians respond swiftly to manage complex patients at home to prevent unwanted hospital admissions. The team manages acute episodes of distress, uncontrolled symptoms or unexpected changes in a patient's condition.

Hospital in-reach – specialist palliative care clinicians attend patients in hospital inpatient settings, overseeing specialist care where that is not provided in-house. The team also assesses patients for facilitated discharge to hospice or home settings for continued specialist care. These are more likely planned ward rounds than reactive to individual patients.

Virtual wards / hospice at home – as with domiciliary care and more generalist community visits, hospices have been caring for patients at home with various degrees of specialist, multi-disciplinary teams. Many hospices call this service hospice at home which fits more easily with NHS definitions of hospital at home type services. Equally, **NHS guidance for palliative care virtual wards**[4] describes the way many hospices provide this service. The team provides specialist care for managing complex symptoms such as pain, breathlessness, nausea and anxiety. There are regular home visits monitoring symptom progression and adjusting treatment including non-medical prescribing. End of life care is managed at home, enabling people to die in their preferred place of death.

Inpatient beds – hospices provide specialist inpatient care but in units that are housed in their community-based building and alongside the other PEoLC services as described above. Hospices are community hubs and designed specifically to accommodate patients and families managing life-limiting conditions and end of life. Inpatient units are needed for round the clock specialist palliative and end of life care for patients with uncontrolled or difficult-to-manage physical symptoms. Increasingly, patients with complex pyscho-social needs or home environments require and prefer end of life care within the hospice setting.

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[4] Note that the published NHS operational framework for virtual wards (in general) has not proved as useful a description of palliative care virtual wards as this original draft guidance. This affects hospices' ability to provide the required service and still meet the NHS virtual ward funding requirement.

# How do you measure outcomes?

## PCOMs

**Patient centred (reported) outcome measures** (PCOMs) are used by clinicians to monitor the quality and outcomes of care for individual patients during their palliative and end of life care. The Hull York Medical School (HYMS) Wolfson Palliative Care Research Centre Resolve programme has produced **training resources for using PCOMs**. They have also piloted the proof of concept for national collection of patient-level PCOMs through their **Outcomes Registry**.

Certain PCOM indicators can also be aggregated at a service level to evaluate how well services are delivering care. Social Finance has developed the **PCOM360 tool** for this purpose. PCOMs could, therefore, be collected via national data collections and used as quality outcome measures in palliative and end of life care service contracts.

## OHID

The Office for Health Improvement and Disparities (OHID) publishes data on place of death and hospital admissions in the last year / three months of life. The **fingertips factsheets** contain updated information on place of death, care homes and patterns of care. Most ICBs, if they track system outcome measures, similarly look at patient flow in particular emergency admissions, length of stay and place of death.

Avoiding unnecessary hospital admissions and dying in a pre-stated preferred place of death are proxy indicators that appropriate end of life care has been provided within the system.

## NACEL

The National Audit of Care at the End of Life (**NACEL**) collects data from NHS inpatient units on the quality and outcomes of care experienced by the individual patient and their family during the last admission leading to death. Hospice UK has facilitated the participation of hospices in a pilot audit, and all parties would like audits extended to deaths in non-hospital settings.

Patient and family reported experience is the best way to measure the quality of end of life care received.

## VOICES

The National Survey of Bereaved People (**VOICES**) surveyed bereaved families of adults on the quality of care delivered in the last three months of life. Their last national survey was conducted in 2015. Marie Curie conducted a more recent **survey published in 2024**. Many services, including hospices, do collect feedback from families and loved ones. Hospice UK and others would like a regular national survey reinstated.

# Appendix A:
# What is the evidence for PEoLC?

## Evidence for SPC efficacy

As a shortlist of the evidence and academic literature, the following are a good introduction:

1. **Report of the Lancet commission on the value of death** (Sallnow et al)
2. **Systematic review of the benefits of specialist palliative care** (Johnson et al)
3. **Duration and determinants of hospice-based specialist palliative care** (Allsop at al)
4. **Models and components delivering good outcomes in home-based palliative and end-of-life care** (Murtagh et al)

These reports evidence the need to recognise dying as more than just a physiological event. They also demonstrate that palliative care services deliver better outcomes for patients and families. But that service commissioning needs to drive needs-based referral to palliative care at least three to six months before death for optimal benefit and reduction in inappropriate hospital admissions. Effective models of palliative care delivery are integrated and coordinated, multidisciplinary, multicomponent and provide care across multiple settings. They are particularly effective in the community and home-based setting. This is why hospices and hospice care are part of the solution.

## Health economics of PEoLC

The **Palliative Care Funding Review** for the Secretary of State for Health in 2011 made recommendations regarding dedicated palliative care services and fair funding mechanisms. Whilst the landscape has changed, these fundamental principles remain, and they are strongly reflected in much of the national commissioning guidance and currencies work described here.

**Public Health England carried out an evidence review** to inform a health economics tool for PEoLC commissioners to use for planning and investing in community services to avoid emergency admissions to hospital.

The **Nuffield Trust analysis** shows where public expenditure currently goes in the last year of life.

# Appendix B:
# What is the ICB's statutory role?

## Statutory requirement

The Health and Care Act 2022 places a statutory responsibility on ICBs specifically to recognise and commission palliative care for their populations. It reads:

> *"An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility:*
>
> *h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service"*

## Statutory guidance

**NHS England (NHSE) statutory guidance** is for ICBs to fulfil their duties under the Act.

The key guidance to ICBs is to **self-assess** their system provision against the **Ambitions for Palliative and End of Life Care** and ensure they set out a clear vision supported by sufficient resource to deliver whole system, flexible, equitable, all-age care.

## Priority and planning

Government and the Secretary of State for Health and Social Care have articulated support for better PEoLC and a more sustainable hospice sector. **A 10-year health plan** is currently under development. Integrated Care System (ICS) Integrated Care Strategies and Joint Forward Plans should include PEoLC or 'dying well'. Currently, prioritisation in ICS strategic documents is patchy and inconsistent (**Marie Curie research** and **Hospice UK ICB FoI**, 2023).

Good examples are:

- Suffolk and North East Essex (SNEE) **integrated care strategy** and **joint forward plan** p74-75.
- Herefordshire and Worcestershire **integrated care strategy** p3 and p9, and **joint forward plan** appendix one p14-16.

# Further information and resources

## Hospice UK. PopNAT.

An interactive tool that brings together relevant and up to date population data for end of life care across the UK.

## Commissioning pack document set

NHS Norfolk and Waveney ICB, Hospice UK. **Commissioning independent hospices guide**. London: Hospice UK; 2025.

Hospice UK. **Hospice service models: a practical guide to the principles and resourcing of care for adults and children**. London: Hospice UK; 2025

Casey A. **Safe and effective staffing for palliative care inpatient services: an improvement resource**. London: Hospice UK; 2025

Hospice UK. **Hospice costing model toolkit**. London: Hospice UK; 2025

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