Sussex Palliative and End of Life Care, and Bereavement Support, Needs Assessment 2025/26

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Glossary, acronyms and abbreviations

Definitions of technical terms, abbreviations and acronyms used throughout the report to support consistent understanding among patients, carers, communities, practitioners, providers, commissioners and policy makers using the report.

Term/Acronym	Definition
A&E	Accident and Emergency department.
AACC	All Age Continuing Care. NHS-funded care for people with complex health needs.
ACP	Advance Care Planning. A voluntary process of discussing and recording a person's wishes, priorities and preferences for future care.
ADRT	Advance Decision to Refuse Treatment. A legally binding decision to refuse specific treatments in predetermined circumstances.
Ambitions Framework	National framework for palliative and end of life care built around six ambitions for improving care.
ASMR	Age Standardised Mortality Rate. A measure that allows mortality comparisons between populations with different age structures.
Bereavement	The experience of loss following the death of someone important.
BHIVA	British HIV Association.
BSMS	Brighton and Sussex Medical School.
CDOP	Child Death Overview Panel. Multi-agency reviews of all child deaths to identify learning and prevention opportunities.
CHC	NHS Continuing Healthcare. A package of care fully funded by the NHS.

Term/Acronym	Definition
CNS	Central Nervous System.
COPD	Chronic Obstructive Pulmonary Disease.
CPR	Cardiopulmonary Resuscitation.
CYP	Children and Young People.
DGH	District General Hospital.
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation. Clinical recommendation regarding CPR if breathing or heartbeat stops.
DRS	Death Reflection Scale. A validated tool used to explore attitudes and preparedness relating to death and dying.
ECHO	End of Life Care Hub. A service providing advice, support and coordination for palliative and end of life care.
EoL Care / EoLC	End of Life Care. Care and support provided during the final phase of life, usually the last year of life.
EPaCCS	Electronic Palliative Care Coordination System. Shared electronic record supporting coordinated end of life care.
ESHT	East Sussex Healthcare NHS Trust.
Fast Track	NHS Continuing Healthcare pathway providing rapid access to funding for people with rapidly deteriorating conditions.
Frailty	A clinical state of reduced resilience and increased vulnerability associated with ageing and multiple health conditions.
GBMSM	Gay, Bisexual and Other Men Who Have Sex with Men.
GP	General Practitioner.
GSF	Gold Standards Framework. Evidence-based framework for improving end of life care.

Term/Acronym	Definition
Health Inequalities	Unfair and avoidable differences in health, wellbeing and access to care experienced by different population groups.
HIV	Human Immunodeficiency Virus.
Hospice	A service providing specialist palliative care, often including inpatient, community, outpatient and bereavement support.
ICB	Integrated Care Board. NHS organisation responsible for planning and commissioning healthcare services.
ICT	Integrated Community Team. Local multidisciplinary teams working together to support population health and care needs.
IMD	Index of Multiple Deprivation. National measure of relative deprivation.
Inclusion Health Groups	Groups experiencing social exclusion and poorer health outcomes, such as people experiencing homelessness, migrants, refugees and Gypsy, Roma and Traveller communities.
JSNA	Joint Strategic Needs Assessment.
LD	Learning Disability.
LeDeR	Learning from Lives and Deaths Review Programme. Reviews deaths of people with learning disabilities and autistic people to identify learning and service improvements.
LGB	Lesbian, Gay and Bisexual.
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer and other sexual and gender minority groups.
Life-limiting Condition	A condition for which there is no reasonable hope of cure and which will ultimately shorten life.

Term/Acronym	Definition
Life-threatening Condition	A condition where curative treatment may be possible but can fail.
LPA	Lasting Power of Attorney. Legal authority allowing an individual to make decisions on behalf of another person if they lose capacity.
LSOA	Lower Layer Super Output Area. Small geographical area used in population and deprivation analyses.
MCA	Mental Capacity Act (2005). Legislation supporting decision-making for people who may lack capacity.
MDT	Multidisciplinary Team. Professionals from different disciplines working together to coordinate care.
MECC	Making Every Contact Count. An approach that uses routine interactions to support health and wellbeing conversations.
MND	Motor Neurone Disease.
MSF	Modern Service Framework for Palliative and End of Life Care.
NA	Needs Assessment.
NACEL	National Audit of Care at the End of Life.
NCMD	National Child Mortality Database.
NHS	National Health Service.
NHS Sussex ICB & NHS Surrey and Sussex Integrated Care Board (ICB)	**NHS Sussex ICB was the organisation responsible for planning and commissioning healthcare services. From April 2026, it merged with NHS Surrey Heartlands and part of NHS Frimley ICB to form NHS Surrey and Sussex ICB. For pre April 2026 material and data NHS Sussex ICB is stated.**
NICE	National Institute for Health and Care Excellence.

Term/Acronym	Definition
OOH	Out of Hours. Care and support provided outside normal working hours.
Palliative Care	An approach that improves quality of life through the prevention and relief of suffering associated with serious illness.
PCC	Palliative Care Code. Clinical code indicating palliative or supportive care needs.
PCN	Primary Care Network.
PEoLC	Palliative and End of Life Care.
POPPI	Projecting Older People Population Information System.
Preferred Place of Care	The location where a person wishes to receive care.
Preferred Place of Death	The location where a person would prefer to die, where possible.
Public Health	The science and practice of protecting and improving the health of populations.
QOF	Quality and Outcomes Framework. National quality improvement and performance framework for General Practice.
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment. Personalised plan recording treatment recommendations and preferences in emergency situations.
SECAmb	South East Coast Ambulance Service NHS Foundation Trust.
SID	Sussex Integrated Dataset. Linked health and care dataset used for population health analysis, service planning and evaluation.

Term/Acronym	Definition
SPICT	Supportive and Palliative Care Indicators Tool. Tool used to help identify people who may benefit from palliative care.
SPoC	Single Point of Coordination. A single access route for advice, referrals and care coordination.
Supported Living	Housing arrangements enabling people to live independently while receiving care and support.
UHSx	University Hospitals Sussex NHS Foundation Trust.
VCSE	Voluntary, Community and Social Enterprise sector.
Vital Signs	A population-based framework for monitoring quality, outcomes, equity and experiences of palliative and end of life care.
WHO	World Health Organization.

Acknowledgements

This Sussex Palliative and End of Life Care, and Bereavement Support Needs Assessment goes beyond the identification of unmet need by also recognising and celebrating examples of excellent practice across Sussex.

A health needs assessment is a systematic, evidence-based process used to understand the health and care needs of a population, identify unmet need and inequalities, and inform priorities for planning, commissioning and improving services. It combines quantitative data, qualitative evidence and stakeholder perspectives to assess current and future needs, understand service gaps, and identify opportunities to improve health and care outcomes and ensure resources are used effectively.

Alongside analysis of epidemiological data, service activity, research evidence, stakeholder engagement and population intelligence, this assessment includes plaudits and feedback from patients, families, carers and professionals that illustrate the impact of high-quality care. These accounts provide powerful examples of compassionate, person-centred and coordinated care, highlighting the dedication, professionalism and kindness of staff working across health, social care, hospice and voluntary sector services in Sussex.

Importantly, this balanced approach recognises that a health needs assessment should not focus solely on deficits, gaps and unmet need.

Reports, annual reviews, quality accounts, inspection reports, patient experience surveys and service websites across Sussex contain numerous examples of excellent care and positive experiences. They demonstrate that many people receive outstanding support at the EoL, characterised by effective care coordination, timely access to services, good communication, compassionate professionals and care that is tailored to individual wishes and needs.

By bringing together both evidence of unmet need and examples of what works well, this assessment seeks to provide a comprehensive understanding of the current system, highlighting opportunities to build on existing strengths whilst addressing the challenges that prevent all residents from consistently accessing high-quality palliative, EoL and bereavement support.

This needs assessment has been developed with input from a wide range of partners contributing to the commissioning, delivery, development and evaluation of palliative and EoL care, and bereavement support within Sussex.

The author would like to particularly thank the analysts that have prepared data for this report, including Clare Brown, Phillip Rowcliffe, Graham Evans, Ella Chitalu and Thye Leow.

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Thanks to all the agencies and partners that shared data and intelligence.

This needs assessment has been developed with the support and leadership of a multi-agency steering group, convened by the Sussex Hospice Alliance, the steering group members include:

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Ella Chitalu	Public Health Intelligence Specialist	Brighton & Hove City Council
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Name	Role	Organisation
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Sophie Permain	Head of Older Peoples Commissioning	East Sussex County Council
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Foreword: Lois Howell, Needs Assessment Steering Group Chair; Chair, Chief Executives Group, Sussex Hospice Alliance; Chief Executive, St Wilfrid's Hospice, Chichester

Death and dying, and the death of loved ones, are amongst the few truly universal experiences everyone undergoes. However, how people experience these events varies considerably thanks to a huge range of factors, including:

- Structural health inequities.
- Levels of health and death literacy, and willingness to talk about death, in the community.
- The communication skills and confidence of clinicians.
- Connectivity, or lack thereof, between services.
- Multiplicity of care models.
- Geography.

An essential starting point for the delivery of effective services which provide holistic, person-centred palliative and EoL care is an understanding of people's needs. Without a thorough assessment of what matters most to individuals and communities at the EoL, commissioners and providers of care can end up misdirecting effort and resources and fail to support people at their most vulnerable.

This jointly commissioned assessment, supported by the Directors of Public Health for West Sussex County Council, Brighton & Hove City Council, and East Sussex County Council, is a detailed examination of the views of a wide range of stakeholders. Existing services are described, mortality data are analysed, performance against national ambitions is assessed, and many voices are given an opportunity to be heard. There are surely, though, those whose views and needs have not yet been uncovered, and this assessment should not be seen as an exhaustive and definitive statement of the aspirations and experiences of every person in our community. The study is, however, the first consideration of palliative and EoL care across Sussex for many years and will enable much more informed decision making about what services should be provided, by whom, when, and where. In the context of significant financial pressures across the public and third sectors, and of coming increases in the number of deaths in Sussex (and all other parts of the country), ensuring that planning and service delivery are supported by reliable evidence and analysis will be essential.

This assessment has the potential to drive some significant improvements to the ways in which people think about, access, and experience palliative and EoL care services in Sussex. Thank you to everyone who has contributed to its development, and to all those who will seek to address the challenges and opportunities it reveals.

Foreword Vicky Stobbart - Deputy Chief Commissioning Officer - Neighbourhood Health and Partnerships, NHS Surrey and Sussex Integrated Care Board

Palliative and end of life care is one of the most important and deeply human areas of health and care that we commission, plan and improve with partners. It matters profoundly to people, families and communities, and the quality of care and support at this stage of life has a lasting impact.

This Needs Assessment helps us understand levels of need, variation and opportunities to improve care for people of all ages across Sussex who require palliative and EoL support. It provides an important evidence base for health and care partners, supporting the commissioning and delivery of the most appropriate services now and in the future.

For NHS Surrey and Sussex Integrated Care Board, this assessment aligns closely with our commissioning priorities and intentions: improving population health, reducing inequalities, shifting care closer to home, strengthening neighbourhood and community-based care, and making best use of resources. Compassionate, high-quality and person-centred PEoLC is central to that ambition. The findings and recommendations of this assessment will inform future commissioning decisions and support a shared approach to improving equity, quality, coordination and experience across Sussex.

This work builds on significant progress already underway across Sussex. Partners across the NHS, local authorities, hospices, social care, the voluntary, community and social enterprise sector, public health, care providers and communities are working with commitment and care to improve access, coordination, integrated models of care, data and insight, and support in the place that is right for each person. All-age palliative and EoL care priorities, work with hospices and providers, improved identification and care planning, and neighbourhood working provide a strong foundation on which to build.

The strength of this assessment lies not only in the data and analysis it brings together, but in the expertise, experience and insight that have shaped it. We are especially grateful to people with lived experience, families and carers who shared what matters most to them. Their insight is invaluable in ensuring future plans are grounded in real experience and focused on what will make the greatest difference. We also extend sincere thanks to all colleagues and partners who contributed to this report.

This needs assessment gives us a shared, robust platform for action. It reinforces our collective commitment to ensuring that everyone in Sussex who needs PEoLC can access compassionate, timely, coordinated and personalised support, and that families and carers are recognised, involved and supported. It reflects the good

work already taking place and calls on us to continue working together with purpose, kindness and ambition for the people and communities we serve.

Foreword Darrell Gale, Director of Public Health, East Sussex, SRO

In Sussex, we are privileged to live in a region of rich diversity, strong communities, and a shared commitment to improving health and wellbeing across every stage of life. Yet, as our population ages, particularly along our coast, and the complexity of health and care needs grows, we must confront one of the most profound challenges in our health and care system, ensuring that palliative and EoL care is compassionate, equitable, and responsive to the needs of individuals and their families.

This needs assessment is not just a technical document, it reflects our collective values and aspirations to ensure we enable people to be well and cared for not only in life, but at the end of it.

This needs assessment reminds us that good palliative and EoL care is not a luxury, but a necessity for all. It is a public health imperative that touches every corner of our health and care system from clinical services, community support and family life, from policy frameworks to personal experiences.

We know that the final stages of life can be marked by pain, uncertainty, and emotional strain. But they can also be a time of dignity, connection, and peace if the right care and support is in place.

From a clinical and care perspective, we must ensure that care is based on need, timely, coordinated, and grounded in the best evidence. We must invest in training, workforce development, and integrated pathways that allow professionals to deliver good healthcare and social care.

For families, the experience of EoL care can shape their grief, their memories, and their trust in the health and care system. We must listen to their voices, honour their stories, and design services that offer not just medical support, but human compassion.

This assessment is a call to action, and I am confident that it will guide us towards a future where every person in Sussex can live and die with dignity.

Darrell Gale MSc FFPH

Director of Public Health

Key strategic points and summary briefing

Key strategic summary points for palliative and end of life care in Sussex

Future demand for palliative and end of life care in Sussex is projected to increase significantly by 25% by 2044 due to increasing deaths, population ageing, frailty and multimorbidity. Planning for this need should start now.

Earlier identification is key. Many people are still being identified too late, limiting opportunities for planning, symptom management and personalised care and the associated benefits.

Unwarranted variation should be addressed, there is variation across Sussex in identification, care planning, recording and access to services, some of which appears unwarranted. Good practice should be shared across the system.

Community and integrated care depend upon strengthening coordinated community-based models of care, use of digital technology and use of public health approaches in the future.

Equity should be addressed through targeted action in collaboration with communities and the VCSE. This is required to reduce persistent inequalities experienced by underserved populations, working with underserved communities and VCSE partners through meaningful engagement and co-production.

Death and dying are universal experiences (1), and everyone in Sussex will be affected by palliative and end of life care (PEoLC) and bereavement at some point in their lives. Good PEoLC involves more than clinical care; it means supporting people to plan ahead, make informed choices, remain comfortable, and receive coordinated care that reflects what matters most to them. This is important at all ages, including for children and young people with complex life-limiting conditions and for adults living with frailty, dementia, cancer and other serious illnesses.

A consistent finding throughout this needs assessment is that opportunities exist to identify people with PEoLC needs earlier. Planning is often initiated too close to death, limiting opportunities for advance care planning, personalised support, symptom management and coordination of care. Earlier identification and proactive planning could improve quality of life, reduce avoidable crises and hospital admissions, and help ensure care is aligned with individual preferences.

Local engagement strongly reflected national evidence on what matters most to people approaching the EoL. People want to be comfortable, and pain free, surrounded by those important to them, treated with dignity and respect, and have their emotional, practical, cultural and spiritual needs recognised. Most people would prefer to be cared for and die, at home or in a familiar community setting where their condition and available support allow. Residents, carers and professionals also identified a need for more accessible information and greater confidence in discussing death, dying and bereavement throughout life.

The assessment highlights important health inequalities affecting access to and experience of PEoLC. Some groups continue to experience barriers to receiving timely and equitable care, including people from minority ethnic communities, LGBTQ+ communities, people with learning disabilities, people living with HIV, those experiencing poverty, people experiencing homelessness, and those living in rural communities. Addressing these inequalities will require both targeted action and improvements to universal services.

Variation, including potentially unwarranted variation, also exists across Sussex in identification of need, advance care planning, ReSPECT plan completion, care coordination and service access. While some variation reflects differing population needs, some appears unwarranted and suggests opportunities to improve consistency, quality and equity across localities. The evidence indicates that people living at home are substantially less likely to have advance care plans or ReSPECT plans in place than those living in care settings, highlighting an opportunity to improve proactive community-based care.

The importance of coordinated community-based care emerges consistently throughout the report. Gaps in care coordination, communication, information sharing and out-of-hours support contribute to avoidable distress, crisis presentations and hospital use. Future service development should focus on strengthening integrated working between general practice, community services, hospices, care homes, hospitals, ambulance services, social care, the voluntary sector, patients and families. Improving interoperability of systems and expanding equitable access to support outside normal working hours are key priorities for Sussex.

Bereavement affects everyone. Most bereaved people are supported through family, friends, workplaces, faith groups and their communities, but approximately one third may benefit from more structured support and around one in ten may require specialist interventions. However, local people reported that bereavement services can be difficult to find and navigate. Strengthening bereavement pathways, community capacity and public awareness represents an important opportunity for improvement.

Much of our population in Sussex can expect to live into their late 70s, 80s and older (2–4). There is increasing multimorbidity (5) and the most significant

strategic challenge for Sussex is rising demand. The population is ageing, more people are living with frailty, dementia and multiple long-term conditions, and the number of people requiring palliative care is projected to increase by around 25% by 2044. This increase is likely to result not only in more deaths but also greater complexity of need, creating increased demand for coordinated community services, carers, social care, primary care, hospices and specialist palliative care. Future models of care will need to focus on earlier identification, proactive planning, reducing unwarranted variation, tackling inequalities and supporting more care closer to home

The recommendations in this report have been developed to address these challenges and opportunities. They are aligned to the Six Ambitions for PEoLC and the emerging Modern Service Framework for PEoLC and are designed to support action at individual, community, organisational and system levels. Together they provide a roadmap for improving equity, quality, sustainability and outcomes for people approaching the EoL, their families and carers across Sussex.

Executive summary

Introduction

The Sussex Palliative and EoL Care, and Bereavement Support (PEoLC) Needs Assessment 2025-26 provides a comprehensive, evidence-based review of current and future children's and adults' PEoLC needs, and bereavement support across Sussex. Developed through a multi-agency partnership, the assessment draws on epidemiological data, service analysis, stakeholder engagement, and national policy to inform strategic planning, commissioning and service improvement. The overarching aim is to describe the PEoLC needs of the population within Sussex.

Context and approach

Death and dying are universal experiences, but the experience and quality of PEoLC varies. A national evaluation of PEoLC stated there is unwarranted variation in access to PEoLC in England. Whilst some variation in service is expected to reflect local geography and population needs, variation in access to services that meet patients' needs and the quality of care provided should be minimised (6).

The Report of the *Lancet* Commission on the Value of Death: bringing death back into life (7) outlines that dying in the 21st century is marked by contradiction. Some people receive intensive hospital-based treatment that sidelines families and communities, others still lack access to basic care and pain relief, dying from preventable conditions. At the same time, there is a disproportionate focus on

clinical interventions at the EoL, often at the expense of wider support and the contributions of community, social, and holistic care.

This needs assessment (NA) recognises the importance of personalised, holistic healthcare and care that addresses physical, social, and spiritual needs, as well as the needs of families and carers.

The NA approach combines epidemiological analysis (using mortality and service data), comparative review (highlighting inequalities and variations), and corporate engagement (incorporating summaries of system partner reports, contributions from stakeholder and public perspectives from national publications and local engagement).

The scope is Sussex residents and those registered with a Sussex GP and excludes the debate on assisted dying, however this legislative context is acknowledged but not evaluated. The bereavement support work analysis excludes any work linked to death by suicide and homicide, pregnancy loss and stillbirths. However, relevant national evidence and signposting are included where appropriate.

The NA is set against the backdrop of an ageing population in Sussex, increasing complexity of needs, and public and professional discourse relating to the legislative and policy developments around PEoLC, and physician assisted death for terminally ill adults.

Alongside this report is a set of slides containing data for each Integrated Community Team (ICT)[1][2][3] to support ICTs in understanding PEoLC needs in their areas, with 'opportunity areas' suggested to improve PEoLC at these localities.

Population profile and health inequalities - How Sussex differs from England

Sussex is home to 1.76 million people, with significant demographic diversity and noticeable health inequalities between areas such as our districts and boroughs / Integrated Community Teams ICTs[4]. Coastal areas, particularly Hastings, experience high levels of deprivation (8). Whilst Rother has some of the oldest populations in England (9), Brighton and Hove is notable for its younger and more diverse population, including a large lesbian, gay, bisexual, transgender, queer (LGBTQ+) community (2). Whilst Crawley is the most ethnically diverse area in Sussex (10).

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[1] Brighton & Hove Palliative and EoL Care (PEoLC) ICT Profile

[2] East Sussex in Figures – Data Observatory – JSNA – JSNA: ICT Profiles 2023

[3] Palliative and EoL Care ICT Profiles - West Sussex JSNA Website

[4] ICTs match most of the boundaries of Integrated Community Teams (ICTs), except for the ICT partnerships in Brighton and Hove.

Sussex demonstrates significant rural variation, with Rother classified as majority rural (60% of the population in rural areas) and Wealden as intermediate rural (35%). Alongside more urban coastal centres such as Brighton & Hove, Eastbourne and Hastings (all 0%). West Sussex has 81% of land area classified as rural, 19.8% of the population living in rural areas, and districts such as Chichester (50%) and Horsham (52%) categorised as majority rural, while others such as Adur, Crawley and Worthing remain predominantly urban.

Many of Sussex's coastal communities experience a combination of older age profiles, higher levels of deprivation, poorer health outcomes and greater workforce pressures than inland areas (11,12). Coastal areas such as Hastings, Eastbourne, Worthing and parts of Arun have larger populations of older people, higher levels of long-term illness and lower healthy life expectancy than more affluent inland districts. These areas often experience greater demand for health and social care services alongside challenges relating to recruitment and retention of health and care staff. Coastal deprivation can contribute to earlier onset of ill health, greater levels of unmet need and increased pressure on healthcare services.

Coastal Sussex faces a double challenge: supporting larger numbers of older people living with complex conditions whilst also addressing the wider social determinants of health that influence EoL experiences, access to care and outcomes.

These demographic factors influence both the prevalence of life-limiting conditions, experience of, and access to healthcare, social care and PEoLC. Older people, those with a non-cancer diagnosis, those from deprived areas, homeless people(13), Gypsy, Traveller and Roma (14) communities, ethnic minorities (15), those living with a learning disability (16), and LGBTQ+ individuals (17) are more likely to experience barriers in accessing PEoLC, including late identification of need, limited service awareness, and cultural differences that impact their care (18), and experience of bereavement.

Local services will need to develop appropriate approaches to address the specific needs of each of these groups and the geography of Sussex.

A wealth of demographic and health data about the population in Sussex is published on the Joint Strategic Needs Assessment websites for Brighton and Hove, East Sussex and West Sussex. An Integrated Needs Assessment for Surrey and Sussex NHS ICB has also been published in June 2026.

Policy and strategic context

National frameworks, such as the NHS Ambitions for PEoLC and NICE guidelines (18-21), emphasise person-centred, equitable, and integrated care. NHS Surrey and Sussex have statutory duties to commission services that meet local needs and reduce health and care inequalities. Local authorities are also responsible for

social care provision. There are local strategic partnerships, with NHS Trusts, local authorities, care providers, hospices and the VCSE sector which aim to strengthen joint working, develop service improvement and improve health and care outcomes. In November 2025, the Government announced it would develop a Modern Service Framework (MSF) for PEoLC in England. The MSF will help address rising demand, late identification of need, inequitable variation in access, experience and outcomes, and the wider pressures facing the health and care system (22). It is expected to be published in full in the autumn of 2026. Ahead of this, NHS England wrote to ICBs on 15 June 2026 with an interim update asking ICBs to prioritise two immediate actions towards strategic commissioning of PEoLC services.

Action 1: Produce an integrated needs assessment and understand service provision and utilisation

In line with the Strategic Commissioning Framework, all ICBs are expected to have completed an integrated needs assessment. This is based on a detailed understanding of their current and future population, including people of all ages with PEoLC needs, and is essential to commissioning services that meet people's needs and deliver value for money.

In line with the Medium-Term Planning Framework, ICBs and relevant NHS providers should understand current and projected service utilisation and costs across their systems – including EoLC needs and services provided by hospices.

Action 2: Move to sustainable contracting of hospice services

While most PEoLC is provided by NHS staff and services, we recognise the vital contribution of voluntary sector organisations including hospices in supporting people and their loved ones.

However, funding and contracting for these services varies and does not consistently reflect population needs. Many hospices receive funding through grants. This is not sustainable. It makes it harder to monitor and evaluate services over time and undermines our ability to improve population health, ensure equitable access and delivery, and reduce health inequalities.

NHS England is therefore asking ICBs to move to sustainable contracting of adult and children and young people's hospice services based on their integrated needs assessments and to ensure that equity is a core objective of their commissioning. Initially, this will involve the move away from short-term grant funding for adult hospice services from 2027/28.(23).

National evidence and local service overview

Public attitudes and experiences

National surveys reveal that most people wish to die at home, free from pain, with psychological support and autonomy over care decisions. However, there is a persistent gap between these preferences and actual experiences (13). Many people die in hospital (25), often contrary to their wishes, potentially due to limited community support and late recognition of PEoLC needs. Carers frequently feel unprepared and unsupported, and inequities persist for non-cancer patients, those from deprived backgrounds, and minority groups (9).

Service provision and system challenges

PEoLC in Sussex is delivered through a network of generalist and specialist providers, including GPs, community nurses, community pharmacies, care homes, hospices, hospitals, and the voluntary sector.

Hospital Specialist Palliative Care Teams and hospices play a key role in specialist care, while NHS Surrey and Sussex commissions and coordinates services across the Surrey and Sussex region. In line with the national picture, a significant proportion of deaths occur in hospitals and in care homes in Sussex (25), with smaller percentages dying in hospice in-patient units.

Previous reviews undertaken by the Sussex system, such as the NHS England maturity matrix, highlights that despite progress in leadership, integration, and workforce development, the system faces ongoing challenges, these include:

1. Fragmented data and limited interoperability, hindering continuity of care between system partners.
2. Variation in service provision and outcomes between localities and population groups.
3. All providers are under increasing budgetary pressure to do more with limited resources.
4. Late identification and planning lead to avoidable hospital conveyances, admissions and missed opportunities for person-centred care, which could be better delivered in the community in homes and care homes, often peoples preferred place of death.

Key data and insights within this report

PEoLC in Sussex must respond to a complex and evolving set of needs across the life course. While most deaths occur in older age, with over 70% of deaths in Sussex in 2024/25 occurring among people aged 75 years and over, it is important to recognise the significant and often complex needs of smaller population groups, including children and young people with life-limiting conditions, people with learning disabilities and autistic people, and those affected by health inequalities across the life course.

Around 80–90% of deaths will likely require palliative care (26,27), yet access, quality, and coordination remain variable. At the same time:

- The Sussex population is ageing, with increasing numbers of people aged over 65 years and 85 years old (28)
- The prevalence of multi-morbidity (average 5.7 conditions among older populations) is rising and projected to rise further in the coming/future years(5)
- Palliative care need is projected to increase by approx. 25% (17,000 to 21,240 by 2044).
- Significant health inequalities persist across deprivation, geography, and protected characteristics such as LGBTQ+ populations and those with disabilities.

There are many examples of excellent care and practice within Sussex. These can be found online in reviews of local care homes, and home care providers, the quality and impact reports for hospices, of which many of these report and use validated metrics such as the Integrated Palliative Outcome Scale. NHS Trusts publish friends and family survey results and much more, whilst many local agencies, such as NHS Trusts and Adult Social Care services are reviewed and assessed by the CQC and participate in audit schemes that demonstrate good care locally.

PEoLC needs identified as part of this NA have been outlined using the Six Ambitions for Palliative and EoL Care (29) to provide a structured assessment of current provision to meet local needs, integrating data, evidence and insights from:

- Adult and older people's care.
- Children, young people and families.
- Learning disability and inclusion health perspectives.
- Workforce and community insights.
- System and national data sets

It's important to note that some of the evidence and intelligence received relates to a small proportion of reported cases and situations where needs haven't been met. Therefore, it's clear that whilst great care is often provided to many, there are examples where care should and must be improved.

Ambition 1: Each person is seen as an individual

Across Sussex, data and insight collected for this NA aligned with national evidence. It highlighted that people consistently report that being seen as an individual is vital and that they need information to support their choices, expect to be treated with dignity, respect for their individual identity, and having autonomy, define a good death, including:

- Being pain free and comfortable, ideally at home if services and their health condition allows.
- Being with the 'right people' (including chosen family and same sex partners) and that those people feel comfortable in the presence of health and care staff.
- Having religious, cultural, or personal beliefs respected, including those of faith and none.
- Being treated with respect, as a whole person, and not a diagnosis (particularly in relation to HIV, where local people report occasionally experiencing stigma; and dementia, where people's cognitive abilities (or limitations) are occasionally assumed rather than assessed and explored before providing health and care advice).

However, local delivery is inconsistent:

- At present, in Sussex, there is wide unexplained variation in practice reported prevalence of severe frailty and palliative care.
- The national reported prevalence of palliative care registers (QOF) is 0.46%. In Sussex the reported QOF prevalence is 0.54% (2024/25). However, this masks wide variation at individual practice levels within Sussex where the recorded prevalence in individual GP practices varies from 0.01% to 2.62%.
- In the population aged over 65 years old within Sussex, practice palliative care register prevalence varies from 0.04% to 10% (a reasonable estimated prevalence for those over 65 would be in the region of 2-3%). (29)(30)(26)(30)(26).
- In the NHS, Advance Care Planning (ACP) and the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process come together as a practical way to turn a patient's personal values and wishes into clear clinical guidance for emergency and future care. ACP is the overall voluntary

process of discussing future preferences, while ReSPECT is a specific, standardised tool used to record the agreed clinical recommendations that stem from those values.

- ReSPECT plans are recorded more frequently than 'Advance Care Plans' (ACPs), which may reflect local commissioning arrangements. However, there is considerable variation across Integrated Care Teams (ICTs), with ReSPECT plan completion rates for people on palliative and supportive care registers ranging from 35% to 66%. Significant differences are also seen between palliative and supportive care register population groups, with 79% of care home residents having a recorded ReSPECT plan compared with approximately 40% of people living at home.
- Only 13% of those on palliative care register have a recorded ACP, potentially indicating limited proactive holistic planning. However, there is variation between ICTs, place of accommodation and different groups.
- There is evidence of unmet needs within acute hospital settings in Sussex (30).

For CYP with life-limiting conditions, data from the Child Death Overview Panel (CDOP) highlights:

- Palliative care involvement is often delayed, if initiated earlier greater benefits may have been achieved.
- ACP is inconsistently offered, and often offered too late to secure benefits.
- Families report limited choice, particularly outside hospital settings for care.

Overall, identification and personalisation of PEoLC is recognised as important by the workforce and patients alike, but awareness is limited amongst the public and occasionally implemented late by professionals, and inconsistently for:

- Certain groups (e.g. people with advanced age, frailty and dementia, those living at home, those with learning disabilities, children and young people with life-limiting conditions) are less likely to have individualised care planning.
- There is evidence of insufficient recognition of:
- Identity and cultural needs, particularly of people with sensory loss disabilities and LGBTQ+ groups.
- Non-traditional family structures, for those without children and LGBTQ+ groups.
- Communication needs for those with sensory loss and learning disability at the EoL.

Ambition 2: Each person gets fair access to care

Across Sussex, clear and persistent inequalities exist in PEoLC access and outcomes, much of these follow similar patterns of deprivation and other characteristics that can result in health inequalities throughout the life course. These include;

- Lower healthy life expectancy and life expectancy in more deprived coastal areas such as Hastings and Eastbourne, compared to Horsham and Mid Sussex.
- There is evidence of good ethnicity data recording in some healthcare records, however, weaker recording of ethnicity, disability, and sexual orientation in primary care, hospices, and care homes which may mask patterns of need and health inequalities.
- There is limited data available from social care providers relating to PEoLC.
- Limited available data relating to groups on palliative and supportive care registers for:
- People with non-cancer conditions (e.g. dementia, frailty, advanced age).
- Inclusion health groups – several local professionals raised concerns that people experiencing homelessness or substance use issues are likely to be underrepresented on PEoLC registers and to experience inequitable access to care more generally.

For CYP, CDOP reviews every death of a child or young person aged up to 18 years of age living in East Sussex, West Sussex and Brighton and Hove. From the 2024-25 report:

- There are persistent issues relating to delayed palliative care and specialist services involvement, gaps in community and out-of-hours services and safeguarding risks and modifiable factors that can be addressed to reduce the risk of future child death.(31).
- There were 68 deaths, lower than 2023/24 and the lowest since 2020/21, with over 50% under age 1 and the largest category, perinatal/neonatal at 37%. A further 16% were children aged 1-9 years old, and 31% of deaths across Sussex were for young people aged 10-17 years.(31).
- Contributing factors to deaths related to social and economic inequalities, including deprivation, poor housing and unsafe sleeping environments.

For people with a learning disability and autistic people, there is a robust system in place, Learning from lives and deaths – LeDeR. LeDeR reviews deaths to see where we can find areas of learning, opportunities to improve, and examples of excellent practice. This information is then used to improve services for people living with a learning disability and autistic people. From the 2024-25 report, 158

deaths were notified to LeDeR during the reporting period. This is an increase of 20 from the last reporting period and confirms a year-on-year increase in notifications received. The range of age of death was 19-91. The median age of people with a learning disability in Sussex was 62 years, significantly lower than the general population.

Identified needs for those with learning disabilities (LD) included physical, psychosocial and spiritual care, alongside clear information and effective communication to support understanding. Whether these needs are met depended on workforce education and skills, staff communication ability, sustained multidisciplinary collaboration, and service level factors such as staffing capacity, funding, and management support across health and social care (32).

There is some evidence that the public and patients in Sussex perceive and experience inequity and challenges in accessing primary care, notably General Practice, however concerns about community pharmacy were also cited. However palliative care calls are usually expedited in general practice.

Concerns, reports and experience of long waits to access General Practice were received, often meaning delays in care, leading to distress for patients and their families. There was some evidence that medications and services from community pharmacies weren't always available when needed.

Sussex has marked rural variation, creating access challenges for PEoLC. In East Sussex, Rother is majority rural (51.9%) and Wealden intermediate rural (35.5%), while Brighton & Hove, Eastbourne and Hastings are urban (all 0%). In West Sussex, 81% of land area is rural and 19.8% of residents live in rural areas, with Chichester (50.2%) and Horsham (51.6%) majority rural, while Adur, Crawley and Worthing are predominantly urban (0%). Mixed rural–urban areas include Lewes (21.3%) and Mid Sussex (19%).

For those with protected characteristics and or that belong to inclusion health groups, local evidence, data and insights identified unmet need for:

People experiencing homelessness and people with substance use, with professional insights stating these groups often have challenges with accessing healthcare. There was anecdotal evidence that these groups aren't accessing hospice care, and concerns were also raised that their bereavement needs are often overlooked, despite potentially experiencing greater exposure to death and loss.

There are over 3,500 people living with HIV and accessing effective lifesaving treatment in Sussex, and this population is ageing. Their needs extend beyond clinical HIV management and viral suppression, particularly where people are also experiencing frailty, multimorbidity, cognitive impairment, poverty, insecure housing, social isolation or reduced informal support. Local engagement and recent research in Sussex highlight that people living with HIV need PEoLC that is safe,

inclusive, trauma-informed and non-judgemental, and which recognises the cumulative impact of stigma, discrimination, loss and marginalisation across the life course. For some people, particularly those diagnosed in earlier decades and some gay, bisexual and other men who have sex with men, past experiences of poor treatment or exclusion continue to shape fears about future care, including concerns about hospitals, hospices, care homes and disclosure of HIV status. Key needs therefore include continuity of trusted care, advocacy, clear information, peer and emotional support, housing and discharge support, and staff who are confident, knowledgeable and sensitive in discussing HIV, ageing, cognition, sexuality, relationships, chosen family and EoL preferences. Local work with partners including Terrence Higgins Trust, Marie Curie, the UPLIFT Study, the BHIVA PEoLC survey and Brighton and Sussex Medical School co-design activity, reinforces the importance of person-centred, co-produced approaches that address physical function, cognition, psychological wellbeing, social connectedness and self-management. The Beacon model was highlighted locally as an example of holistic, compassionate support that helps people live well, reduces crisis demand and responds to physical, emotional and practical needs in an integrated way.

Local PEoLC inequalities operate across:

Diagnosis, condition and trajectory, e.g. Cancer vs non-cancer, and the limited access to PEoLC for advanced aged and frail patients.

Geography and rurality, with those in rural communities experiencing barriers to healthcare, care and support.

Age, with care, support and experience varying considerably for CYP, adults in their 60’s and those over 80. Much of this is influenced by the diagnosis, condition and trajectory.

Social determinants such as poverty and housing, with those experiencing challenges or barriers accessing care, stating that money to access services or support, or their housing (or lack of housing), limit their engagement with care, and possible treatment and care options.

Many members of the public, of all types, engaged in this project, reported there is limited information, both online and paper-based information, available to aid consideration, discussion, and understanding of PEoLC and bereavement services locally.

Ambition 3: Maximising comfort and wellbeing

Maintaining comfort, dignity and effective symptom control is a fundamental aspect of PEoLC and remains a priority need identified by both Sussex residents and the professionals who support them.

Current delivery would suggest that local acute hospitals remain the default setting of EoLC, with 63% of CYP deaths occurring in hospital in 2024/25(31). Across all geographies, most adult deaths also occur in hospital despite preferences often stated as otherwise. Hospitals are often described as settings that may not provide the most appropriate environment to support comfort and wellbeing.

The National Audit of Care at End of Life (NACEL) findings suggest that Sussex hospitals generally recognise when patients are entering the last phase of life, with between 78% and 83% of deaths identified as expected, broadly in line with the national average. However, indicators relating to comfort and wellbeing show variation. Assessment of emotional and psychological needs ranged from 51% to 85% across Sussex hospitals (national average 82%), while documentation of discussions about hydration was consistently below the national average of 62%, ranging from 31% to 54%. Although anticipatory prescribing for symptom control was relatively strong in some hospitals (79–89% compared with 87% nationally), individualised care plans were documented for only 67–77% of patients, below the national average of 84%. While many patients receive effective symptom management, opportunities remain to improve holistic assessment, communication, hydration discussions and personalised care planning to ensure consistently high levels of comfort, dignity and wellbeing during the final days of life across Sussex hospitals.(33).

A national study, that included Sussex hospitals, states that 93% had unmet holistic needs, including physical symptoms (75%) and psycho-socio-spiritual needs (86%). People were more likely to have unmet needs and require specialist palliative care intervention at a district general hospital (DGH) than a teaching hospital/cancer centre (30). Local data from Specialist Palliative Care Consultants across all hospitals indicates large percentages of patients that could be treated and supported in alternative settings, to improve comfort and wellbeing. There are partner reports describing patients that were also found to be waiting to be discharged and for step down palliative care to transition the patient from an acute hospital to a less intensive setting, such as a hospice, or a residential care facility.

Data from the Ambulance Service and Healthwatch within Brighton and Hove, and Healthwatch East Sussex highlights examples where some patients experience delays in hospital discharge, with care and medications to support comfort and wellbeing either being late, or not available.

Many deaths don't lead to complaints relating to care, however across the reviewed sources such as ICB complaints and Healthwatch evidence, there is consistent evidence of unmet need relating to comfort and wellbeing at the EoL in Sussex.

Healthwatch East Sussex received 14 separate pieces of feedback or enquiries relating to PEoLC services between March 2023 and January 2026. It highlighted repeated delays in accessing pain relief, with patients spending 'many hours without pain relief' or waiting several hours for medication, directly compromising physical comfort. In several accounts, inadequate symptom control led to severe distress, with patients described as 'agitated and distressed', 'frightened', or 'suffering in silence and pain', and in one case dying 'in agony… terrified and totally confused'.

Dignity at EoL is also compromised, with reports of individuals being 'stripped of any dignity' or cared for in inappropriate environments, care being provided in temporary 'hospital up beds', while experiencing unmanaged symptoms. These experiences have a profound impact on emotional wellbeing, with families describing the experience as 'traumatic and distressing', with lasting psychological effects.

There is evidence locally that digital innovation can support improved pain and symptom management, with local reports highlighting the positive impact the 'Comfort Tracker'[5] can have for clinicians and patients.

Carers themselves experience unmet wellbeing needs, including physical exhaustion, social isolation and a lack of information or support to manage the dying process. At a system level, these issues are compounded by poor coordination and delays in accessing care, which contribute directly to unmanaged symptoms and distress; for example, complaints analysis identifies poor communication and coordination as a dominant issue affecting care quality.

Ambition 4: Care is coordinated

There is evidence from positive feedback received and shared for this report via the workforce survey and NHS Sussex ICB complaints and plaudits data, which demonstrates the benefits that can be achieved when services work effectively together.

The workforce survey highlighted the benefits of integrated working and what is possible when care is well coordinated, for example areas of Sussex served by the SPoC, ECHO, a telephone service for support and advice 24 hours a day, 7 days a week, was often cited as a service that works well to address needs at the EoL.

[5] Comfort Tracker app supporting patients with EoL care

A consistent theme across a small number of plaudits received was the value of well-coordinated, responsive care that enabled people to receive the right support. Families frequently described how coordination between GPs, Continuing Healthcare (CHC), community nursing teams, hospices and care providers enabled individuals to remain in their preferred place of care.

One family reported that coordinated support from GPs and the CHC team enabled their father to remain at home until his death, creating a “familiar, loving, safe and effective caring environment” which improved his quality of life and reduced stress and disruption for the wider family. They particularly praised the CHC process for being “manageable, straightforward and responsive” during a difficult period.

Timely and effective coordination of care packages was also repeatedly highlighted. Community nursing staff praised the CHC team for rapidly arranging night-sitting services for palliative patients, while families described how these services provided reassurance and enabled people to remain safely at home. Similarly, a daughter reflected positively on the coordinated support that enabled her relative to access both night sitters and a nursing home placement when care needs increased. She reported that the family felt reassured that he was settled and comfortable when he died and believed this outcome would have been more difficult to achieve without the coordinated involvement of multiple services.

The importance of having a named professional or coordinator was evident throughout the feedback. One bereaved spouse described the specialist nurse supporting her husband's lung cancer care as an invaluable link between the family and oncology services. The nurse provided advice, coordinated treatments around important family events, acted as a trusted point of contact and continued offering support following bereavement. The family stated that having a dedicated professional to navigate services and provide continuity had a significant positive impact on their experience.

Professionals also highlighted examples of effective operational coordination within the system. One clinician praised the rapid response to two urgent EoL discharges, describing how equipment was prioritised and delivered on the same day in both cases, enabling discharge plans to proceed without delay. This responsiveness reduced avoidable hospital stays and ensured patients could be discharged to their preferred setting quickly and safely.

However, improving coordination of PEoLC across Sussex remains a system challenge to be addressed, with consistent evidence and intelligence demonstrating fragmentation across organisational and professional boundaries. Patients and families reported being left to navigate, advocate, and coordinate care themselves, particularly during periods of rapid deterioration or crisis. Subsequently, ambulance crews are often then used when there is no alternative support in the rapid deterioration periods or crisis.

Evidence drawn from a small number of detailed cases via Healthwatch East Sussex, highlights repeated examples of breakdowns in communication between hospitals, GP practices, community nursing, hospices, pharmacies and urgent care services, with families describing situations where professionals “did not communicate with each other” and essential care, such as medication provision or hospice referral, was delayed or unclear.

These experiences are reinforced by findings from reports published by Healthwatch Brighton and Hove, and within focus groups, which describe a lack of coordinated discharge planning, limited GP follow up, and confusion among families about who to contact for support once patients return home, particularly when not supported by specialist palliative care teams.

Key issues include poor discharge planning processes, delays in crisis response and inconsistent out-of-hours provision. Patients approaching EoL are sometimes discharged without fully established care packages, appropriate equipment, or clear contingency plans, leading to distress and avoidable readmissions through Emergency Departments, often via 999 and then the ambulance service.

Healthwatch Brighton and Hove evidence shows that many patients were ‘stranded’ in hospital prior to discharge and subsequently experienced multiple failed discharges and rapid readmissions, reflecting a lack of coordinated pathway planning across hospital and community services(34). Similarly, local intelligence identifies delays in accessing urgent support out of hours, with reliance on NHS 111 or 999 pathways contributing to inefficiencies and prolonged periods without symptom relief or clinical intervention.

Coordination challenges are particularly pronounced in relation to children, young people and safeguarding contexts. Evidence from system reports highlights delays in information sharing and joint agency working, contributing to missed opportunities for early intervention, particularly for children with complex needs. These challenges are echoed in wider system intelligence which identifies fragmented multi-agency responses, safeguarding concerns, and inconsistent communication between services as contributing factors in adverse outcomes and preventable harm.(31).

Effective coordination is therefore a critical enabler for meeting needs, and of high-quality EoLC, requiring improvements in integrated discharge planning, shared information systems, clearly defined care coordination roles, and consistent 24/7 access pathways. Without addressing these structural and operational barriers, patients and families will continue to experience fragmented care at the point of greatest need.

Ambition 5: All staff are prepared to care

The PEoLC workforce across Sussex is widely described as compassionate and committed, but in keeping with other areas of the country, operating under sustained pressure, with workforce shortages, high workload and limited capacity affecting the responsiveness and consistency of care.

The workforce survey findings and service data highlight some skills gaps, particularly in communicating and initiating advance care planning, EoL conversations, recognition of dying, and culturally competent care, which contribute to variation in care quality and inequities in access.

Hospices and community nursing teams are consistently identified as delivering high-value, holistic care, however, hospices' and other voluntary sector services' ability to meet demand is constrained by finite capacity and a reliance on charitable funding, raising concerns about long-term sustainability.

The commissioned Sussex PEoLC Education Collaborative Programme, delivered across providers, demonstrates a structured multi-provider approach to workforce development, with multiple courses planned across the system, including training on advance care planning, recognising dying, communication skills, learning disabilities, and health inequalities.

This programme is delivered through a combination of online and face-to-face models across hospices including St Barnabas House, St Catherine's Hospice and St Wilfrid's Hospice, improving access and equity of training while aiming to reach a broad multidisciplinary workforce across care home, community, primary care and acute settings. Quarterly delivery data indicates ongoing demand, with 250–300 staff trained per quarter. This is despite some challenges with workforce capacity and release for training, particularly for 'soft skills' programmes such as communication and bereavement.

During the last year, Specialist PEoLC teams across the three Sussex NHS Trusts that deliver acute services, delivered education and training on PEoLC to over 3,000 staff.

This equates to over 700 hours of training delivered by the palliative care teams last year. In addition, over 400 Healthcare Professionals spent time shadowing the palliative care teams last year.

The NHS Sussex ICB Child Death Review (CDR) nurse team continues to offer bi-monthly face-to-face and online Child Death Review training, providing an overview of the Sussex CDR process and the role of the CDR nurse. This training is open to any professional interested in developing their knowledge of child death review processes or involved in the support process following a death. During 2024/25, 202 professionals from across the wider multi-agency network attended.

In addition, the ‘Safer Sleep for Babies and Coping with a Crying Baby’ training, launched in November 2023, continues to be delivered to multi-agency professionals by the NHS Sussex ICB CDR and safeguarding team. In 2024/25, 392 professionals attended, including health visitors, community nursery nurses, community midwives, social workers, teachers, nursery staff, and foster carers. Feedback indicates that practitioners value the continued sessions, particularly for keeping up to date with evolving guidance. (31)

Overall, this reinforces that workforce capability is a critical enabler of high-quality PEoLC, without consistent access to education and protected learning time, variation in skills will persist, leading to inequitable care experiences.

There is therefore a clear requirement to expand multidisciplinary training provision, including specific focus on children and young people, learning disability, and communication needs, while embedding PEoLC learning within core workforce strategies and professional education pathways to ensure sustainable improvement.

Other national (11) and local reports (35) outline the current and future challenges of ensuring we have a health and care workforce, particularly on our coastal strip, with capacity to meet local demand and need.

Ambition 6: Each community is prepared to help

VCSE and general community capacity across Sussex represents a significant but underutilised asset in supporting people at the EoL and through bereavement. There are examples of many voluntary groups representing specific groups, including carers, places and/or conditions supporting communities at EoL and those bereaved.

Hospices and many other agencies across Sussex are actively supporting the development of compassionate communities by creating opportunities for local people, community groups and organisations to engage in conversations about death, dying and bereavement. For example, the Community Conversations event hosted by St Michael’s and St Wilfrid’s Hospices brought together over 60 participants from around 30 organisations to explore attitudes towards EoLC and barriers to accessing support. Through partnership working, community engagement and shared learning, the event helped strengthen local networks, reduce stigma around death and dying, and encourage communities to play a greater role in supporting people approaching the EoL and those who are bereaved.

Evidence demonstrates that bereavement support operates within a recognised tiered model, whereby:

- The majority of bereaved people are supported informally through family, friends, workplaces, faith groups and wider community networks
- Around one third require structured support, including peer groups, hospice-led services and voluntary sector provision.
- Approximately 10% require specialist interventions, including mental health or trauma-informed support.

In Sussex, informal community and peer support are highly valued and widely relied upon. Carers and professionals consistently describe the importance of being able to 'just speak things through' in informal settings, with peer networks and community-based approaches play a critical role in reducing isolation and facilitating coping.

Focus groups praised the provision available, which was often not specific condition or bereavement provision, but many of the other social groups and networks that exist served as support when people were bereaved. However many said there needed to be more support to sustain many of the groups and charities that provide coffee mornings, food and friendship, day services and meet ups.

Similarly, bereaved carers report heavy reliance on family, friends, and faith communities, particularly during early stages of grief.

However, these strengths exist alongside significant structural and system limitations. Provision of bereavement and community support is described as:

- Fragmented, with multiple providers operating without clear coordination or aligned pathways
- Difficult to navigate, with no single, trusted source of information and inconsistent referral processes
- Uneven across Sussex, with variation in availability, waiting times, and service models depending on geography and local funding arrangements.

Public, professional and carer insight highlights low awareness of available support and limited understanding of EoL and bereavement processes. Many individuals report that planning is:

- Poorly understood, with uncertainty about available support, roles, and responsibilities.
- Introduced too late, often during crisis or near death rather than as part of earlier, proactive conversations.

Carers describe feeling unprepared for both the dying process and bereavement, with limited emotional and practical guidance provided in advance. Awareness of services is low, and support is often reactive rather than proactive, relying on individuals to seek help independently.

More broadly, societal factors such as discomfort discussing death and grief contribute to low ‘death literacy’, limiting confidence within communities to support one another effectively.

In addition, inequalities in access to community and bereavement support persist, affecting groups such as people experiencing poverty, those with limited social networks, minority communities, and individuals with complex needs.

Public and professional engagement highlighted specific communication needs for those bereaved who have learning disabilities, autism and sensory loss. Professionals acknowledge some groups who are in recovery or experience substance misuse may have experienced a significant amount of bereavement amongst their peers and that there is considerable unmet need that addresses this trauma, whilst often experiencing multiple compound needs.

Fragmentation and lack of coordination specifically around bereavement support further compound these inequalities by creating barriers to timely and appropriate support.

The evidence indicates that communities in Sussex are willing and able to support people at EoL and through bereavement, but this potential is not yet fully realised. Informal support networks play a central role and are often the first and most consistent source of help, yet they are not systematically supported or enabled by the wider health and care system.

Two core issues underpin this position for improvement:

1. Community, voluntary and formal services operate in parallel rather than as an integrated system, resulting in duplication, gaps, and unclear pathways into support across the health and care system.
2. Individuals, carers and communities often do not know what support is available, how to access it, or how to provide support themselves.

This leads to a system where support is uneven, reactive, and dependent on individual knowledge, confidence and advocacy, rather than being consistently available and proactively offered. As a result, people may experience avoidable isolation, delayed support, and unmet need, particularly at key points such as immediately after death or during later stages of grief.

The current model therefore underutilises the strengths of communities, while placing greater pressure on formal services and contributing to inequities in experience and outcomes.

PERSONAS – Bringing the needs and experience to life

The following personas and case studies are designed to illustrate the needs of the Sussex population.

Case study 1: Late presenting cancer with delayed engagement

Cancer trajectory, hospice death after late referral, bereavement support

Background

David was a 62-year-old man living alone in coastal West Sussex. He had limited contact with family and rarely engaged with health services. He had a long-standing mistrust of healthcare and tended to ignore symptoms, preferring to 'get on with things' and not wanting to waste his time accessing services. He had tried several times to call his GP but was met with a long wait on the phone.

Illness trajectory

Over several months David experienced increasing breathlessness, fatigue and weight loss. He did not contact his GP. Eventually, he presented to hospital acutely unwell, where he was diagnosed with advanced lung cancer that was no longer treatable or curable.

Care and support

Due to the late diagnosis, David moved rapidly to a palliative phase. Specialist palliative care was involved only shortly before death, and referral to hospice inpatient care occurred very late.

Hospice staff provided compassionate, high-quality care, but there was limited time for symptom optimisation, psychological support, or advance care planning.

Family experience

A distant sister was contacted shortly before David's death. She felt shocked and distressed by the suddenness of events and regretted not having clearer information about his wishes.

Outcome

David died in a hospice inpatient unit. David's sister was able to access some bereavement support from the hospice as David was a patient.

Learning points

- Late engagement with healthcare led to late diagnosis and ability to treat the cancer and identification of palliative needs.
- Opportunities for earlier support, ACP and community palliative care were missed.
- Hospice care was excellent but accessed too late to maximise benefit
- Bereavement support offered to his sister but only as he was a patient of the hospice.

Case study 2: Dementia with strong family and care home support

Frailty / dementia trajectory well planned and supported death

Background

Margaret was an 88-year-old woman living in a residential care home in East Sussex. She had advanced dementia and had lived in the care home for several years. Her family lived locally and were closely involved.

Illness trajectory

Margaret's decline was gradual and predictable. This was explained by Margaret's GP and her family attended her appointments to ask questions. Dementia was recognised as a life-limiting condition, and care focused increasingly on comfort and quality of life rather than medical intervention.

Care and support

The care home had a stable workforce and strong links with the GP, community nursing and palliative services. Margaret's family has been proactive in discussing Margaret's wishes and care with her and her care-givers. Margaret had a documented ReSPECT plan, and her preferences focused on avoiding hospital admission and remaining in the care home, where she was comfortable.

As her condition deteriorated, symptoms were managed in the care home with support from community clinicians.

Family experience

Her family felt engaged, informed, prepared and supported. They were involved in decision making throughout and felt reassured that Margaret was comfortable and treated with dignity.

Outcome

Margaret died peacefully in the care home, with her family around her.

Learning points

- Early identification and planning enabled a good EoL experience.
- Strong relationships between care home, primary care and family were key.
- Demonstrates effective PEoLC for dementia and frailty.

Case study 3: Frailty and multimorbidity with poor coordination

Frailty and organ failure – crisis driven care

Background

George was an 81-year-old man living at home with his wife in Hastings. He lived with heart failure, COPD, diabetes and increasing frailty. His wife was his main carer.

Illness trajectory

George's health declined slowly with frequent exacerbations. He experienced repeated crises, often out of hours, leading to ambulance calls and emergency hospital admissions.

Care and support

George was not clearly identified as approaching the EoL. He did not have an Advance Care Plan or ReSPECT plan. His care was fragmented across multiple services, with no single professional coordinating his needs. Hospital admissions focused on acute problems and discharge, rather than his overall trajectory and holistic needs.

Family experience His wife felt exhausted and unsupported, often unsure who to contact when George deteriorated. She described the experience as stressful and unpredictable.

Outcome

George died in hospital following another emergency admission, rather than at home.

Learning points

- Lack of early identification for frailty trajectory.
- Poor coordination and gaps in out of hours support.
- Carer strain contributed to hospital use.

Case study 4: Young person supported by Children and Young People's hospice

CYP life-limiting condition – long term holistic support

Background

Ella was a 19-year-old young person living with a complex, life-limiting neurological condition. She lived with her parents in Sussex.

Illness trajectory

Ella had been known to children's palliative care services from childhood. Her condition was progressive but relatively stable for long periods, with gradual deterioration over time.

Care and support

Ella received long term support from a Children and Young People's (CYP) hospice. Care focused on symptom management, emotional wellbeing, independence where possible, and supporting family life. Care plans were reviewed regularly, and her parents were supported alongside her.

As Ella approached the EoL, care was already established, and her death was anticipated.

Family experience

Her parents described the hospice as central to their ability to cope. They felt emotionally and practically supported before and after her death.

Outcome

Ella died in the CYP hospice, with her family present.

Learning points

- Early and sustained palliative involvement improves experience
- CYP hospice model supports both patient and family
- Demonstrates good transition into EoL care.

Case study 5: Organ failure with effective community coordination

Organ failure trajectory – planned death in preferred place, hearing loss.

Background

Aisha was a 74-year-old woman living with her husband in Crawley. She was a practicing Hindu. She had advanced heart failure and periods of relative stability punctuated by acute deterioration. She also lost her hearing in her late 60s.

Illness trajectory

Following a significant hospital admission, clinicians recognised that Aisha was likely approaching the EoL, despite not having a cancer diagnosis.

Care and support

Her GP initiated Advance Care Planning and completed a ReSPECT plan. She ensured she asked her what was important to her at the EoL, and how her religious and spiritual needs needed to be discussed, documented and adhered to.

Her GP also ensured she could understand what was being communicated using written materials, acknowledging she had lost her hearing.

She was linked to community heart failure services and specialist palliative care. Clear plans were put in place for deterioration, including who to contact out of hours.

When her condition worsened, rapid community support prevented unnecessary hospital admission.

Family experience

Her husband felt confident and supported, particularly knowing who to call when things changed.

Outcome

Aisha died peacefully at home, her preferred place of death.

Learning points

- Recognition of non-cancer trajectories is critical.
- Coordinated community care reduces hospital use.
- Planning enabled care aligned with preferences.

Case Study 6: Sudden deterioration with limited opportunity for planning

Rapid decline – minimal time for PEoLC involvement

Background

Michael was a 69-year-old man living with his male partner in Brighton & Hove. He was previously active and had no known life-limiting illness.

Illness trajectory

Michael became suddenly unwell and was admitted to hospital, where he was diagnosed with advanced cancer. His condition deteriorated rapidly.

Care and support

Although care was compassionate, there was little time for Advance Care Planning or discussions about preferences. Palliative care involvement was brief and focused on immediate comfort.

Family experience

His partner, Stuart, described shock and disorientation and reflected that they had never discussed EoL wishes earlier in life. His partner felt uncomfortable displaying affection in the last hours of life and felt judged by the healthcare workers who he felt were homophobic.

Outcome

Michael died in hospital within days of diagnosis. His partner is concerned about experiencing homophobia at the end of his life.

Learning points

- The workforce needs to be equipped to provide inclusive, affirming end-of-life care, so all patients and those important to them feel safe, respected,

and able to express their relationships without fear of discrimination or judgement.

- Some deaths allow little time for planning.
- Highlights the importance of earlier, population level conversations about EoL.
- Reinforces need for flexible and rapid PEoLC responses.

Recommendations development and prioritisation

The recommendations were developed through a robust three-stage process to ensure they were evidence-based, co-produced and supported by partners across Sussex.

First, the needs assessment brought together evidence from routine data, service performance information, literature reviews, stakeholder interviews, surveys, focus groups, strategic documents, national guidance, and patient, carer and public feedback to identify unmet need, inequalities, service gaps and opportunities for improvement.

These findings informed an initial set of recommendations, which were reviewed and refined with the project steering group. The draft recommendations were then tested and further developed through system-wide engagement involving NHS organisations, local authorities, hospices, primary care, adult social care, VCSE organisations, equality and inclusion leads, bereavement services and people with lived experience.

Around 50 stakeholders participated in a workshop on 30 June 2026, expressing strong support for the recommendations and highlighting the importance of community-based care, coordinated services, digital integration, workforce sustainability, Advance Care Planning, reducing inequalities, supporting children and young people, and strengthening compassionate communities and bereavement support.

A subsequent recommendation development event on 27 July 2026 used structured exercises and the APEASE framework to assess recommendations against acceptability, practicability, effectiveness, affordability and equity, identify "must do" and "should do" priorities, and determine system-wide implementation priorities.

The highest-ranked recommendations focused on establishing a Sussex-wide Single Point of Coordination and out-of-hours model, developing a shared demand, capacity and investment plan, and implementing interoperable digital shared records.

Stakeholders also identified improved equality data collection as a priority that could be advanced using existing resources. Feedback indicated strong agreement that the recommendations were comprehensive, with calls for a clear delivery plan, strong leadership, ongoing governance and co-production, measurable outcomes, and renewed system oversight.

Following both workshops, the recommendations were revised to reflect stakeholder feedback, reduce duplication and strengthen clarity, resulting in the final recommendations presented within this needs assessment.

Recommendations

10 strategic recommendations have been developed which are aligned to more detailed all age recommendations and a Babies, Children and Young Peoples subset of recommendations. The rationale for the more detailed recommendations is outlined within the recommendations chapter.

Strategic Recommendation 1: Implement a consistent Sussex-wide Single Point of Coordination and 24/7 PEoLC support model, ensuring equitable access to care navigation, clinical advice, urgent response, prescribing support, pharmacy advice and hospice expertise regardless of postcode.

Strategic Recommendation 2. Develop and implement a Sussex interoperable PEoLC digital record that enables access to Advance Care Plans, ReSPECT plans, preferred place of care and death, key contacts, medication information and carer details across all settings.

Strategic Recommendation 3. Develop a Sussex demand, capacity and investment plan for PEoLC and bereavement support that aligns future commissioning, workforce development and resource allocation to projected increases in deaths, dementia, frailty and multimorbidity.

Strategic Recommendation 4. Embed PEoLC within Sussex Neighbourhood Health, MDT and Integrated Community Team models, strengthening multidisciplinary working between general practice, community nursing, social care, hospices, care homes, ambulance services and VCSE partners.

Strategic Recommendation 5. Implement a Sussex-wide ReSPECT and Advance Care Planning improvement programme that increases the quality, consistency, visibility and use of personalised care planning.

Strategic Recommendation 6. Develop a Sussex PEoLC workforce strategy that addresses recruitment, retention and workforce development challenges, with specific focus on communication skills, frailty, dementia, neurodiversity, learning disability, HIV, bereavement support, inclusion and culturally competent care.

Strategic Recommendation 7. Establish a Sussex PEoLC equity programme that combines improved recording of protected characteristics, communication needs, targeted engagement, co-production and service improvement to reduce inequalities in access, experience and outcomes.

Strategic Recommendation 8. Develop a Sussex Compassionate Communities and Death Literacy Strategy that normalises conversations about death, dying and bereavement, increases public understanding of available support and strengthens community-based networks.

Strategic Recommendation 9. Re-establish a Sussex PEoLC Oversight Group and develop a Sussex-wide Implementation Plan with named leads, delivery partners, milestones, measurable outcomes, governance arrangements and regular public reporting.

Strategic Recommendation 10. Further develop existing services and implement a Sussex Babies, Children and Young People (BCYP) PEoLC programme that establishes coordinated all-age pathways, equitable access to specialist support, 24/7 paediatric advice and response, named care coordinators, integrated transition arrangements and coordinated bereavement support for children, young people and families.

Chapter 1 Introduction and Background

Death and dying are inevitable for us all (36). The needs of people who are near the end of their lives must be understood, whilst the needs of their family, friends and those who provide their care must also be considered.

Palliative care is defined by the World Health Organisation (WHO) as 'an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-limiting illness, usually progressive.' It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual. (1)

In England, the term ‘EoL care’ refers to care that is provided in the last year of life.

Personalised and holistic care, based on people’s physical, social and spiritual needs, preferences and wishes will result in better, person-centred, more sustainable and dignified health and care services at EoL. (23)

Grief is a normal reaction to bereavement, and many people use their personal resilience, combined with support from family and friends, as sufficient help to manage their distress, the life changes and adjustments triggered by loss. (38)

However, awareness and understanding of grief is often lacking, which can leave bereaved people feeling lost and misunderstood. Bereavement is associated with risks to health and wellbeing and can give rise to a wide range of needs. Services that can help people manage their grief range from the provision of information through health promoting community-based resources to more intensive, specialist help for those whose reactions are complex or prolonged and affect their ability to manage everyday life.(38)

This PEoLC NA for Sussex has been overseen by a multiagency steering group to ensure that the experience, expertise, data and insights from all those working in the PEoLC system within Sussex have been involved and have shaped this work. This has included representatives from Local Authorities with Public Health and Social Care responsibilities, NHS Sussex ICB, the Sussex Hospice Alliance, East Sussex Partners in Care and West Sussex Partners in Care representing residential care and nursing home providers.

A health and care needs assessment is the systematic approach to ensuring that the health and care system uses its resources to improve the health of the population in the most efficient way.

Defining need

Need is an important concept in public health, particularly in relation to the assessment, planning, allocation and equity of healthcare services and programmes. Bradshaw outlines four types of social need. (39)

Normative need

This need is described and defined by experts. Different experts may specify different standards or requirements of this type of need. Normative need can include healthcare interventions prescribed by a doctor or nurse, such as prescribing pain relief or antibiotics.

Felt need

This type of need is linked to the individual, felt need will be associated with knowledge of services, physiological functions and processes leading to symptoms such as pain, distress or something that triggers a physical or emotional response. This can include feeling pain or a dying patient that may feel overwhelmed and express a need for respite care or support groups for caregivers.

Expressed need

Expressed need is when a felt need turns into action. This is a need (a request for intervention) to address the felt need. This could include attending a GP appointment, seeking a dentist or a request for home care services to help manage the final stages of a loved one's life, ensuring they remain comfortable at home.

Comparative need

Comparative needs arise when comparing services and interventions between groups and/or individuals to another, highlighting a need that needs to be met for the group that may not have the service or intervention that exists for the other group. For example, identifying that some ethnic or socio-economic groups receive less comprehensive EoL care due to language barriers or lack of access to healthcare services.

Health, healthcare, need, supply and demand

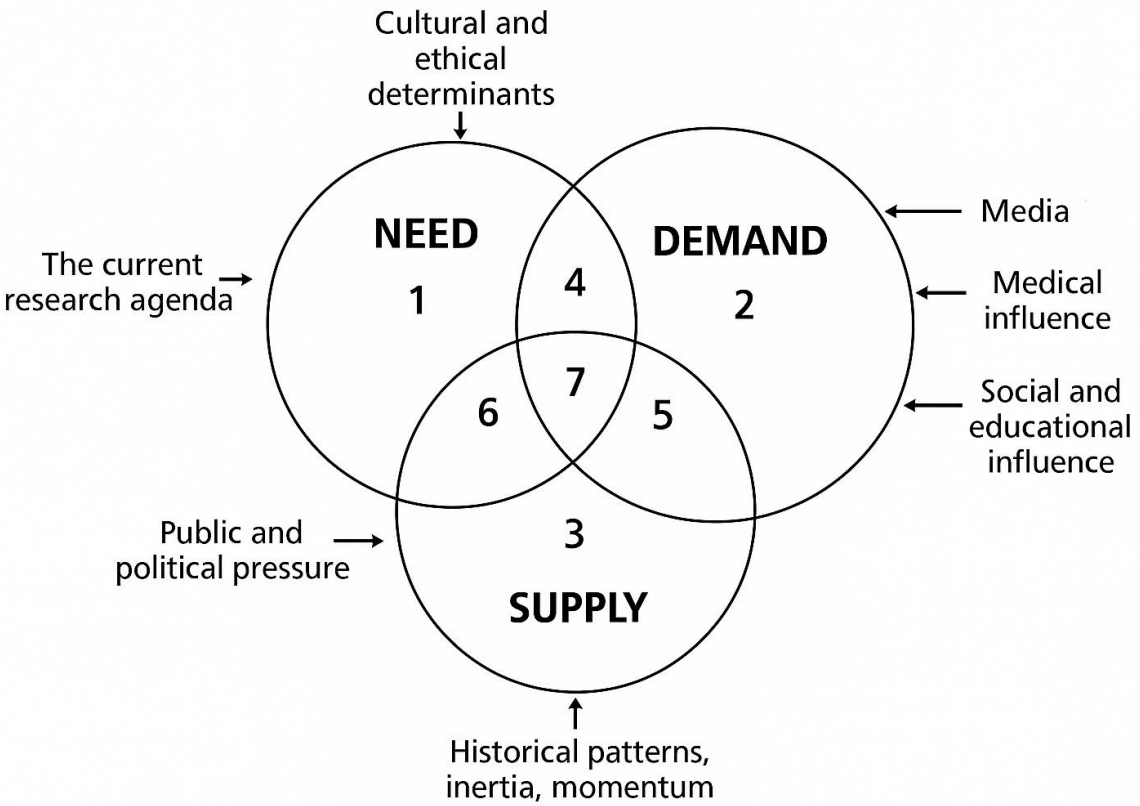
The need for health and the need for healthcare, should be considered as different concepts, as the need for healthcare emerges when there is an acceptable intervention, often reactive, that is likely to positively impact the condition or illness afflicting an individual. Whereas the need for 'health and wellbeing' is a broader concept, influenced

by many factors across the life course, it may include health issues and problems for which there are no healthcare interventions (39)

Within the UK context, our health system often defines need as 'capacity to benefit.' This relies on the proposed benefits of preventative or treatment services to address a health-related problem. However, Stevens states the capacity to benefit is influenced by many factors such as scientific knowledge, research, and the cultural and moral factors of a society. (39)

Furthermore, health economists distinguish need from supply and demand. Need is influenced by the factors previously outlined. Demand can be influenced by the media, medical and professional influences, and educational and social influences. Supply can be influenced by public and political pressure and historical patterns and inertia and momentum. Need, demand and supply overlap, creating seven different fields (eight if you include an external field where services are neither needed, demanded, nor supplied).

Figure 1 Need, demand and supply, influences and overlaps.



Field 1: Services are needed but not demanded or supplied.

Field 2: Services are demanded but not needed or supplied.

Field 3: Services are supplied but not demanded or needed.

Field 4: Services are needed and demanded but not supplied.

Field 5: Services are supplied and demanded but not needed.

Field 6: Services are needed and supplied but not demanded.

Field 7: Services are needed, demanded and supplied.

This PEoLC needs assessment includes data and intelligence that considers all the types of need outlined. The author is conscious that this needs assessment is being conducted in a time where there is considerable focus on PEoLC due to the Terminally Ill Adults (EoL) Bill (40) going through legislative processes and subsequently not progressing through the House of Lords. The public health and professional discourse relating to this matter will continue. Therefore, this needs assessment has coproduced recommendations that acknowledge identified needs, whilst understanding the current, and future, demand and supply of PEoLC will be influenced by many forces and factors over the coming years. For example, should assisted dying for terminally ill adults be legalised or not, local planners, commissioners, providers and the public will need to consider how the need, supply and demand of PEoLC may change as a result, alongside advances in healthcare and treatment and our ageing population.

Approach to this needs assessment

This needs assessment uses the following approaches:

Epidemiological

This approach considers the epidemiological data, current service provision, and the effectiveness and cost effectiveness of interventions and services. Within this needs assessment this includes using existing data published on mortality, new and novel analysis of primary care data and mortality data, and data from local adult and child hospices.

Comparative

This approach compares service provision between different populations. Large variations in service use may be influenced by a number of factors and not just differing needs. This includes comparing data sets of service use and access between groups such as LGBTQ+ groups and different ethnic groups in relation to healthcare relevant to PEoLC. This needs assessment has also summarised existing synthesised evidence, including systematic reviews, on which groups experience differences and inequities in PEoLC.

Corporate

This approach is based on eliciting the views of stakeholders, which includes professionals, patients and service users, the public and politicians on what services are needed. Elements of the corporate approach (i.e. community engagement and user involvement) are important in informing local policy (41). Where existing views and perspectives of stakeholders have already been collected and reported, this needs assessment has sought to include them rather than repeat recent relevant engagement activities. Additional engagement activities were conducted in 2026 to ensure novel and local data and intelligence was collected and analysed for this report.

Aims and scope

Aims

This Sussex PEoLC Needs Assessment aims to further understand the current and future PEoLC needs across the Sussex Health and Care System. It uses a range of epidemiological data, considers the context of current provision, patient family and carer experience, and will identify current and potential future gaps, to inform future service developments and implementation of Neighbourhood Health in Sussex.

Recommendations are provided within the executive summary and at the end of this document. These have been co-produced with the multi-agency steering group to meet the needs identified, in line with the legislation and national guidance published at the time.

Scope

The scope of this needs assessment is the whole population residing and or registered with a GP Practice in Sussex. It includes:

- a summary of national and local evidence and policy relating to PEoLC and Bereavement Support needs.
- a summary of local service provision at the time of writing, with more detailed service descriptions within the appendix.
- analysis of the available epidemiological information relating to PEoLC in Sussex
- Analysis from a workforce survey, focus groups and other public engagement events with residents.

It excludes:

- the debate on the concept of assisted or physician assisted death, or the specific Bill. As this needs assessment is initiated in 2025, the year in which the Terminally Ill Adults (EoL) Bill is under scrutiny by Parliament. The Bill aims to allow adults

who are terminally ill, subject to safeguards and protections, to request and be provided with assistance to end their own life (42). The Bill has brought further attention to the care of those at the end of their lives. There are many strongly held views on both sides of the debate on the Bill, and a huge range of materials and literature has been published on the topic (43). The Bill is supported and challenged for multiple reasons by the public, professionals, including medical professionals, law makers and politicians.

Key evidence gaps and data limitations.

This needs assessment draws together a wide range of data, evidence and insight from health, social care, hospice, voluntary sector, public and professional sources. However, several evidence gaps and limitations were identified. The most significant relates to the availability of social care data, where comparatively little routine intelligence was available compared with NHS datasets.

Limited data were available on care home and domiciliary care activity, workforce pressures, outcomes, advance care planning, place of care, place of death, inequalities, quality of experience and unmet PEoLC need. As a result, the contribution of social care to supporting people approaching the end of life is likely to be underrepresented within the available evidence base.

A further limitation is that it was not always possible to use data from the same reporting periods across all sections of the assessment. Different organisations collect, analyse and publish data at different times and frequencies, and in some areas the most recent available data were several years older than other sources. Whilst every effort was made to use the best and most up-to-date evidence available, some variation in reporting periods was unavoidable and should be considered when interpreting trends and making comparisons between datasets.

Future intelligence priorities should focus on strengthening the collection, sharing and use of data across the whole PEoLC system, particularly within social care. Priorities include developing a common social care PEoLC dataset, improving the recording of protected characteristics and inclusion health groups, strengthening information on carers and bereavement support, improving interoperability between systems, and increasing the availability of outcome and experience data.

Linked health and care intelligence and resources

This needs assessment synthesises existing data and published information to provide insight to complement existing health and care data and insight resources. This includes the wealth of health and care data published and available on the Joint Strategic Needs Assessments for Brighton and Hove City Council, East Sussex County Council and West Sussex County Council. There are also specific data profiles for Integrated Community

Teams outlining their respective population profiles. This needs assessment should be read and considered alongside such resources. The NHS Insight bank also provides a range of data sets relevant to the protected characteristics and inclusion groups and their experience of health and care.

PEoLC background information

Definitions

A good death

Marie Curie, the UKs leading EoL charity, outlines a ‘good death or good EoL experience as having the right support, care and systems in place to enable people to feel protected and safe, and those that provide such care and loved ones understand what support is available’. A good death is personal and differs between people. However, Marie Curie states some principles of a good death, applicable to most people regardless of the specific condition(s) afflicting them (44). These are stated in table 1:

Table 1 Principles of a good death (adapted from Marie Curie)

Principal	Information
Pain and symptom management	For those living with an illness that they are likely to die from, it is important to manage any pain and symptoms and get the right medical care to help them live as well as they can, in line with their wishes. This means being able to access and plan the care they need and get urgent, unplanned care if they need it.
Emotional and spiritual support	If someone is living with an illness, they're likely to die from, or are close to someone who is, they might be feeling a range of emotions, from shock and anger to anxiety and loneliness. To feel safe and supported, emotional and spiritual care can be just as important as physical care.
Focusing on what matters most	This could mean spending as much quality time as possible with their loved ones. It might be physio support to do an activity they love when they didn't think they could. Or being in the place they call home as they take their last breaths, with their favourite people and pets by their side.

Principal	Information
Coordinated and easy to use services	A smooth and joined up experience of the health and social care system they're using can mean they're better able to focus on the important things at the hardest of times.

Palliative care and EoL Care (EoLC) are two terms often used interchangeably, however they are distinct with specific differences, these are defined below:

Palliative care

Palliative care aims to improve the quality of the life of patients and their families who are experiencing life-threatening illnesses. It prevents and reduces pain and suffering through the identification, assessment and treatment of pain, other symptoms, and wider issues such as psychosocial and spiritual matters associated with dying. (45)

EoLC

EoLC includes healthcare, care and other support provided in the final weeks and months of life, it also includes the preparation and planning of such care. For some conditions, this could be months or years (20). A wide range of health and social care professionals provide EoLC in a number of settings, often simultaneously to a single individual at the EoL. This includes hospital doctors and nurses, General Practitioners, community pharmacies, community nurses, hospice staff and counsellors. Social care staff working in care homes and domiciliary settings, chaplains (of all faiths or none), physiotherapists, occupational therapists or complementary therapists also contribute to the delivery of EoLC. In England, the term EoLC refers to the last year of life, however disease trajectories and prognosis aren’t fixed.

Care of the dying

Care that includes the physiological, psychological, social and spiritual needs of a person deemed to be entering the last days of life. (21)

Figure 2 Tiers of palliative and EoL care

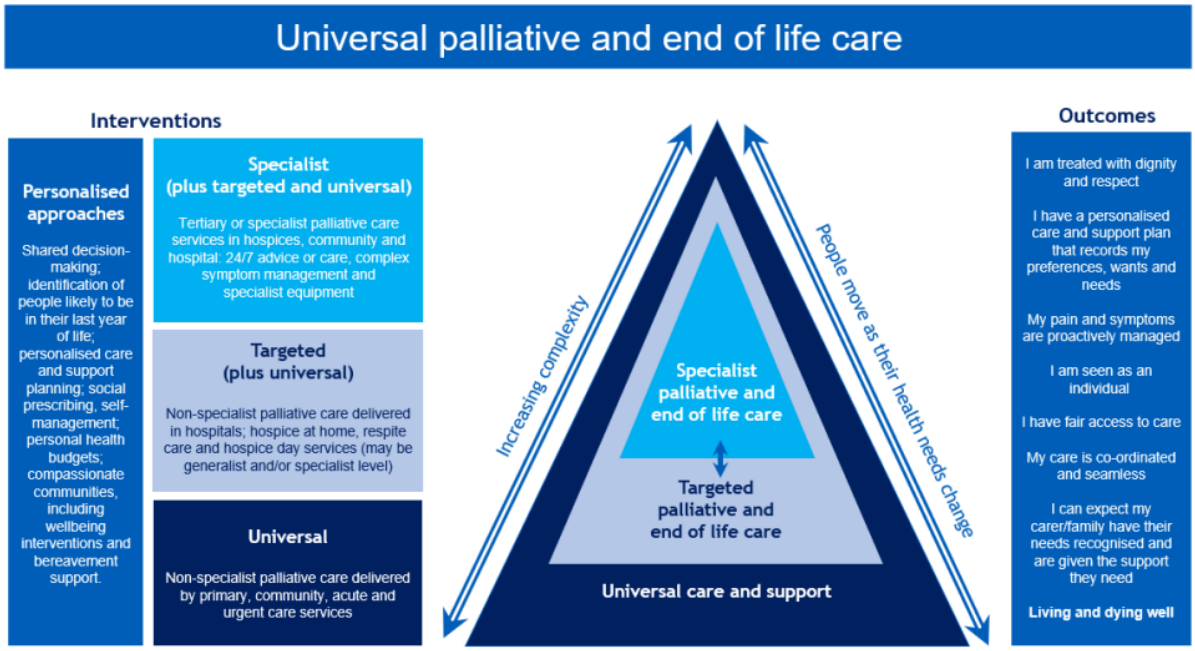


Figure 3 Main organisations involved in commissioning and providing EoL care [Dying Well At Home: Commissioning Quality End-of-life Care | The King's Fund]

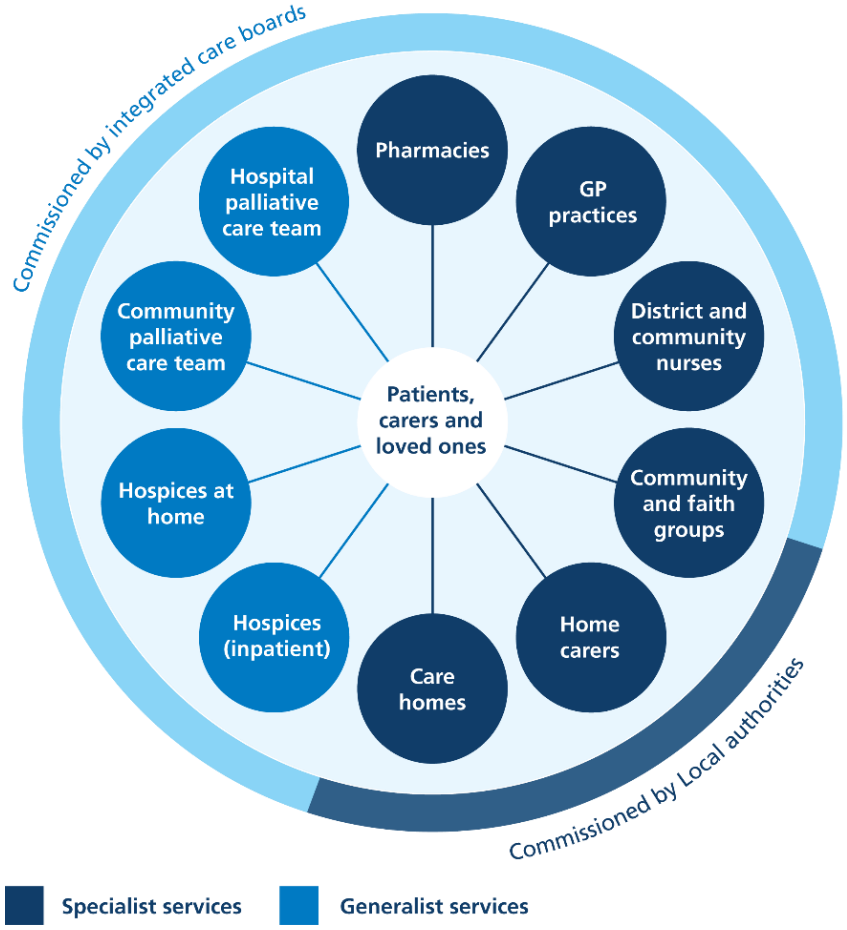


Figure 4 Disease trajectories

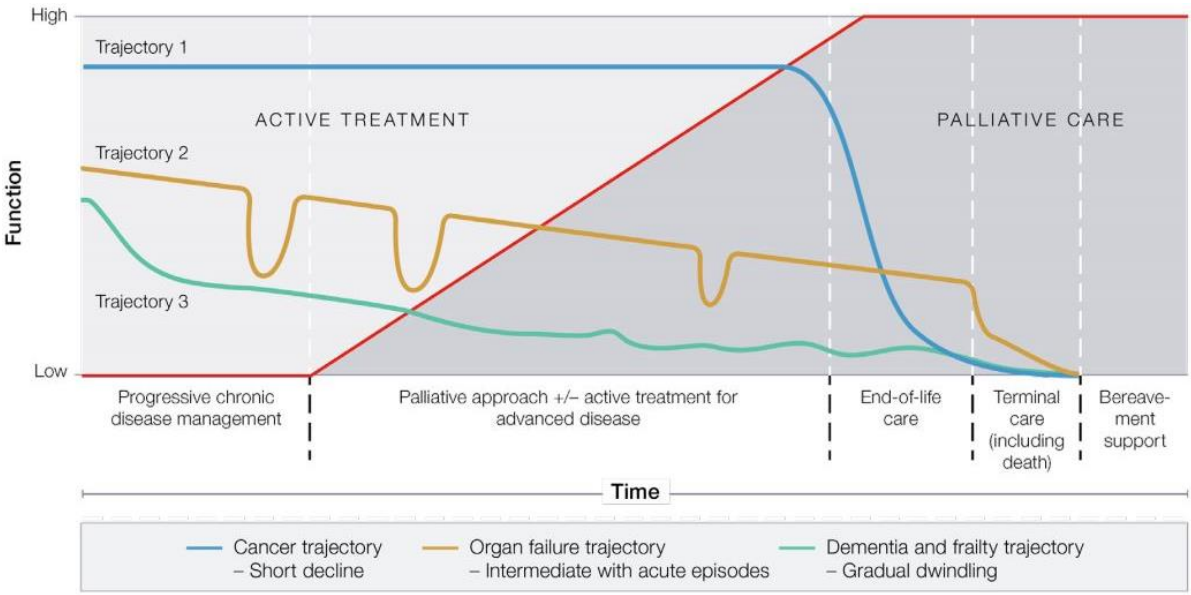


Figure 4 shows three general illness trajectories and their relationship to PEoLC. This figure excludes sudden death trajectories that may require no or a very short period of healthcare and care.

Trajectory 1, the blue line, depicts cancer patients. The figure highlights they will likely have high levels of function for a period with the condition, requiring active treatment and potentially less social care until a point where their condition deteriorates quickly requiring intervention to manage their symptoms before death.

Trajectory 2, the yellow line, depicts those experiencing organ failure, this could be lung, liver, heart or neurological, the period of deterioration may be longer compared to cancer, with periods of acute healthcare need before reaching a terminal phase and death.

Trajectory 3, the green line, those with dementia and other conditions contributing to their frailty, the trajectory outlines a more gradual decline in function, which may require a wide range of care and support, prior to a terminal phase and EoL.

These disease trajectories are not fixed, and healthcare and care professionals will appreciate that every patient will have a unique path at their EoL. However, being aware of these trajectories will help clinicians and commissioners to plan care to meet current and future needs better. (46)

Considering these trajectories alongside population data, including the prevalence and incidence of specific conditions, population growth, and the age profile of the local population, will provide a more comprehensive understanding of current and future palliative and end of life care (PEoLC) needs across Sussex. Bringing these data sources together will support local decision-makers in planning services that are responsive to

population need. Combining this information will support local decision makers to further understand what the needs of the population may be relation to PEoLC in Sussex. As described later within this report, Sussex is projected to observe larger numbers and proportions of our population requiring care and intervention for multiple conditions as they age.

Bereavement support

Grief is a normal reaction to bereavement, and many people use their personal resilience, combined with support from family and friends, as sufficient to help them manage their distress and the life changes and adjustments triggered by loss. (38)

However, awareness and understanding of grief is often lacking, which can leave bereaved people feeling lost and misunderstood. Bereavement is associated with risks to health and wellbeing and can give rise to a wide range of needs. Services that can help people manage their grief range from the provision of information through health promoting community-based resources to more intensive, specialist help for those whose reactions are complex or prolonged and affect their ability to manage everyday life.(38)

Figure 5 The public health model of bereavement support, predicted proportions (in brackets) and actual proportions for the three risk groups. (47)

The Public Health Model of Bereavement Support presents estimated proportions of bereavement support need across a population. These proportions were intended as planning assumptions rather than observed prevalence estimates and may differ from findings reported in more recent empirical studies. The model remains useful as a framework for organising bereavement support across universal, targeted and specialist levels of need.

National and local policy, guidance and service context

NHS England works with the Government, partners from across the health and care system, voluntary, community and social enterprise (VCSE) partners and people with lived experience, to improve PEoLC across England.

PEoLC standards are underpinned by NICE guidance for adults and children's care, an NHS England palliative and EoL care standard, NHS England service specifications for adults and children's PEoLC, and an Ambitions Framework co-produced by the NHS with stakeholders. The majority of PEoLC is provided by NHS staff and services, but voluntary sector organisations, including hospices, also play a key role in service provision.

They form part of the National Palliative and EoL Care Ambitions Partnership, and jointly developed the system-wide Ambitions for palliative and EoL care: a national framework for local action 2021 26, refreshed in May 2021. NHSE are also working with the government and partners across the health and care system to deliver the EoL Care Commitment. The government made a six-point commitment, which particularly highlights ambitions. In November 2025 the Government is developing a Palliative Care and EoL Care Modern Service Framework for England, with a planned publication date of Autumn 2026. This will be aligned with the ambitions set out in the recently published 10 Year Health Plan, which prioritises shifting care out of hospitals and into community settings to ensure personalised, compassionate support for individuals of all ages and their families.

Ambitions for PEoLC

The Ambitions framework was developed by a partnership of national organisations across the statutory and voluntary sectors. It sets out our vision to improve EoL care through partnership and collaborative action between organisations at local level throughout England:

Ambition 1 – Each person is seen as an individual.

Ambition 2 – Each person gets fair access to care.

Ambition 3 – Maximising comfort and wellbeing.

Ambition 4 – Care is coordinated.

Ambition 5 – All staff are prepared to care.

Ambition 6 – Each community is prepared to help.

NICE

The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care produce useful and usable guidance for the NHS and wider health and care system. (48) Their recommendations help practitioners and commissioners get the best care to people, fast, while ensuring value for the taxpayer. (19)

NICE produce a range of products to support organising and delivering EoL care services. This includes the guidance titled EoL care for adults: service delivery Guidance NICE which provide care and support in the final weeks and months of life (or for some conditions, years), and the planning and preparation for this. It aims to ensure that people have access to the care that they want and need in all care settings. It also includes advice on services for carers.

This guideline is intended to be used alongside the NICE guideline on care of dying adults in the last days of life, which covers clinical care for people who are considered to be in the last days of life.

NHS Surrey and Sussex ICB

NHS Surrey and Sussex has a legal duty under the Health and Care Act 2022, to commission palliative care services which “meet the reasonable requirements of the people it serves”, its local population.

In November 2025, The government announced it would develop a Modern Service Framework (MSF) for Palliative Care and End-of-Life care in England. This MSF is one of the only six MSFs announced, which clearly demonstrates that palliative care and EoL care is a top priority for this government. The MSF will help address rising demand; late identification of need; inequitable variation in access, experience and outcomes; and the wider pressures facing the health and care system.

This framework builds on previous initiatives like the 2021 - 2026 "Ambitions for Palliative and EoL Care" framework and requires Integrated Care Boards (ICBs) to ensure more consistent delivery of care, with a final plan expected in autumn 2026. The Framework aims to make care more personalised and accessible, with a focus on partnership approaches between different healthcare organisations and incorporating patient and family experiences.

Key aspects of the Modern Service Framework for PEoLC.

Improving quality and consistency: The framework aims to set national standards and ensure that everyone receives high quality EoL care regardless of their location.

Integrated approach: It promotes collaboration between different parts of the health and social care system, including primary and secondary care, and encourages the involvement of people with lived experience.

Personalised and accessible care: The goal is to ensure care is personalised to individual needs and is more accessible, potentially including improved 24/7 access to support.

Reducing inequalities: A key aim is to reduce health inequalities to improve equity of access and outcomes for underserved populations.

Strategic priorities: The framework aligns with the three strategic priorities of improving access, improving quality, and improving sustainability in EoL care.

Building on existing frameworks: This new government plan is an evolution of existing work, such as the "Ambitions for Palliative and EoL Care" framework, which already requires ICBs to align their commissioning of EoL care with the set ambitions.

Delivery through Integrated Care Boards: The framework puts a formal responsibility on ICBs to deliver its objectives and ensures that national standards are met at a local level.

The duty is intended to ensure that the palliative and EoL care needs of people of all ages, with progressive illness or approaching the EoL, and their loved ones and carers, receive the care and support they need to live and die well. The ICB's core responsibility is to commission safe, high-quality services tailored to individuals' needs.

All organisations providing palliative and EoL care must understand and comply with their legal and professional duties. This includes addressing health inequalities by improving access to services and reducing inequity of outcomes, using population health approaches to identify underserved groups. (49)

NHS Surrey and Sussex commissions and works with a range of generalist and specialist providers to meet the local population's needs. This includes GP practices, pharmacies, NHS acute, community and ambulance trusts, hospices, adult social care, out of hours services, and voluntary/community partners. Some services are fully funded by NHS Sussex, while others receive a contribution towards their services, e.g., hospices.

In September 2024, NHS Sussex ICB and the Sussex Hospice Alliance (6 hospice organisations) entered a Strategic Partnership to strengthen joint working and improve health outcomes.

NHS Sussex ICB commissions a Pan Sussex PEoLC training programme from the Sussex Hospice Alliance, offering low or no cost training to health and care professionals.

NHS Sussex ICB hosts PEoLC webpages with information about local services and resources on care planning, respecting faith and culture, and carer support.

The Sussex ICB Palliative and EoL Care Maturity Matrix

The Sussex ICB Palliative and EoL Care Maturity Matrix provides a structured assessment of the region's progress in delivering high-quality PEoLC for adults and Children and Young People, it was completed in Feb 2025 It evaluated the system across eleven key areas, identifying strengths, gaps, and priority actions for further development. The matrix was designed to inform a refresh of the Sussex PEoLC Strategic Action Plan from 2025/26, with input from system partners and oversight groups.

Table 2 Summary of NHS Sussex ICB PEoLC for adults' maturity matrix findings

Area	Spring 2025 Position	Development priority
Leadership and governance	Strategic vision, partnerships and oversight arrangements are established, with the system described as maturing.	Refresh governance within the new ICB structure, strengthen collaborative leadership, and improve transparency of PEoLC funding, activity, outcomes and resource utilisation within larger provider contracts.
Data and quality improvement	Data was recognised as a priority, with work underway on local systems, benchmarking and population health analysis.	Improve interoperability, real-time data sharing and routine use of outcomes to support quality improvement.
Integrated care	Joint working was progressing through coordination hubs, shared clinical roles, education programmes and emerging Integrated Community Teams.	Embed PEoLC within Integrated Community Teams, improve transitions between CYP and adult services, and strengthen peer review.
Resources and commissioning	Financial planning, resource mapping and commissioning discussions were underway, including hospice sustainability and high-cost activity.	Align funding with national specifications, improve equity and transparency, and develop shared contracting approaches.
Co-design and community assets	Stakeholder engagement was developing, with growing focus on lived experience, diverse groups, social prescribing and VCSE involvement.	Strengthen co-production and fully involve VCSE and community partners in planning and delivery.
Workforce	Education and training programmes are in place, with commitment to equality, diversity and flexible cross-organisational working.	Develop sustainable staffing models, long-term recruitment plans and protected learning opportunities.
Patient identification	All practices maintain palliative/supportive care	Improve consistency through tools such as EARLY and SPICT,

Area	Spring 2025 Position	Development priority
and care planning	registers, but identification, ACP and ReSPECT processes vary.	strengthen EPaCCS use, and improve care planning data quality.
24/7 advice and support	Coordination and advice services exist in parts of Sussex, with commissioners aware of remaining service gaps.	Expand equitable 24/7 access, align provision with national specifications, and use patient and carer feedback to shape development.

Table 3 Sussex Children and Young People's Palliative and End of Life Care Maturity Matrix Summary, February 2025

Area	Spring 2025 Position (February 2025 assessment)	Development Priority
Leadership and governance	Strategic leadership arrangements are established through the Sussex PEoLC Oversight Group, CYP PEoLC Working Group, executive and clinical leadership, and an all-age commissioning team. A strategic action plan is in place and governance arrangements are continuing to mature within the evolving ICS structure.	Finalise the refreshed CYP Strategic Action Plan, strengthen links with wider CYP and ICS governance structures, refresh stakeholder mapping, update governance arrangements, and improve communication and engagement across partners.
Data and quality improvement	Data has been identified as a priority workstream, with planning underway to improve population health intelligence, benchmarking, shared learning from deaths, and development of reporting systems. Interoperability and consistent data sharing remain limited.	Develop a Sussex-wide CYP data workstream, improve interoperability and shared care records, strengthen benchmarking and population health analysis, and improve use of data to support service planning, quality improvement and outcomes monitoring.

Area	Spring 2025 Position (February 2025 assessment)	Development Priority
Integrated care	Sussex has established a dedicated CYP PEoLC Working Group and is developing more coordinated approaches to service delivery. However, integrated models, transitions, peer review arrangements and access to specialist support remain variable.	Improve transition pathways between children's and adult services, strengthen integrated working across health, social care and education, develop peer review processes, and improve access to specialist expertise and multidisciplinary support.
Resources and commissioning	Responsibility for commissioning CYP PEoLC has transferred to the ICB, with commissioning oversight and financial planning arrangements developing. Greater transparency regarding activity, costs and funding remains necessary.	Improve understanding of resource utilisation, align services with national specifications, develop costing frameworks, and strengthen commissioning approaches for sustainable CYP PEoLC provision.
Co-design and community assets	Engagement with stakeholders is underway and system partners recognise the importance of lived experience, community assets, bereavement support, carers, social prescribing and VCSE involvement. However, mapping and co-production remain at an early stage.	Expand stakeholder and community asset mapping, strengthen co-production with children, young people and families, improve engagement with VCSE partners, and increase awareness and use of community support services.
Workforce	Workforce challenges are recognised across Sussex, particularly regarding specialist CYP PEoLC expertise and workforce sustainability. Existing training opportunities	Develop workforce mapping, education and training plans, sustainable recruitment and retention strategies, flexible cross-organisational working arrangements, and workforce

Area	Spring 2025 Position (February 2025 assessment)	Development Priority
	exist but there is no fully developed system-wide workforce strategy.	models that support 7-day and 24/7 specialist care.
Patient identification and care planning	All GP practices maintain palliative care registers, but identification of CYP requiring palliative care, consistency of care planning, data quality and information sharing are still developing. No single agreed identification approach exists for CYP.	Improve identification processes and data quality, strengthen use of care planning tools, develop a dedicated identification and care planning workstream, improve sharing of information through digital systems and explore CYP-specific approaches to identification.
24/7 advice and support	Commissioners and providers have identified significant gaps in access to specialist 24/7 advice, nursing and medical support, particularly for non-oncology CYP patients. Collaborative work is underway to identify solutions.	Develop sustainable 24/7 specialist advice, nursing and medical support arrangements, align services with national specifications, and improve equitable access across Sussex.

Plans outlined in the Maturity Matrix were paused due to the NHS Sussex ICB restructure (which included a revision of ICB functions).

PEoLC providers and partners

General Practice, community services, hospices, hospitals, pharmacies, care homes, the VCSE sector, and families all play essential and interconnected roles in delivering palliative and EoL care (PEoLC) across Sussex. Around 0.5% of the GP registered population in England is identified and, on a register, to be approaching the EoL at any one time, a figure expected to rise as the population ages and levels of multimorbidity and frailty increase. In Sussex, over 150 GP practices provide the foundation of PEoLC, identifying patients, undertaking advance care planning, reviewing medications, prescribing anticipatory medicines, and supporting people to die in their preferred place wherever possible.

Although national GP contracts do not explicitly mandate EoL care, requirements relating to frailty[6], medication review and use of the Summary Care Record support proactive identification and planning. Local commissioning arrangements strengthen this further. Since 2020, NHS Sussex ICB has commissioned a Frailty and EoL Locally Commissioned Service, with most practices participating. This promotes personalised care planning, use of ReSPECT, maintenance of EoL registers, named clinical leads, and multidisciplinary working. A time-limited Proactive Care Scheme has further supported integrated working, risk stratification, improved data quality, engagement with clinical pharmacists, and adoption of quality frameworks such as the Daffodil Standards.

Community pharmacies play a critical role in PEoLC, particularly through timely access to symptom control and emergency medicines. Seventy-two pharmacies across Sussex are commissioned to provide an Emergency EoL Care Medicines service, improving continuity of care and enabling more people to remain at home. However, Pharmaceutical Needs Assessments highlight ongoing challenges with out-of-hours and rural provision, which can significantly affect patients and families at the EoL.

Care homes and nursing homes are a major setting for EoL care in Sussex, supporting residents through person-centred, holistic care that addresses physical, emotional, spiritual and practical needs. Effective PEoLC in these settings relies on skilled staff, anticipatory planning, strong links with general practice, community pharmacy and hospices, and appropriate documentation to avoid unnecessary hospital admissions. Support following death is also vital for families, staff and other residents.

Hospices provide specialist palliative care across Sussex through inpatient, community, outpatient and remote services. Hospices support people with complex needs across all diagnoses, provide 24/7 professional advice, deliver education to the wider workforce, and offer extensive wellbeing and bereavement support. Despite their central role, hospices remain financially fragile, relying heavily on charitable funding, with historic funding variation contributing to inequalities in access.

NHS Hospitals, including community trusts and integrated services such as Urgent Community Response, Virtual Wards and EoL Care Hubs provide specialist and urgent support, enabling symptom control, rapid discharge, and coordinated care in people's usual place of residence.

[6] Frailty is a state of increased vulnerability resulting from reduced physical and physiological reserve, leaving individuals less able to recover from illness or other health stresses. General practice supports frail patients through proactive identification, holistic assessment, personalised care planning, medication reviews, multidisciplinary working and care coordination to help maintain independence and prevent avoidable hospital admission

Alongside statutory services, VCSE organisations, families and carers are fundamental to PEoLC, offering advocacy, practical and emotional support, continuity and compassion, all of which are essential to dignified, person-centred care at the EoL.

National overview of PEoLC needs

PEoLC is a significant and growing public health issue in the UK, driven primarily by population ageing, rising multimorbidity (5), and increasing prevalence of non-cancer life-limiting conditions such as Dementia and Frailty. National evidence from the ONS and Marie Curie indicates that annual deaths in England are projected to rise from around 500,000 to 685,000 by 2050 (50), that is 138,000 more people compared to today. Around 90% of people who die are expected to have palliative care needs. (27).

Nationally around 1% of the population dies each year (51). Between 80–90% of deaths are predictable and would likely benefit from palliative care, whilst 10–20% of deaths are sudden or unexpected. (52,53)

Morbidity is increasingly dominated by multimorbidity, with projections suggesting older people approaching the EoL will live with an average of five or more long term conditions, significantly increasing complexity of care and reliance on informal carers.

Mortality data show clear social gradients, with lower life expectancy and higher mortality rates in more deprived areas (54). Whilst men experience higher mortality rates than women, women are more likely to spend a longer period of their lives living with frailty at the EoL.

Conditions and care needs

Unmet need is challenging to define because every person's situation is different. Symptoms, concerns and priorities vary, and care needs can be complex (55). PEoLC needs vary by condition group, disease trajectory and individual circumstances. Many needs relate to symptom management, communication, advance care planning, service coordination and carer support, rather than diagnosis alone.

Table 4 The dominant causes of death requiring PEoLC nationally (adapted from Marie Curie and NICE)

Condition group	Range of conditions and illnesses	PEoLC needs
Cancer	Solid tumours (e.g. lung, bowel, breast, prostate), haematological malignancies (e.g. leukaemia, lymphoma,	Early integration of palliative care, complex pain and symptom management, psychological support related to diagnosis and prognosis,

Condition group	Range of conditions and illnesses	PEoLC needs
	myeloma), early to advanced and metastatic disease, variable treatment response	ACP, coordination between oncology, hospice and community services, carer support, rapid access to specialist palliative care close to death
Cardiovascular disease	Heart failure, ischaemic heart disease, cardiomyopathy, valvular disease, advanced vascular disease, often long term conditions with unpredictable deterioration	Symptom control (breathlessness, fatigue, anxiety), support with uncertainty and fluctuating prognosis, ACP and ReSPECT discussions, coordination between primary care, cardiology and palliative services, crisis prevention and rapid response, bereavement support
Respiratory disease	COPD, interstitial lung disease, pulmonary fibrosis, severe asthma, bronchiectasis, often progressive with acute exacerbations	Management of breathlessness and anxiety, oxygen and non pharmacological support, early palliative care involvement, anticipatory care planning, support during acute exacerbations, carer education, coordination between respiratory, community and palliative teams.
Neurodegenerative and neurological conditions	Dementia (all types), Parkinson's disease, motor neurone disease (MND), multiple sclerosis, stroke with severe disability	Long term holistic support, symptom management (pain, swallowing, communication), decision making support for patients lacking capacity, ACP and best interest decision processes, support with behavioural and psychological symptoms, carer strain management, EoL care in care homes and community settings.
Frailty and/or multi morbidity	Older adults with multiple long term conditions, functional decline, recurrent falls, sarcopenia, cognitive impairment	Proactive identification of declining health, person-centred goal setting, ACP and coordination across services, prevention of unnecessary hospital admissions, support at home and in care homes, carer support,

Condition group	Range of conditions and illnesses	PEoLC needs
		recognition of EoL despite absence of a single diagnosis.
Liver disease	Cirrhosis, alcohol related liver disease, viral hepatitis related liver failure, hepatic cancer	Complex symptom burden, management of encephalopathy and ascites, psychological and social support (including stigma), coordination between hepatology and palliative care, ACP in the context of uncertain trajectory, carer and bereavement support.
Children and young people with life-limiting conditions	Congenital conditions, genetic and metabolic disorders, childhood cancers, severe neurological disability	Family centred care, symptom management appropriate to age and development, emotional and psychosocial support for the whole family, education and transition planning, respite care, bereavement care before and after death.

While cancer historically dominated palliative care provision, national evidence now clearly shows that noncancer conditions account for most deaths, and yet these remain less likely to trigger timely identification, planning, or referral to specialist palliative care. Dementia is often not recognised as a terminal condition, leading to late or absent EoL discussions, reduced autonomy, and poorer outcomes (18).

Patient and public expressed PEoLC need

National surveys (56,57) consistently highlight a gap between what people say they want at the end of life, comfort, dignity, support, choice, and, where possible, to die at home, and what many actually experience. This includes higher levels of hospital use in the final months of life than may be desired, alongside significant unmet psychological and social needs.

The DueCare project's definition of 'unmet need':

> Unmet palliative care needs are present when a person with a life-limiting illness has symptoms, psychosocial concerns, or care requirements that are not adequately addressed through available services, with inability to access or receive person-centred care.

In 2023, a survey of bereaved family carers in England and Wales commissioned by Marie Curie gathered insights on the care received by the person who died(55). The unmet

need definition above was used to analyse the survey results and someone was considered to have unmet palliative care needs if they had both:

- unaddressed symptoms and concerns – measured using the internationally used Integrated Palliative Care Outcome Scale.

and

- insufficient access to GP support – based on what bereaved family members reported.

Researchers applied the survey findings to national mortality data for England in the same year (536,311 deaths). The results reveal the scale of the issue:

46% – around 248,000 people – had unaddressed symptoms and concerns.

46% – around 245,000 people – lacked sufficient access to GP support.

32% – around 170,000 people – experienced both, meaning they had unmet need.

Findings show that almost one in three people each year die with unaddressed symptoms and concerns, in pain or distress and with little or no access to GP support, despite evidence that the right care would help them. Without action to improve care, the situation will get worse; unmet palliative care need is expected to rise by 21% over the next 25 years. This means that by 2050, over 212,000 people each year in England could die without the care they need (58)

Economic cost of PEoLC

National modelling estimates that public expenditure in the final year of life is approximately £22 billion per year (59). Of this:

- £11.7 billion (53%) is spent on healthcare, £18,020 per person who died.
- Around 81% of healthcare spend is on hospital care.
- 56% (£6.6 billion) is spent specifically on emergency hospital services.

Therefore, for every £5 of healthcare spend, £4 was spent in hospital, with £2.80 spent on emergency hospital care.

- 11% (£1.3 billion) of healthcare spending goes to primary and community care.
- Less than 4% (£414 million) is spent on hospice care.

Over half of people attend A&E at least once in their final three months, generating an estimated £307 million in A&E costs alone in the last year of life. The UK therefore spends five times more on hospital inpatient care than on community and hospice services combined, despite strong public preference for community-based care.

Where economic evaluations have been completed (60) they demonstrate that ACP and palliative care programmes can:

- Reduce avoidable emergency admissions.
- Shorten length of stay.
- Improve quality of life.
- Deliver better value for money.

However, there is need to ensure that the innovation happening to improve EoL care has robust evidence to prove it works and has economic benefits for healthcare systems (61). There is both an economic and ethical case for shifting investment away from reactive hospital-based care towards proactive, community centred models.

Protected characteristics and inclusion health groups

National evidence consistently shows unequal access to and experience of PEoLC across multiple protected characteristics and inclusion groups. The recent Expert Panel Evaluation of Palliative care in England outlines

> 'Persistent inequities continue to shape the experiences of people from vulnerable groups and those with protected characteristics in PEoLC. These individuals often face poorer access to services, lower quality of care, and worse outcomes compared to the general population. Across all four focus areas of our evaluation, this issue consistently emerged as a central concern, highlighting a deeply embedded challenge within the system.'(62)

Race & ethnicity

There are persisting inequities in the provision and delivery of PEoLC services for ethnic minorities, in particular for South Asian, African and Caribbean communities, with national publications reporting, discrimination, poor communication, and a lack of culturally appropriate care (62). Studies and service use data highlight that older people from minority ethnic groups experience inequalities and have a range of preferences and experience specific barriers to accessing PEoLC. Key themes in the literature relate to their knowledge of hospice and palliative care, societal and structural issues, language and health literacy, migratory experiences, trust in healthcare services and professionals, religion and hope, and cultural values (63,64). Data also shows lower rates of palliative care registration and higher emergency service use at EoL (64). Better data collection is required for this group (65). Religious and faith-based needs are outlined separately within this document.

Children, young people and babies

Children and young people represent a particularly vulnerable and underserved group in palliative and EoL care, with significant variation in how services are planned, funded, and delivered depending on where they live. Most child deaths occur in hospital, and many do not access palliative care services due to a lack of awareness among professionals, limited referrals, and perceptions that services may not meet their needs. Additionally, a significant proportion of children experiencing EoL care face multiple health inequalities, including disability, socioeconomic disadvantage, and barriers related to language or mental health, highlighting the need for more equitable, accessible, and coordinated support.(62)

Older adults

There is evidence to suggest that older patients (aged 70 and over) have more untreated pain, less access to generalist and specialist palliative care, and greater information needs than younger patients. In older people, the early indicators of palliative care need may be less clearly defined, which can make it more challenging to identify individuals who may benefit from palliative care and to initiate timely referral. The lack of a clear diagnosis of dying and the association of palliative care with cancer also hinders older people's access to good end-of-life care. More efforts should be made to identify older patients who would benefit from a palliative care approach in all settings.

Gender

Quantitative analysis of routinely collected data from more than 90,000 patients receiving hospice and community nursing services across the United Kingdom between January 2019 and December 2022 found limited differences in access to care or service utilisation by gender. However, qualitative evidence suggests that experiences of palliative care may vary between sexes and genders, highlighting potential differences in how care is perceived and experienced (66). Evidence also suggests men may be more likely to prefer dying at home, while women in the community may be less likely to achieve their preferred place of death, although more evidence is needed. Gender may influence how people seek, access, and accept care, with men often perceived as less likely to engage proactively as patients or carers. Unpaid caring responsibilities tend to fall more heavily on women, while men in caring roles may be less likely to seek support. Staff also report some uncertainty about asking about gender identity and pronouns, and these issues may be shaped further by age, deprivation, and rurality.(67)

Sexual orientation / Transgender

Evidence suggests LGBTQ+ people approaching the EoL have distinct and complex needs shaped by lifelong experiences of discrimination, stigma and exclusion, which can result

in distrust of healthcare services and delayed or avoided access to care (62).Evidence consistently states that LGBTQ+ people want safe, inclusive and affirming environments where their sexual orientation and gender identity are respected, and where assumptions about relationships, identities and family structures are avoided. A key need is the recognition of chosen family and support networks in care planning and decision making alongside early and proactive engagement with services to reduce inequalities in access. Care must be personalised and responsive to the diversity within LGBTQ+ communities, acknowledging intersecting identities rather than treating individuals as a homogeneous group. There is also a strong need for culturally competent, confident healthcare professionals who can communicate sensitively and build trust, supported by ongoing training and organisational commitment to addressing heteronormative cultures. Advance care planning is particularly important to ensure preferences, identities and decision-making roles are respected. In addition, LGBTQ+ individuals may require enhanced emotional, psychosocial and spiritual support, particularly in relation to fears about discrimination, isolation, and how their identity will be recognised in death and bereavement.(68)

Learning and intellectual disabilities

Evidence shows that health inequalities linked to disability, significantly affect the quality and accessibility of PEoLC. Individuals living with one or multiple disabilities often face delays in diagnosis and treatment, especially in PEoLC. Health and social care staff often lack the relevant training to identify when a person's health is deteriorating, leading to missed opportunities for timely intervention.

People with learning disabilities at the EoL have a range of interconnected needs centred on communication, autonomy, relationships and equitable access to care. They require clear, accessible and tailored communication to understand their condition and express preferences, alongside support to participate fully in decision making and advance care planning, ensuring their wishes are respected. (69)

Maintaining strong relationships with family, carers and trusted supporters is essential for emotional support and advocacy. They also have complex physical, psychosocial and spiritual needs, which require skilled assessment and careful symptom management, particularly given challenges such as communication difficulties and diagnostic overshadowing. There is a critical need for person-centred , individualised care that treats each person with dignity and recognises their unique preferences, as well as improved access to timely palliative care, as people with learning disabilities are often identified late or experience inequalities in service provision. Finally, individuals with learning disabilities benefit from care delivered in familiar environments with continuity, comfort and routine, supported by trained professionals and coordinated services to ensure high quality, inclusive and equitable EoLC.(70)

People with sensory loss

People with sensory loss (including hearing and/or vision impairment) at the EoL have distinct needs primarily centred on communication, access to information, emotional wellbeing and safe, person-centred care. A key need is for clear, accessible and adapted communication, as sensory impairments can significantly hinder understanding, expression of needs, and participation in key conversations about care, leading to misunderstanding, uncertainty and poorer care decisions. This includes providing information in formats that individuals can access (e.g. verbal explanations, written, audio or visual aids), checking understanding, and creating quiet, calm environments that support effective interaction (71).People with sensory loss also need support to fully engage in decision-making and express preferences, as communication barriers can otherwise limit autonomy and involvement in care planning.(72)

Religion / belief

People from different faith backgrounds approaching the EoL have a range of spiritual, cultural and practical needs that should be recognised to ensure person-centred and dignified care. Across faiths, there is a common need for spiritual support, including access to prayer, sacred texts, and faith leaders, as religious beliefs often become more important at this stage of life and provide comfort to individuals and families. Many require the opportunity to undertake specific EoL rituals, such as last rites, chanting, or recitation, and may need a quiet, respectful environment to do so. There is also a significant need to involve family and community members, as collective decision making, presence at the bedside, and support networks are often central within many faith traditions. (73)

Practical care needs vary by faith but commonly include dietary requirements, modesty considerations, and gender sensitive care, as well as respect for religious symbols or items. As death approaches, individuals may have preferences relating to positioning of the body, timing of death rituals, and the handling of the body after death, including washing, preparation and burial practices, which may need to occur quickly or follow specific religious rules. For example, some faiths prioritise rapid burial, while others emphasise ritual cleansing or prayers immediately after death. There is also a need for clear, sensitive communication that acknowledges beliefs about dying, the afterlife and suffering, and supports individuals to align care decisions with their faith.

Table 5: Major religions and EoL needs, summarised from faith at EoL: a resource for professionals, providers and commissioners working in communities.

Faith	Perception of Death	Key EoL needs
Christianity	Death is a transition to eternal life; importance of forgiveness and reconciliation	Access to prayer and pastoral care; sacraments (e.g. Last Rites); presence of family; respectful handling of the body
Islam	Death is part of Allah's will; life is temporary and followed by judgement	Facing Mecca; recitation of the Shahada; modesty and same gender care; quick burial; ritual washing of the body
Hinduism	Death is part of a cycle of rebirth (samsara); aim is peaceful transition for the soul	Prayer and chanting (mantras); family presence; minimal disturbance; ritual washing and cremation practices
Sikhism	Death is seen as a natural process and union with God's will (Waheguru)	Prayer (reading of scriptures); calm environment; family involvement; no excessive mourning rituals
Judaism	Life is sacred; death leads to an afterlife, but preserving life is a priority	Continuous presence (not leaving person alone); prayers; no unnecessary intervention; rapid burial; careful handling of the body
Buddhism	Death is a transition in the cycle of rebirth; mental state at death is important	Quiet, calm environment; meditation and chanting; minimal disturbance at time of death; respect for body after death

Post death practices may vary according to faith, culture and religion (and personal beliefs and family preferences). These differences can affect the urgency of death certification, release of the body, burial or cremation arrangements, religious rituals, family involvement and bereavement support needs. Health and care services should ensure staff have appropriate cultural competence and systems are sufficiently flexible to accommodate diverse needs.

Informal and unpaid carers

Informal and unpaid carers supporting individuals at the EoL have a set of clear and consistent needs across multiple domains, reflecting the complexity and intensity of

their role. They require timely, accessible information and communication about the person's condition, care tasks, and what to expect, alongside clear coordination and a named professional contact, as carers are often left to navigate fragmented systems themselves.(74–76) There is a strong need for practical support, including help with hands-on care, access to equipment, respite opportunities, and reliable 24/7 services, particularly as many carers provide high-intensity care over long periods without breaks.

Carers also have substantial emotional and psychological needs, including support to manage stress, anxiety, and anticipatory grief, as well as access to counselling and bereavement services before and after death.(62,77) Maintaining carers' own health and wellbeing is critical, as caring roles frequently lead to physical exhaustion and declining mental health, which can undermine their ability to continue providing care. Financial need is also significant, with carers requiring income protection, employment flexibility, and financial support, as caregiving often results in loss of earnings and additional costs, sometimes leading to poverty during and after the caring period.

There is a clear need for carers to be recognised, assessed, and included as partners in care, with dedicated assessment of their own needs rather than being viewed solely in relation to the patient. In addition, many carers require training and skill development to feel confident managing complex medical and care tasks, as they are frequently unprepared for the role.

People experiencing poverty

People experiencing poverty at the EoL in England have complex and often unmet needs, shaped by the interaction of financial insecurity, health inequalities, and barriers to accessing care. Marie Curie's research highlights that a terminal diagnosis frequently results in a sudden loss of income alongside rising costs, including increased spending on heating, transport, and medical equipment, creating significant instability at a time when security is critical. This financial strain can force individuals to make difficult choices, such as reducing spending on food, heating, or care, which can negatively impact their quality of life and health.

People living in poverty are also more likely to experience inequalities in access to PEoLC including reduced ability to die at home, lower engagement with hospice services, and poorer overall outcomes. Structural factors such as inadequate welfare support, insecure housing, and higher living costs compound these challenges, while fuel poverty is a particularly critical issue, with many people unable to afford adequate heating or the electricity required to run essential medical equipment. Poverty at the EoL is associated with psychosocial impacts, including stress, anxiety, and reduced ability to focus on relationships, care planning, and personal priorities. These challenges disproportionately affect certain groups, including working-age adults, women, and people from minoritised ethnic backgrounds, reflecting wider social inequalities across the life course.

Prison population

The prison population in England have significant and often unmet PEoLC needs, driven largely by an ageing population, high levels of frailty, and complex health and social circumstances.

The British Geriatrics Society highlights that prisoners experience accelerated ageing (around 10 years earlier than the general population) and high levels of frailty, with many living with multiple health conditions in environments that are not designed to meet their needs, such as limited accessibility for mobility aids and long distances to healthcare facilities. As a result, deaths from natural causes in custody are increasing, and many individuals will require EoL care within prison rather than being released, often due to lack of external support or ineligibility for compassionate release.

The NHS England Dying Well in Custody Charter emphasises that people in custody should receive equitable, person-centred and coordinated care, but recognises that delivering this is particularly challenging in a custodial environment. Barriers include restrictions on family involvement, the tension between security and care, and the need for multidisciplinary coordination across prison, healthcare, and external services. The Charter highlights the importance of maintaining dignity, ensuring access to care equivalent to the community, and supporting families and staff, who are often overlooked in prison-based EoL care.

Evidence from Marie Curie supported research further demonstrates that prisoners with life-limiting illness often experience unmet palliative care needs, including difficulty accessing timely care, limited availability of 24/7 health and social care, and challenges in symptom control and medication access within prison regimes. The prison environment, including fixed routines and overnight lockdown, can restrict the flexibility needed to provide responsive, person-centred care, while staff may lack confidence or specialist training in palliative care delivery.

Workforce challenges and needs in PEoLC.

The UK Parliament report, Evaluation of Palliative care in England (62) states:

1. the health and social care workforce is ill-equipped to meet the needs of people at the EoL because of the insufficient provision of education and training.
2. The specialist palliative care workforce is in a critical situation and there are additional workforce shortages across the generalist workforce.
3. Children and young people's PEoLC services have serious workforce shortages, including social care shortages.

The following table aims to summarise some of the specific barriers, challenges and needs of the workforce that are outlined in the published literature and reports.

Table 6 Key challenges and barriers experienced by the workforce and their needs

Profession / Workforce Group	Key challenges, barriers and needs
General Practitioners (GPs)	• Limited resources and workforce pressures reduce GPs' ability to deliver palliative care effectively • Fragmented multidisciplinary working, with poor coordination across services • Challenges in communication with patients and carers, particularly around EoL discussions • Gaps in GP training to manage the complexity of palliative care needs • Difficulty accessing specialist palliative care teams, creating delays in support • Low patient awareness or reluctance to engage in advance care and EoL conversations (78)
Community Pharmacy	• Delays in accessing medicines due to limited stock and national supply issues • Poor communication between services, leading to inefficiencies and delays in care • Limited training and experience in palliative care among pharmacists • Logistical barriers such as no NHS commissioned delivery service and reliance on patients/carers to collect medicines • Lack of shared patient information restricting pharmacists' ability to provide tailored support • Variation in service provision, creating inequitable access across different areas (79)
Care Home Staff (including nurses and care workers)	• Workforce pressures, limited training, and lack of specialist support • Fragmented system with poor integration across services • Limited early identification and advance care planning • Inequitable access and variation in quality of care • Increasing complexity of residents (frailty, dementia, multi-morbidity) • Uncontrolled symptoms and avoidable hospital admissions • Funding and commissioning gaps across the system

Profession / Workforce Group	Key challenges, barriers and needs
Community Nurses (District Nurses)	• Rising demand and increasing complexity of EoL care for people dying at home • Need for rapid role evolution and advanced expertise among community health nurses • Requirement for effective coordination and integration with multiple services and providers • Impact on staff wellbeing and morale due to workload pressures and complexity • Need for enhanced training and recognition of evolving roles in palliative care • Limited understanding of safe caseloads for community health nurses • Lack of robust data on the scale and scope of PEoLC delivered
Social Workers	• Emotional burden and risk of burnout • Resource constraints limiting support • Ethical and cultural challenges in care decisions • Increasing complexity of patient and family needs • Under-recognition within multidisciplinary teams • Need for enhanced training and professional support
Nurses (acute, community and hospice care around the UK)	Nursing Standard-Marie Curie survey. A survey of 5,346 UK nurses and healthcare assistants results: • Safe staffing levels and protected time for EoL care • Better emotional and psychological support for nurses • Improved integration and continuity across services • Expanded community care capacity • Faster access to discharge, equipment, and funding processes • Ongoing training to manage complexity and emotional burden

Population profile summaries

Each ‘Place’ (Unitary, or County Council) District, Borough, City, and Integrated Community / Neighbourhood Team within Sussex has its own unique identity,

demographic and health profile. Further detailed information at specific localities can be viewed at:

- Brighton and Hove City Council Joint Strategic Needs Assessment (JSNA)
- East Sussex County Council East Sussex in Figures – Data Observatory – JSNA
- West Sussex County Council West Sussex County Council

Sussex is a relatively affluent region, but it also has pockets of significant deprivation particularly along the coast. People living in deprived circumstances may experience poor housing, low incomes, a lack of access to good food and places to exercise, and a sense of social isolation (80). These factors, which are the building blocks of health, often have a negative influence on people's health choices and outcomes, with smoking, alcohol misuse, obesity and poor mental health more likely.

This in turn increases the risk of them developing long term conditions and reduces their life expectancy. We call these influences the 'social determinants of health' and their impact on individuals and communities that experience these 'health inequalities,'. These factors influence PEoLC too.

The population of the whole of Sussex, including East Sussex, West Sussex and Brighton and Hove was 1,759,789 in mid-2024. The population of the Sussex grew by 1.0% over the year and was 6.8% higher than in 2014. Over the decade, growth in East Sussex at 4.3% was lower than in West Sussex (9.7%), but higher than in Brighton and Hove (2.9%). West Sussex grew faster than England as a whole (7.8%) and the South East region (8.4%) in the 10 years from 2014 to 2024, and at the same rate as England and the South East in the year from 2023 (1.2%). (9)

Sussex demonstrates significant rural variation, with Rother classified as majority rural (52% of the population in rural output areas) and Wealden in East Sussex as intermediate rural (36%), alongside more urban coastal centres such as Brighton & Hove, Eastbourne and Hastings (all 0%). In West Sussex, the 2021 Rural Urban Classification shows a similarly dispersed geography, with 81% of land area classified as rural, 19.8% of the population living in rural areas, and districts such as Chichester (50%) and Horsham (52%) categorised as majority rural, while others such as Adur, Crawley and Worthing remain predominantly urban (0%). Across Sussex, intermediate areas such as Lewes (21%) and Mid Sussex (19%) illustrate mixed rural–urban populations. This combination of rurality and ageing creates challenges for equitable access to palliative and EoL care, as residents in rural areas are more likely to experience greater travel distances, reduced service availability, and increased reliance on community and informal care.

In relation to PEoLC, parts of coastal East and West Sussex have populations affected by deprivation, with Hastings now ranked third most deprived Local Authority District based on rank in England (8). Other coastal areas have large populations of older people residing in care homes. Rother has the second highest proportion of people aged 65 and over (32.5%), and aged 85 and over (4.9%) of all local authorities in England. At 53.7

years, Rother has the third highest median age of all districts/UAs. It has the highest median age out of all Sussex districts and unitary authorities (9).

Brighton and Hove has a younger population compared to its neighbours, however it has a significantly more diverse LGBTQ+ population. A total of 25,250 people (11%) said that their sexual orientation was LGB; this is higher than England and the Southeast (both 3%) (34). Crawley is the most ethnically diverse area, with 38.2% of the population identifying as a minority ethnicity in 2021 (up from 27.9% recorded in the 2011 Census). The most common minority ethnicities in Crawley were Asian or Asian British ethnicities (15.4%, equivalent to around 18,200 people), followed by the Other White ethnicity (82).

Understanding the population and the demography of Sussex, particularly its diversity, is very important as LGBTQ+, ethnic minorities, older people and those that experience social and economic disadvantage may experience inequalities relating to PEoLC.(18)

A range of resources, related needs assessments and reports have been produced for Sussex linked to protected characteristics, geography, and inclusion health groups which should be read alongside this NA.

These include:

3. Black and Minority Ethnic Needs Assessment - West Sussex JSNA Website
4. East Sussex in Figures – Data Observatory – JSNA – JSNA: Lesbian Gay Bisexual Trans Queer + (LGBTQ+) Needs Assessment 2021
5. Deaths of people with a homelessness or housing support need in West Sussex - West Sussex JSNA Website
6. Health and Wellbeing of West Sussex Coastal Communities - West Sussex JSNA Website
7. East Sussex in Figures – Data Observatory – JSNA – JSNA: Postcards from the coast 2024/25
8. Health Counts
9. Brighton & Hove Joint Health and Wellbeing Strategy 2019 to 2030
10. Healthy people: Dying well

Chapter 2 Babies, Children and Young People's Palliative and End of Life Care

Key takeaways

A growing number of CYP are living longer with life-limiting conditions, requiring long-term, complex, and multidisciplinary palliative care support.

There is significant variation in provision with gaps in 24/7 and community care, workforce capacity, and coordinated care.

Child mortality and access to care are strongly influenced by deprivation and ethnicity, with worse outcomes for disadvantaged and marginalised groups.

Sussex hospices show high levels of activity and long-term care needs, and bereavement support for families.

Key issues include the need for earlier referral from primary care, better coordination across services, improved transitions to adult care, sustainable funding (especially for hospices and community services), and stronger bereavement support pathways.

National overview for children and young people (CYP) PEoLC

NHS England state there are over 85,000 children and young people (CYP) with life-limiting and life-threatening conditions who could benefit from palliative care. In England, the number of children and young people with life-limiting or life-threatening conditions almost trebled over 17 years, from 32,975 in 2001/02 to 86,625 in 2017/18.(83)

Prevalence increased from 26.7 per 10,000 in 2001/02 to 66.4 per 10,000 in 2017/18. Prevalence is higher in boys than girls, highest for congenital abnormalities, and greatest in babies under 1 year, where deaths are also highest.

More young people with life-limiting conditions are surviving to age 19, rising from 921 in 2001/02 to 3,075 in 2017/18, with many deaths occurring in the early 20s.

Prevalence is highest among the most deprived groups, who are least able to afford the financial burden of caring for a child with complex needs.

Prevalence is increasing across all English regions, by 2030, the number of children with life-limiting conditions is projected to rise from 95,000 to 97,000, an 10-12% increase from the 86,625 in 2017/2018.

CYP requiring palliative care have complex and often long-term needs arising from life-limiting and life-threatening conditions, including cancer, severe neurological and neurodegenerative disorders, congenital abnormalities, genetic conditions, and complex multi-system illnesses that may extend from infancy into young adulthood.

Evidence presented to parliament highlights that these children often require holistic, multidisciplinary support over many years, with fluctuating and unpredictable trajectories that demand continuous symptom management, psychosocial support, and coordinated care across hospital, community and hospice settings. However, nationally, access to appropriate services is highly variable, with significant gaps in the availability of 24/7 community-based care, specialist workforce capacity, and coordinated commissioning, resulting in many families being unable to access timely, consistent support at home or in their preferred setting. The report emphasises a 'postcode lottery' in provision, driven by underfunding, workforce shortages, and inconsistent service planning, alongside weaknesses in social care integration and data systems that hinder early identification and continuity of care.(84)

These challenges are further compounded by inequalities affecting disadvantaged and marginalised groups, including those experiencing poverty, social exclusion, or cultural barriers, who are less likely to access high-quality, culturally appropriate palliative care and bereavement support.

The NCMD Child Death Review Data Release 2025 shows that child mortality in England remains relatively stable but above pre-pandemic levels, with 3,492 deaths among children aged 0–17 years in the year ending March 2025. (85)

Deaths are heavily concentrated in infancy, which accounts for around 61% of all deaths, highlighting the critical importance of the perinatal and neonatal period as the highest-risk stage of life. (85)

A defining feature of the national picture is persistent and marked inequality. Mortality rates are more than double for children from Black and Asian ethnic groups compared to White children, and higher in the most deprived areas compared to the least deprived, with clear variation also observed across regions. These inequalities are longstanding and indicate that wider determinants of health including poverty, maternal health, and access to services are key drivers of risk. (85)

In terms of causes, perinatal and neonatal conditions (e.g. prematurity and birth complications) represent the largest contributor to deaths, followed by congenital anomalies and genetic conditions, particularly in infancy. A significant proportion of children who die also have life-limiting or complex health conditions, requiring coordinated palliative care, while acute illnesses (such as infections) and external causes in older children (including injury) are also important contributors. Notably, around 48% of deaths include modifiable factors, such as delays in accessing care,

maternal health issues, and system coordination failures, indicating substantial scope for prevention through improved services and public health action.

CYP PEoLC Services in Sussex are delivered through a multi-agency system spanning hospice, community, and acute settings. These services provide support across the full trajectory of illness, from diagnosis and ongoing management through to EoLC and bereavement support for families.

Sussex children and young people hospices

This section draws on hospice activity data across Sussex to examine the activity, characteristics of the population receiving care, and patterns of service use across the care pathway.

The following data pools activity data from CYP Hospice services. The three hospices have distinct services and are based in different parts of Sussex, however the majority of the activity relates to Chestnut Tree House.

Southern Hospice Group, made up of three hospices; **Chestnut Tree House** children's hospice near Arundel, Martlets adult hospice in Hove and St Barnabas House adult hospice in Worthing. Chestnut Tree House is also commissioned to provide COAST (Children's Outreach and Symptom Team).

COAST (Children's Outreach and Symptom Team) is a service delivered by Southern Hospice Group, based out of Chestnut Tree House, providing specialist 24/7 consultant led paediatric palliative and end of life care for babies, children, young people and their families across East and West Sussex. Following a successful proof of concept, Southern Hospice Group was directly awarded a five-year contract by NHS Surrey & Sussex ICB, to expand COAST, including the provision of a 24/7 service.

As part of this service, Demelza has contributed, via secondment, an experienced Children's Palliative Care Nurse into the COAST service as a Clinical Nurse Specialist for 30 hours per week. This role will be key to the development and mobilisation of the service, meeting the increasing demand and complexity of babies, children, young people and their families across Sussex.

Demelza provides clinical care and wraparound support for children and young people with serious or life-limiting conditions, and their families. Demelza East Sussex delivers hospice care at home, with therapies, short breaks and a community hub in St Leonards for children and families.

Naomi House and Jacks Place is a local independent charity that provides expert care for seriously ill children, young adults and their families across central southern England. They provide specialist care and short breaks (respite), play and activities, therapeutic support, end of life care and bereavement support.

The following data from all three CYP Hospice services covered the time period from the 1 April 2022 to 31 March 2025. Data related to patients that either have a GP or residential postcode in Sussex. Noting Demelza and Naomi House and Jacks Place also provide services to neighbouring populations.

Hospice in the Weald, based in Kent, confirmed a single young adult on their caseload from East Sussex within the time period stated below. They had an East Sussex address and Kent based GP. They are excluded from the data analysis below.

Referrals to Sussex CYP hospices

During the reporting period, Sussex CYP hospices accepted 216 new external referrals for specialist paediatric PEoLC including 25 urgent cases, indicating a sustained level of demand for both routine and urgent support.

In addition, hospices provided bereavement-related support through:

- 9 referrals for physical care of the deceased child, and.
- 22 referrals for bereavement support to families and carers, highlighting the role of hospices in both EoL and post-death care pathways.

These measures count referrals activity, not individual patients or family members. A single patient or family may therefore be counted more than once if they are referred for more than one type of support.

Table 7 Referrals that were accepted by Sussex CYP Hospices April 2022 to 31 March 2025

Referrals accepted	Number	% of total
All new external referrals for specialist paediatric palliative and EoL care	216	79.4%
New external referrals for specialist paediatric palliative and EoL care that are urgent	25	9.2%
New external referral for bereavement care for physical care of the deceased child/body	9	3.3%
New external referrals for bereavement care for families and carers post death of baby, child or young person	22	8.1%
Total	272	100.0%

The number of new external referrals that were not accepted by hospice services during the reporting period, categorised by referral type and purpose.

Table 8 Referrals that were rejected by Sussex CYP Hospices April 2022 to March 2025

Referrals (rejected)	**Number**
All new external referrals for specialist paediatric palliative and EoL care	78
New external referrals for specialist paediatric palliative and EoL care that are urgent	'Very few'
New external referral for bereavement care for physical care of the deceased child/body	0
New external referrals for bereavement care for families and carers post death of baby, child or young person	0

Chestnut Tree House and COAST reported that referrals for children requiring EoL care are not declined. Where a child is approaching the EoL, services work with the child, family and wider professional network to ensure that appropriate specialist palliative and EoL support is provided. This may be delivered directly through Chestnut Tree House or COAST, or in partnership with other services where this best meets the child and family's needs.

No referrals were rejected by Naomi House and Jacks Place during the period.

However, 78 referrals for specialist paediatric palliative care were not accepted. Where a referral may not be accepted into a specific service, this may occur where the child does not meet the service's eligibility criteria, where the referral does not require specialist palliative care input, where the service is not the most appropriate provider for the identified need, or where the requested intervention falls outside the remit of Chestnut Tree House or Demelza. In these circumstances, the service seeks to work with the referrer and family to identify appropriate alternative support rather than simply turning the child or family away.

Examples of referrals not accepted into specialist services included:

- Being out of area.

- children and young people whose current needs did not meet the threshold for specialist input, or
- whose conditions were clinically stable and being managed without significant involvement from specialist healthcare services.

In some cases, there was no evidence of a life-limiting or life-shortening condition requiring specialist support. These decisions reflected the child's current level of need, and re-referral would be appropriate should their condition deteriorate or their care needs change.

Notably, urgent needs are prioritised and accommodated. No bereavement referrals were rejected, suggesting good access to bereavement support services.

Current capacity reflects what can be safely and sustainably provided within existing resources, which are largely dependent on voluntary income from donors.

Sussex CYP hospices service activity

The majority of hospice activity focused on community nursing (over 12,000 contacts), counselling support (over 3,200 contacts), and family support, highlighting the breadth of ongoing care provided to children and families beyond EoL care. in-house activity included 1,672 respite admissions, while EoL admissions are relatively low (15), reflecting the small number of deaths and the longer-term nature of many conditions. This is reinforced by duration data, which shows that most children are supported for more than two years, indicating that palliative care is often delivered over extended periods rather than just at EoL for CYP.

35 deaths occurred in hospice inpatient units, with a relatively short average stay of around 5 days, suggesting inpatient hospice involvement in providing end of life support is often concentrated in the final phase of life. Bereavement support is also a key component of care, including In-house bereavement nights for physical care of the deceased child/body and new referrals for families, demonstrating continued support after death.

Table 9 Breakdown of support provided by CYP hospices. April 2022 to March 2025

Type and mode of care/support delivered	Activity count	% of total activity
Activity (FTF, telephone contact) community nursing team	12,036	59.9%
Activity (FTF contact) in-house nursing support	1,760	8.8%

Activity (FTF, telephone contact) family support work	2,409	12.0%
Activity (FTF, telephone contact) specialist palliative and EoL care	205	1.0%
Activity (FTF contact, telephone contact) therapies	294	1.5%
Activity (FTF, telephone contact) counselling support	3,242	16.1%
Activity (FTF contact, telephone contact, email) pharmacist support	0	0.0%
Activity (FTF contact, telephone contact) safeguarding/place of safety/emergency	147	0.7%
Total	20,093	100.0%

Table 10 In house clinical care activity provided by Sussex CYP hospices. April 2022 to March 2025

Type and mode of care/support delivered	Activity count	% of total activity
In-house admission for respite care/break	1,672	88.6%
In-house admissions for end-of-life care	15	0.8%
In-house admissions for step down care	0	0.0%
FTF contact with NHS Hospital providers	67	3.5%
FTF contact perinatal team into NHS providers	0	0.0%
In-house bereavement nights for physical care of the deceased child/body	122	6.5%
New in-house referrals for bereavement care for families and carers post death of baby, child or young person	9	0.5%

Type and mode of care/support delivered	Activity count	% of total activity
Total	1,885	100.0%

There were less than 5 episodes of in-house admissions for specialist symptom control over the period.

Table 11 Duration of care for a patient of Sussex CYP hospices. April 2022 to March 2025.

These measures describe the total length of time an individual patient is supported by hospice services, calculated from the start of the patient's first referral or engagement with the hospice to their final discharge or death within the reporting period.

Each patient is counted once, based on their overall length of contact with hospice services.

Duration category	Number of patients	% of total patients
Up to 1 month	40	7.3%
From 1 month up to 6 months	41	7.5%
From 6 up to 12 months	46	8.4%
From 1 year to 2 years	72	13.1%
More than 2 years	351	63.8%
Total	550	100.0%

These measures describe deaths and patterns of care for patients admitted to a hospice inpatient unit.

Table 12 Death location of patients of Sussex CYP Hospices. April 2022 to March 2025

Measure	Count / Value
Number of deaths in hospice in-patient unit	35
Average length of stay before death (days)	5.43

There were less than five patients admitted for EoL but subsequently discharged from a hospice. Deaths may include people admitted under another category or during a different part of the care pathway.

Usual or temporary residence under the current care of hospice community teams.

Table 13 Death Location - Community (usual or temporary residence) under the current care of hospice community teams. April 2022 to March 2025.

Measure	Count / value
Number of deaths in community under 1 year of age	5
Number of deaths in community over 1 year of age	44
Total count-based outcomes	49
Average episodes of care in the community for EoL from first on-call to last on-call contact	18

There were less than 5 patients receiving community EoL care who subsequently did not die within the reporting period.

Sussex CYP bereavement support

Bereavement support forms a core component of the CYP PEoLC. Services provide both support to families newly referred, including those not previously known to services, and continued support following the death of a child. This includes counselling, family support interventions, and hospice-based bereavement care. The scale and intensity of provision are substantial, with large active caseloads and multiple contacts per family over extended periods. Bereavement care is therefore both long-term and resource intensive.

Table 14 Bereavement support activities provided by Sussex CYP hospices. April 2022 to March 2025.

Measure	Count / value
Number of new referrals for bereavement support, including accepted and not accepted referrals	22

Measure	Count / value
Number of bereavement support packages that are a continuation of care following the death of a patient receiving care from the hospice	133
Number of open referrals / episodes of bereavement support accepted and receiving interventions	89
Number of closed bereavement support referrals accepted but no longer receiving interventions	12
Total number of people receiving bereavement support during this time period	392
Average contacts per bereaved child/family per year, including FTF, telephone and virtual contacts, excluding admin or emails	33

Population and health characteristics of Sussex CYP hospice patients

The CYP population receiving PEoLC in Sussex spans a wide age range, with the largest cohorts aged 5–15 years and 18–25 years. The presence of a substantial transition-age group reflects improved survival for those with complex, life-limiting conditions and highlights the need for stronger, coordinated pathways between children's and adult services to ensure continuity of care.

Male patients are more prevalent than female patients, consistent with epidemiological patterns in neurological, congenital, and genetic conditions. This reinforces the need for service planning to reflect condition-specific demand rather than assuming equal distribution across sexes.

Most CYP are recorded as White, although a high proportion of ethnicity data is unknown or not stated. This limits assessment of equitable access and raises concerns about the potential underrepresentation of minoritised ethnic groups, as well as the cultural appropriateness of care.

Clinically, the population is characterised by high complexity and multimorbidity. The most common conditions include neurological, genetic, metabolic, and congenital disorders, with cancer representing a minority. This reflects the distinct nature of CYP palliative care, where non-malignant conditions predominate and care needs are often prolonged and unpredictable.

The CYP hospice population in Sussex is dominated by children and young people with multiple or complex conditions (n=168), highlighting the high level of need and

multimorbidity. Other common diagnoses include genetic and metabolic conditions (n=35), neurological conditions (n=23), and cancer (n=28), while smaller numbers are seen with congenital, cardiac, and other conditions.

Table 15 Sex of CYP Hospices patients April 2022 to March 2025

Sex	Number
Male	185
Female	134
Total	319

Less than 5 patients had their sex recorded as Intersex / other / not recorded.

Table 16 Age group of CYP Hospices patients April 2022 to March 2025.

Age Group	Number	%
0-1 years	65	20%
2-4 years	42	13%
5-9 years	69	21%
10-15 years	91	28%
16-17 years	17	5%
18-26+ years	38	12%
Total	322	100%

Table 17 Ethnicity of CYP Hospices patients April 2022 to March 2025.

Ethnicity	Number	%
White	232	72%
Asian / Asian British	14	4%
Mixed ethnicity	10	3%

Ethnicity	Number	%
Arab, Black / Black British & Other ethnic group	8	2%
Not known / not stated	58	18%
Total	322	100%

Learning disability status was not recorded by local CYP hospices, representing a key data gap in understanding equity and need.

Each patient is counted once only, based on their diagnosis category.

Where patients have multiple conditions, they have been counted in the 'multiple' section.

Table 18 Primary diagnosis of Patients of Sussex CYP Hospice April 2022 to March 2025

Diagnosis category	Patient count	%
Cancer / malignant	28	9%
Congenital	12	4%
Genetic / metabolic	21	7%
Neurological	41	13%
Cardiac / circulatory	11	3%
Multiple / complex	168	52%
Other / Respiratory / uncoded / remaining	41	12%
Total	**322**	**100%**

Child mortality data

The National Child Mortality Database (NCMD) was launched on 1 April 2019 and collates data collected by Child Death Overview Panels (CDOPs) in England, including reviews completed of all children who die at any time after birth and before their 18th birthday. National data demonstrate that child mortality is not evenly distributed, but instead concentrated among:

- Infants,

- Ethnic minority groups,.
- Children living in deprivation, and
- Children with complex or life-limiting conditions.

These patterns reflect intersecting health inequalities, where social, economic, and service-related factors combine to increase risk. The presence of modifiable factors in many deaths further highlights significant opportunities for prevention through targeted, equity-focused action.

Across Sussex and England between 2020 and 2023, neonatal, infant, and child death rates remain broadly comparable, with only minor variation between areas. Overall patterns are relatively stable over time, with no marked divergence between Sussex and national trends. The data suggests that Sussex generally aligns with, or is slightly below, England averages across neonatal, infant, and deaths in children aged 1–17, indicating similar population health outcomes in these age groups. However, we know that average outcomes can mask significant inequalities for some groups.

Although Sussex experiences comparatively good outcomes in many areas, it remains affected by national patterns of inequality and pockets of deprivation, particularly along the coastal strip. Reducing child mortality requires a proportionate universalism approach, focusing additional support and resources on those at greatest risk while maintaining universal provision for all.

ICB Palliative EoL Dashboard – CYP Focus

The ICB Palliative EoL Care report provides an overview of the services accessed by patients during the last 90 days of life. The dashboard presents service utilisation across multiple years, enabling analysis of trends and changes in activity over time. It has been designed to allow users to tailor the focus of the report by selecting specific criteria, including Integrated Care Board (ICB), financial year, and defined sub-groups such as age group, cause of death, place of death, ethnicity, and levels of deprivation.

The tables below compare Sussex ICB to All ICBs in England for the year 2024/25. It is important to note that the total number of deaths recorded of those under 18 is different to the CDOP figures.

Table 19 Number and % of CYP deaths for Sussex ICB and All England ICBs 2024/25

Measure	**All ICBs (England)**	**Sussex ICB**
Under 18s (% of total deaths)	0.6%	0.2%
Under-18 deaths	3,108	45

Why Child Death Overview Panel (CDOP) figures are often higher than those shown in an EoL dashboard.

CDOP collects data on all live born babies (there is no lower gestation limit) and includes all children usually resident in the area, regardless of where the death has been confirmed. This will include deaths in the community, hospitals outside of the local authority area and sometimes overseas.

Differences may reflect variation in scope, inclusion criteria, coding, timing or case capture and should not be interpreted as a direct measure of unmet need without further analysis.

Table 20 Place of CYP deaths (% of total deaths) for Sussex ICB and All England ICBS 2024/25

Place of Death	All ICBs (England)	Sussex ICB
Hospital	82%	71%
Home	11%	16%
Hospice	5%	7%
Elsewhere/Other	2%	7%
Care Home	0%	0%

Percentages may not total 100% because of rounding.

Table 21 Cause of CYPs deaths (% of total deaths) for Sussex ICB and All England ICBS 2024/25

Cause of Death	All ICBs (England)	Sussex ICB
Sudden Death	54%	44%
Organ Failure	22%	24%
Other Terminal Illness	15%	24%
Cancer	8%	7%
Frailty	0%	0%

Table 22 Index of Multiple Deprivation (IMD) Quintile (% of total CYP deaths) for Sussex ICB and All England ICBS 2024/25

IMD Quintile	All ICBs (England)	Sussex ICB
20% most deprived	34.3%	20.0%
2nd quintile	22.9%	20.0%
3rd quintile	17.3%	22.2%
4th quintile	13.9%	20.0%
20% least deprived	11.6%	17.8%

Table 23 Service use in last 90 days of life (% of cohort) for Sussex ICB and All England ICBS 2024/25

Service Type	All ICBs (England)	Sussex ICB
A&E Attendances	42.1%	75.0%
A&E Emergency	40.9%	78.3%
Day Case	45.6%	75.0%
Elective Inpatient	30.6%	100.0%
Regular Day Admission	22.7%	100.0%
Outpatient First Appointment	34.1%	60.0%
Outpatient Follow-up	45.4%	70.0%

Table 24 Under 18s deaths, service utilisation within the last 90 days of death for Sussex ICB and All England ICBS 2024/25

Measure	All ICBs (England)	Sussex ICB
Average days known to services	68	63
Average contacts per person (last 90 days)	3.2	3.6

Sussex ICB represents a very small cohort compared to England as a whole (45 deaths vs 3,108), with deaths of under 18's accounting for a smaller proportion (0.2% vs 0.6%), suggesting either lower incidence or potential differences in case capture.

Percentages derived from relatively small numbers should be interpreted with caution, as they can fluctuate considerably and may exaggerate apparent differences between groups. Small sample sizes reduce reliability and make it harder to draw firm conclusions about underlying patterns or trends.

In terms of place of death, Sussex shows a lower proportion of hospital deaths (71% vs 82%) and higher proportions of deaths at home (16% vs 11%), in hospices (7% vs 5%), and in 'other' settings (7% vs 2%). These patterns warrant further investigation but should not be interpreted as evidence of service quality or unmet need without linked case-level and pathway analysis.

For cause of death, Sussex has a lower proportion of sudden deaths (44% vs 54%) and higher proportions of deaths from organ failure (24% vs 22%) and other terminal illness (24% vs 15%). This suggests a comparatively higher proportion of children with predictable, life-limiting conditions, which should allow for earlier identification and planning of palliative care needs.

The deprivation profile in Sussex differs notably, with fewer deaths among the most deprived groups (20% vs 34.3%) and more in less deprived quintiles. This could reflect the underlying population distribution but may also raise questions about equity of access and whether more deprived groups are underrepresented in service data or experience different care pathways.

However, hospital service utilisation in the last 90 days of life is substantially higher in Sussex across almost all metrics. This includes markedly higher rates of:

- A&E attendances (75% vs 42.1%).
- Emergency A&E (78.3% vs 40.9%).
- Elective inpatient and regular day admissions (both 100% vs 30.6% and 22.7%).
- Outpatient activity.

This pattern suggests that children in Sussex are experiencing higher healthcare contact and hospital-based activity at the EoL, which may indicate greater complexity of need, but also raises concerns about potential unmet need in community-based, coordinated palliative care provision. High emergency and inpatient use can signal gaps in anticipatory care planning, timely support at home, or access to 24/7 community services, leading families to rely more on hospital care.

For under 18s specifically, Sussex shows slightly fewer days known to services (63 vs 68) but more contacts per person (3.6 vs 3.2). This suggests that although children may be identified slightly later, they receive more intensive interaction once known, again pointing towards reactive rather than proactive care patterns.

The data suggests that while Sussex may be performing relatively well in enabling deaths outside of hospital, there are clear indicators of unmet need within community and palliative care pathways, including:

- High reliance on urgent and hospital-based services, suggesting insufficient community support or crisis prevention.
- Late identification of children, reducing opportunities for early planning and coordinated care.
- Potential inequities in access, particularly for more deprived populations.
- Reactive patterns of care, with high intensity of service use near death rather than sustained, anticipatory support.

Child Death Overview Panel

Between April 2024 and March 2025, the Sussex CDOP was notified of 68 deaths of children living in Sussex. This is lower than 2023/24 and the lowest since 2020/21. (31)

In 2024/25, 38% of deaths notified to Sussex CDOP were for babies younger than 28 days old, 15% for babies 28-364 days old and 16% for children aged 1-9 years old. 31% of deaths across Sussex were for young people aged 10-17 years.

The majority of deaths of children in 2024/25 occurred in hospital (63%). 24% were at home, 7% in a public place, 3% in a hospice and 3% elsewhere.

Categories of child death

During CDOP meetings, panel members categorise all child deaths by cause. Both nationally and at a Sussex level, the largest category of child death is perinatal/neonatal event (37% for Sussex, 31% England).

This is followed by chromosomal, genetic and congenital anomalies (20% for Sussex, 24% for England). Cancers are the third highest cause of death (9% for Sussex, 8% for England). (31)

Table 25 Category of death confirmed by Sussex CDOP reviews (2015/16–2024/25)

Category of death (2015/16-2024/25)	**Sussex Total no.**	**Sussex %**	**England (reviews in 2023/24)**
Perinatal/neonatal event	277	37%	31%
Chromosomal, genetic and congenital anomalies	148	20%	24%

Category of death (2015/16-2024/25)	Sussex Total no.	Sussex %	England (reviews in 2023/24)
Malignancy	68	9%	8%
Sudden unexpected, unexplained death	49	6%	8%
Trauma and other external factors, including medical/surgical complications/error	51	7%	6%
Suicide or deliberate self-inflicted harm	38	5%	3%
Chronic medical condition	34	4%	5%
Infection	36	5%	5%
Acute medical or surgical condition	38	4%	8%
Deliberately inflicted injury, abuse or neglect	16	2%	2%

Other categories include sudden unexpected unexplained deaths, trauma and external causes, suicide or deliberate self-inflicted harm, chronic medical conditions, infections, acute medical or surgical conditions, and deliberately inflicted injury, abuse or neglect. All within single figures ranging from 2-9%.

Modifiable factors are those which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths.

For deaths reviewed by the CDOP in 2024/25, modifiable factors were identified in 14 cases (16%), compared with 43% for England. This represents a slight increase from 2023/24, when modifiable factors were identified in 11 local cases (15%). The percentage of deaths each year with modifiable factors may vary depending on when cases become available for review and are subsequently completed.

Determining whether a factor is modifiable is complex and subject to considerable discussion at CDOP meetings. Over the past two years, Sussex CDOP has significantly reduced the amount of modifiability it assigns in response to clearer national guidance.

To classify a factor as modifiable, the panel assesses whether a practical intervention could realistically have been implemented at the time of the child's death. It is uncommon for the panel to categorise a factor as modifiable if an effective intervention was already in place.

Key findings

During the review process, where Sussex CDOP identifies a matter of concern affecting the safety or welfare of children, or wider public health or safety concerns, immediate action is taken and specific recommendations are made.

Table 26 Summary of Sussex CDOP learning themes annual report 2024/25

Theme	Summary of issue	Key learning and implications
Information sharing	Delays in sharing information can prevent agencies and professionals from responding effectively to children who need support, including where concerns relate to safeguarding, mental health, substance misuse or suicidal ideation.	Strengthen timely information sharing between hospitals, GPs, community services and partner agencies; clarify responsibilities; improve multidisciplinary working for children with complex needs; and ensure early sharing of emerging concerns, even where individual indicators appear minor.
Safeguarding	Safeguarding issues remain a feature of several reviewed cases, including substance misuse by parents or carers, domestic abuse, school non-attendance, missed appointments and risks that may not be fully recognised during home visits.	Maintain professional curiosity, strengthen assessment of parenting capacity and domestic abuse risk, ensure neonatal admission processes identify substance misuse, actively follow up missed appointments for children in need or subject to child protection plans, and ensure home visits include meaningful engagement with the child and household environment.
Sudden Unexpected Death in Infancy and unsafe sleeping	Unsafe sleeping environments remain a leading cause of potentially preventable infant deaths. Risks include hazardous co-sleeping, soft	Continue consistent safer sleep messaging through maternity, neonatal services and health visitors; incorporate cultural considerations into safer sleep

Theme	Summary of issue	Key learning and implications
	sleep surfaces, over-wrapping, toys or cushions in sleeping areas, and bed sharing where adults have used drugs or alcohol.	campaigns; and recognise the role of deprivation, overcrowding, poor housing, lack of heating and mould in increasing infant vulnerability.
Road safety	Several reviewed deaths involved young drivers, passengers and pedestrians, with consideration given to whether graduated driving licence schemes could reduce risk.	Continue road safety prevention work, including seatbelt campaigns and awareness of risks for children and young people near roads; monitor national policy discussions on graduated driving licences and consider how local partners can support prevention messaging.
Asthma	Poor asthma control has been identified as a contributing factor in some deaths, including patterns of excessive reliever inhaler use that may indicate unmanaged risk.	Support GP practices to monitor asthma prescribing, respond proactively to excessive reliever use, follow NICE asthma guidance, and consider combined preventative and reliever inhalers where clinically appropriate, particularly where adherence to preventer medication is poor.
Bereavement support	High-quality bereavement services are available across Sussex, but access is inconsistent for families with limited English proficiency, and reliance on interpreters may reduce the effectiveness of support.	Increase access to culturally and linguistically appropriate bereavement support so that all families can receive timely, equitable and meaningful support following the death of a child.

Learning identified from Neonatal Reviews (31)

Of the 85 reviews completed during 2024/25, 37 (44%) were neonatal reviews. These cases identified additional learning including:

- The need for clearer local policies and sufficient resourcing for maternity telephone triage services.
- Enhanced training around endotracheal intubation in pregnant patients.
- Improved documentation of informed decision making when induction of labour is offered, ensuring alternative options are discussed and recorded.

CDOP shared additional evidence and intelligence for this NA report on Learning from deaths of children with life-limiting conditions and malignancy.

CDOP Learning from deaths of children with life-limiting conditions

All children aged 0–17 years (inclusive) with a life-limiting condition, whose deaths were reviewed by the CDOP between 1 April 2023 and 31 March 2026 were included within analysis. Deaths by malignancy have been excluded and explored later within this report.

Children with a life-limiting condition were identified through completion of the supplementary reporting form "Death of a Child with a Life-limiting Condition." Reporting forms are completed by professionals across any agency who had been directly involved in the child's care.

There has been a total of 33 cases that were resident to Sussex and reviewed over the three-year period.

Age distribution

Of the 33 children:

- 10 were infants (under 1 year of age)
- 12 were aged 1–9 years
- 11 were aged 10–17 years

Among children aged over 4 years (n=18), all but one also had a confirmed learning disability.

Categorisation of death

20 of the 33 deaths were categorised as chromosomal, genetic, or congenital anomalies. All infant deaths (n=10) fell within this category. The remaining 13 cases were categorised as either chronic medical conditions or infection.

Note: CDOP categorises deaths using a hierarchical system as defined in the national CDR analysis form. The highest-ranking category selected is recorded as the primary category, with additional categories recorded as secondary where applicable. As a result, even when infection had been identified as a cause of death, it may be recorded

in the CDR dataset under broader categories, such as chronic medical conditions or chromosomal/genetic conditions.

Key themes and learning identified across these cases:

- Improving understanding and perceptions of palliative care, ensuring it is recognised as a service that supports children and families throughout the course of a life-limiting condition, not solely at EoL.
- Recognition that the needs of children with life-limiting conditions are dynamic, requiring ongoing reassessment and regular review of Advance Care Plans and ReSPECT documentation.
- Delayed involvement of palliative care services was a recurring issue, often related to parental readiness or delayed recognition of a child's deterioration.
- Professionals should initiate timely and confident conversations about Advance Care Planning, introducing palliative care at the earliest appropriate opportunity following diagnosis or deterioration.
- Ensuring ACP documentation is accessible to all members of the multidisciplinary team (MDT), including ambulance services, in a timely manner.
- Supporting families to understand and recognise signs of disease progression, deterioration, and the likely clinical trajectory.
- Undertaking thorough ACP discussions to ensure families are informed about what to expect after death, particularly in cases where death may occur suddenly, including potential coroner involvement.
- Providing families with clear information about care limitations within hospice settings to prevent distress during transitions from hospital care.
- Ensuring effective communication and engagement with both parents, including those who are non-resident or separated.
- Significant gaps in out of hours and community palliative care provision, which impact families' ability to achieve their preferred place of care and death. These gaps increase distress for both families and professionals. Services should be formally commissioned to ensure equitable and reliable provision, rather than reliance on goodwill.
- Ensuring children with learning disabilities and underlying health conditions are up to date with routine vaccinations and receive seasonal vaccinations. Clinical staff should utilise opportunities to engage parents or carers in discussions around the importance of vaccinations and ensure that a vaccine history is reviewed at every opportunity.

Sussex Child Death Overview Panel (CDOP) thematic findings on malignancy related child deaths

Analysis on the deaths of children, resident to Sussex, who have died due to malignancy between 1 April 2020 and 31 March 2025 (5 years). Although rare in children compared to adults, cancer remains one of the leading causes of death in children over the age of one.

In Sussex, malignancy has been recorded as the most common category of death for children over one year of age, accounting for 23% of all child death reviews (based on pooled CDOP data from 2015/16 to 2024/25). This is followed by chromosomal, genetic and congenital anomalies which account for 14% of reviews.

Characteristics of children (1-17 years)

- Between 1 April 2020 and 31 March 2025, there were 152 deaths of children aged over one year who were resident to Sussex. Of these, 22 deaths (14%) were cancer related. Due to the relatively small number of cases, statistical findings should be interpreted with caution, as they may not be statistically significant.
- A higher proportion of deaths occurred for children who were resident to West Sussex (55%) followed by East Sussex (27%) and Brighton and Hove (18%). This distribution reflects differences in child population sizes across the three local authority areas.
- Just over half of the children who died from cancer (12, 55%) were aged 15–17 years at the time of death, followed by six children (27%) aged 5–9 years.
- At the time of initial diagnosis, 41% (9 children) were aged 10–14 years, 23% (5 children) were 15–17 years, and 36% (8 children) were aged 1–9 years.
- There was a higher proportion of males (68%) compared with females (32%).
- The majority of children were of White – British ethnicity (91%).
- Many of the children and their families were supported by professionals in choosing their preferred place of care and death, which was often at home or in a hospice. Among children who died of cancer, just over half died at home, nearly one third died in a hospice and a small proportion died in a hospital setting. All deaths that occurred in the hospital setting involved pneumonia as a contributing factor in children with leukaemia.
- At the time of diagnosis, 50% of cancer cases were classified as localised, 32% as metastatic and 18% were either unknown or unstageable.
- The most common types of cancer were Central Nervous System (CNS) and miscellaneous intracranial and intraspinal neoplasms (41%) followed by Leukaemias, myeloproliferative diseases, and myelodysplastic diseases (18%).
- The majority of children (82%) had an ACP in place at the time of their death. In the remaining cases (less than five children), the absence of an ACP was either due

to the unexpected nature of the child's death or families declining the opportunity when it was offered.

Key themes and learning

Over the past 10 years in Sussex, only 3% of all child death reviews related to malignancy identified modifiable factors7, this represents the lowest proportion across all other categories of death. Nonetheless, these reviews provide valuable opportunities for learning and system improvement that could enhance the timeliness of diagnosis and treatment pathways, strengthen communication between agencies and improve the quality of end-of-life care.

Key themes and learning identified following CDOP reviews

It was reported by professionals that although most children had received a rapid and timely diagnosis, 32% of cases had identified delays in the diagnosis of the child's condition. The most significant factor contributing to delayed diagnosis was largely due to the rarity and subtle presentation of childhood cancers which can be challenging. Notably, 57% of these delays occurred in children who died from brain tumours.

Key themes and learning:

- Clinicians misattributed symptoms such as vomiting, growing pains or headaches to more common or benign conditions (e.g. bulimia, reflux, anxiety or musculoskeletal pain). Clinicians should remain alert to cognitive bias that may favour psychological or functional diagnoses when children and young people present with persistent or subtle symptoms.
- A normal neurological examination does not exclude the presence of a brain tumour. Behavioural changes or altered mental state in children and young people may indicate a CNS tumour and should prompt further investigation.
- Evolving symptoms such as new onset headaches, radicular pain, vomiting on waking and persistent leg pain were under recognised or poorly documented, leading to missed opportunities for early escalation.
- In some cases, non-urgent referrals were used even when red flag symptoms emerged. More timely communication might have expedited review and diagnosis with concerning symptoms. Primary care and Urgent Treatment Centres (UTCs)

[7] Modifiable factors are those which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths.

should be aware of the importance of urgent telephone referrals to paediatric inpatient assessment units when children present with urgent, complex or rapidly evolving symptoms.

- Children requesting regular prescriptions for pain relief associated with prolonged bony pain should be recognised as a red flag and should prompt an urgent referral to paediatrics.

Improvements in EoLC:

The following themes emerged from the reviews which may provide opportunities to improve EoLC for children:

- Communication difficulties and unclear leadership were noted between adult and paediatric oncology services. Professionals reported unfamiliarity in collaborating across services and challenges in supporting teenagers in community settings.
- Families express a desire for continuity of care, particularly with staff they had built trusted relationships with throughout the child's illness.
- Out-of-hours access to specialist palliative care consultant and community nursing support for oncology patients is insufficiently commissioned and often reliant on professional goodwill.
- Professionals described challenges in initiating and engaging families in advance care planning, discussing prognosis and how families can recognise disease progression. Sometimes this was due to complex family dynamics or a readiness to engage.
- Timely access to spiritual or religious support aligned with family beliefs and preferences post-death was reported as a challenge.

Good practice identified:

Many families expressed gratitude for the compassionate, respectful, and personalised care they received by professionals. The CDOP acknowledges the exceptional efforts of professionals in many cases, often exceeding what is considered standard good care.

Examples of good practice include:

- Effective coordination and communication across multidisciplinary teams to deliver seamless care.
- Child and family involvement in decision making and advance care planning.
- A strong focus on personalised care, with professionals adapting to individual needs and creating meaningful experiences for both the child and family.

- Comprehensive symptom management plans were well developed and promptly implemented.
- Families had 24/7 access to specialist advice and support despite services not being formally commissioned.
- Effective emotional and bereavement support for families.

The following recommendations were made by the panel:

- Better Safe Than Tumour (previously HeadSmart) guidance and training resources should be embedded into routine training for all medical and nursing staff involved in the care of children. This includes staff in A&E, UTCs, CDCs, mental health services and other child-assessing services. These resources should be promoted widely, especially among GPs, to support earlier recognition and referral.
- Primary care and Urgent Treatment Centres (UTCs) should be routinely reminded of the availability of local on-call paediatric advice lines and encouraged to make direct contact when concerned, to ensure timely assessment and investigation.
- Children presenting to A&E with the same symptoms on more than two occasions should be reviewed by a senior clinician.
- Separate analysis was undertaken on the data from the workforce survey where the respondents worked with children only. Respondents were based in CYP Hospices or Hospitals and were made up of medics and other support staff.

Analysis of responses from 10 workforce survey respondents who work exclusively with children identified several consistent themes regarding what is working well in PEoLC, respondents highlighted high-quality hospice care and symptom management, strong multidisciplinary and partnership working, and the importance of effective coordination and information sharing in delivering positive care experiences. Services were seen to work particularly well when they enabled choice over place of care and death, supported by community and hospice provision.

In paediatric settings, close collaboration between children's hospices, community nursing teams, GPs and specialist services was consistently identified as a strength.

Respondents also emphasised the critical role of committed and flexible staff, often working beyond expected capacity to meet family needs.

> 'I am privileged to be a Volunteer and pleased to see there are lots of voluntary help in Sussex but wish the Government would help with funding and would like to see something done about this'.

However, these strengths are frequently supported by limited resources and hospice funding challenges, and while care is described as high quality for those who access it, this is not always consistently available to all children and families.

> ‘Improved understanding for professionals on what hospices can offer and the confidence to explain this to patients and their families - often the conversations and referrals don't happen due to professional anxiety or lack of understanding. Children’s hospices work very differently to adult hospices and the EoLC is only a small part of what we offer’.

Bereavement support for children and families is primarily delivered through hospice-led services and the voluntary sector, with several key themes emerging. Respondents consistently highlighted the strength of hospice bereavement services, including specialist teams, events, and whole-family psychological support, alongside valued provision from organisations such as Demelza and local charities.

> ‘Hospices have bereavement teams and events - volunteers support this. Our team offer post bereavement care at home so a child can remain at home post death for 48 hours. Our organisation offers psychotherapeutic services for the whole family’.

There is also evidence of compassionate, flexible care, including the ability to support families at home immediately after death. However, these services are often described as reliant on volunteers and charitable funding, with limited statutory provision. Awareness and involvement in bereavement support vary across the workforce, suggesting inconsistent access and visibility of services.

The most prominent theme is the need for increased and sustainable funding for hospice services, moving beyond reliance on charitable donations and volunteers to ensure capacity to support children and families throughout the care pathway and into bereavement. Respondents also emphasised the importance of earlier and increased referrals to hospice and palliative care services, supported by clearer pathways and improved transitions, particularly between children’s and adult services.

> ‘early referrals to hospices and a clear pathway for families transitioning from children to adult care’.

A further theme is the need for better communication and coordination across multidisciplinary teams, including stronger links between community, acute, and social care services. There is also a need to raise awareness and understanding of hospice services among both professionals and the public.

Chapter 2 Conclusion – What does this mean for Sussex?

Need

Although CYP account for a relatively small proportion of deaths in Sussex, they often have highly complex PEoLC needs that may extend over many years. Advances in

healthcare mean that increasing numbers of children with life-limiting and life-threatening conditions are surviving into adolescence and adulthood, creating demand for coordinated, long-term support across health, social care, education, hospice and voluntary sector services. The evidence highlights the importance of delivering family-centred care that recognises the emotional, practical, educational, financial and social impacts on children, young people, parents, siblings and carers.

Unmet need

The assessment identifies several areas of unmet need. Opportunities exist to strengthen earlier identification of palliative care needs and increase the use of Advance Care Plans and ReSPECT documentation. The relatively low proportion of children and young people with documented care plans suggests that some families may not be receiving timely opportunities to discuss preferences, future care decisions and support needs.

Transition from children's to adult services emerged as one of the most significant challenges. Young people with complex conditions can experience fragmented care, changes in professional relationships and variation in the availability of support as they move into adult services. Strengthening transition arrangements is essential to ensure continuity of care and prevent young people and families from experiencing gaps in support.

Variation

Variation exists in the identification of need, care planning, access to specialist support and approaches to care coordination. Whilst some variation reflects differing service models and local circumstances, the findings suggest opportunities to improve consistency across Sussex. Ensuring that all children and young people with palliative care needs have equitable access to high-quality care planning, coordinated support and transition services should be a priority.

Inequalities

CYP with complex needs, rare conditions, learning disabilities and those requiring support from multiple agencies may experience additional barriers in accessing coordinated care. Families living in areas of deprivation, rural communities, or those facing wider social and economic challenges may experience greater difficulties navigating services and accessing support. Continued efforts are therefore required to ensure services are accessible, family-centred and equitable for all children and young people across Sussex.

Future Demand

Demand for children's PEoLC care is likely to increase over time. Whilst the number of deaths may remain relatively low, advances in treatment and survival mean more children and young people are living longer with complex and life-limiting conditions. This is likely to increase demand for community nursing, specialist paediatric palliative care, hospice services, psychological support, respite care, bereavement support and transition services. Future demand will increasingly be driven by complexity rather than volume alone.

What this means for Sussex

Sussex has established specialist paediatric, community and hospice services providing high-quality care and support to many children and families. Increasing complexity of need, growing survival into adulthood, challenges around transition, variation in care planning and the need for greater coordination indicate that further system-wide improvement is required.

Future priorities should focus on strengthening earlier identification, increasing advance care planning, improving coordination across agencies, reducing variation, enhancing transition pathways and ensuring equitable access to specialist palliative and bereavement support.

Aligning service development with the emerging Modern Service Framework for PEoLC and wider ambitions to shift care closer to home will help ensure that children, young people and their families receive timely, coordinated and person-centred support throughout their care journey.

Recommendations for babies, children and young people PEoLC

The following recommendations form a targeted subset of the wider recommendations developed through this needs assessment. They have been shaped with input from professionals and partners working with babies, children and young people, including those working in specialist paediatric palliative care and children's hospice services.

During the recommendation development day there was an acknowledge that much of Recommendation A stated below is being delivered through the COAST service, however this recommendation was described as a 'Must do' recommendations for BCYP PEoLC. Recommendation E was also described as a 'Must do'. Recommendations G and O were also described as 'Should do's' for specific BCYP workstreams going forward.

The wider recommendations for the needs assessment have been developed as all-age recommendations. However, the needs of babies, children and young people (BCYP), and their families, in relation to PEoLC and bereavement support are distinct in several

important respects. This subset of recommendations is therefore intended to support any future targeted work programmes focused specifically on BCYP, specialist paediatric palliative care, and bereavement support for families following the death of a baby, child or young adult.

A. **Recommendation: Recognise BCYP with life-limiting and life-threatening conditions as a distinct population within Sussex PEoLC strategic planning and commissioning. This should include population-level needs assessment, demand and capacity modelling, workforce planning and service development across universal, core and specialist services.**

   Why: The needs assessment identifies that the population of BCYP living with life-limiting and life-threatening conditions is increasing, with improved survival resulting in more children living longer with complex healthcare needs. Children's palliative care often begins at diagnosis, continues alongside active treatment and may extend over many years, creating different patterns of need to adult services. Recognising BCYP as a distinct population will support more accurate demand modelling, workforce planning, service development and commissioning, ensuring services are responsive to current and future need and enabling more equitable access across Sussex.

B. **Recommendation: Develop a Sussex-wide BCYP palliative care population health approach. This should identify prevalence, projected growth, complexity of need, service utilisation, unmet need and inequalities by geography, diagnosis, deprivation, ethnicity, age and access to specialist paediatric palliative care.**

   Why: The needs assessment identifies gaps in local intelligence regarding prevalence, service utilisation, unmet need and inequalities for children and young people requiring palliative care. Evidence suggests higher prevalence among some ethnic minority communities and areas of deprivation, alongside variation in access to specialist services. A population health approach would support evidence-based planning, identify unmet need, improve understanding of future demand and enable targeted interventions to reduce inequalities across Sussex.

C. **Recommendation: Assess and reduce inequalities in access to children's palliative care services across Sussex. This should include specialist paediatric palliative care, community children's nursing, hospice respite, hospice at home, advance care planning, emergency healthcare planning and bereavement support.**

   Why: The needs assessment highlights variation in access to services according to geography, diagnosis and wider demographic factors. Families may experience differing levels of support depending on where they live and the services available locally. Assessing and addressing inequalities will help ensure care is delivered

according to need rather than circumstance, improve family experience and outcomes, and inform future commissioning and investment decisions.

D. **Recommendation: Develop an integrated Sussex model of community-based paediatric palliative care. The model should coordinate acute, community, hospice, primary care, ambulance, social care, education, SEND, short breaks and VCSE services, enabling BCYP to receive care in their preferred setting wherever clinically appropriate.**

   Why: Evidence from the needs assessment highlights the importance of coordinated community-based care and identifies gaps in service integration that can contribute to avoidable hospital attendance, fragmentation of care and increased burden on families. Many children spend the majority of their lives at home, supported by family carers. An integrated model would strengthen care coordination, improve quality of life, support personalised care and enable more children and young people to receive care in their preferred setting.

E. **Recommendation: Establish equitable access to 24/7 paediatric palliative care advice and urgent response across Sussex. This should include access to specialist consultant advice, community children's nursing, hospice at home and clear escalation routes for children approaching end of life.**

   Why: The needs assessment identifies that access to out-of-hours support is variable and can contribute to avoidable hospital admissions, ambulance callouts and distress for families. Consistent access to specialist advice and urgent community-based support would improve care coordination, reduce inequalities, support timely clinical decision-making and increase opportunities for care to be delivered in the child and family's preferred setting.

F. **Recommendation: Ensure every BCYP with a life-limiting or life-threatening condition has access to a named medical lead and identified key worker. This role should coordinate care across health, social care, education, SEND, short breaks, hospice and voluntary sector services.**

   Why: Children with complex conditions often receive support from multiple agencies over many years. The needs assessment highlights the challenges families face navigating services and coordinating care. A named medical lead and key worker would improve continuity, strengthen multidisciplinary communication, support families to access appropriate services and ensure care remains coordinated around the child and family.

G. **Recommendation: Strengthen early identification, proactive advance care planning and parallel planning for BCYP. Pathways should include prenatal,**

neonatal and paediatric services, and support children with diagnosed life-limiting conditions, life-threatening conditions, severe medical complexity or significant prognostic uncertainty.

Why: Learning from Child Death Overview Panels (CDOP) identifies the importance of timely identification, ongoing review and early planning. Children with serious conditions often experience uncertain and changing illness trajectories. Early identification and parallel planning support timely access to palliative care, improve coordination, reduce crisis-driven decision-making and ensure care reflects the wishes and priorities of children, young people and families.

H. **Recommendation: Implement consistent use and sharing of CYP-specific advance care plans, emergency healthcare plans and ReSPECT plans where appropriate. These should be routinely shared across maternity, neonatal, paediatric, community, hospice, ambulance, primary care, social care and education settings.**

Why: The needs assessment identifies fragmented information sharing as a significant barrier to coordinated care. Consistent use and routine sharing of advance care planning documentation can improve communication between professionals, support shared decision-making, prevent unwanted interventions and ensure care remains aligned with the child's and family's wishes during periods of deterioration or crisis.

I. **Recommendation: Develop a children's palliative care workforce model for Sussex. This should define the roles, responsibilities and competencies of universal, core and specialist providers, including escalation and de-escalation pathways, transition to adult services, and sustainability of the specialist multidisciplinary workforce.**

Why: The needs assessment identifies workforce challenges, including specialist capacity constraints, variable confidence across the wider workforce and the need for clearer pathways between universal, core and specialist services. A defined workforce model would improve consistency, strengthen care coordination, support workforce sustainability and ensure children receive the right level of support according to the complexity of their needs.

J. **Recommendation: Provide targeted training and specialist support for professionals caring for BCYP with palliative care needs. Training should cover sensitive conversations, trauma-informed practice, cultural humility, paediatric advance care planning, ethical decision-making, conflict resolution, transition, and support for children with learning disabilities, neurodevelopmental conditions or communication needs.**

Why: The needs assessment highlights professional uncertainty and variation in confidence when caring for children with complex and life-limiting conditions. Staff require specialist knowledge and support to undertake difficult conversations, manage ethical complexity and deliver equitable care to diverse families. Enhanced training and access to specialist advice will improve quality, consistency and family experience across Sussex.

K. **Recommendation: Ensure timely access to medicines and specialist pharmacy advice for BCYP receiving palliative and end of life care. Pharmacy arrangements should support equitable access regardless of geography or time of day.**

   Why: Timely access to medicines is critical for effective symptom management and comfort. The needs assessment identifies potential inequalities in pharmacy access, particularly outside normal working hours and in rural areas. Consistent pharmacy provision and specialist support would reduce delays, improve symptom control, prevent unnecessary admissions and support safe care in community settings.

L. **Recommendation: Strengthen coordinated emotional, psychological, practical and bereavement support for families of BCYP. This should include anticipatory grief support before death and ongoing bereavement support for parents, carers, siblings and wider family members, delivered across health, hospice, education, social care and VCSE partners.**

   Why: The needs assessment demonstrates that the impact of a child's illness extends beyond the child and affects the wider family. Families frequently require emotional, psychological, practical and bereavement support throughout the care journey and beyond death. Coordinated support can improve wellbeing, reduce distress, strengthen family resilience and ensure support remains accessible and responsive at all stages of care.

M. **Recommendation: Develop accessible, culturally sensitive and age-appropriate information for children, young people and families. Resources should explain palliative care, what to expect before and after death, care in different settings, baby loss support, bereavement services, sibling support and local and national sources of help.**

   Why: Families often report uncertainty about available support, practical arrangements and what to expect during serious illness, death and bereavement. Providing accessible, culturally appropriate resources can improve understanding, support informed decision-making, reduce distress and help ensure families from all communities can access relevant information and support when needed.

N. **Recommendation: Develop age-appropriate death literacy and community engagement approaches for CYP and families. This should include play-based, creative, arts-based, storytelling and compassionate communities approaches, with adaptations for children with learning disabilities, neurodevelopmental conditions and communication needs.**

   Why: The needs assessment identifies that conversations about death, dying and bereavement are frequently avoided or delayed. Children and young people often understand and communicate about these issues differently from adults. Creative and developmentally appropriate approaches can improve understanding, promote emotional expression, reduce stigma and support engagement among diverse groups of children, young people and families.

O. **Recommendation: Embed BCYP indicators within Sussex PEoLC quality improvement, audit and system learning processes. This should include CDOP learning, equity indicators, family experience, access to specialist services, advance care planning, place of care/death, bereavement support and service outcomes.**

   Why: The needs assessment highlights the importance of monitoring quality, experience and outcomes to inform improvement activity. Child-specific measures are not consistently available within current reporting arrangements. Embedding BCYP indicators will support ongoing evaluation, strengthen accountability, identify inequalities and ensure service development remains informed by evidence and family experience.

Chapter 3 Adults

Key takeaways

Many adults who could benefit from PEoLC are not being identified early enough, particularly those with frailty, dementia, and non-cancer conditions.

There is variation in ReSPECT planning and Advance Care Planning. Both are not routinely taking place, and/or not being recorded, with variation between groups, settings and potentially under recording.

People living at home are significantly less likely to have an Advance Care Plan or ReSPECT plan in place than those living in care or nursing homes.

People from minority ethnic groups, LGBTQ+ communities, and other inclusion health groups continue to experience barriers to accessing timely and equitable care and support.

Many receive great care, however there is evidence of poor coordination between services, limited information sharing, and inconsistent out-of-hours support, contributing to unmanaged symptoms, avoidable hospital admissions and crisis-driven care.

Palliative / supportive care register QOF prevalence and the Sussex Integrated Data set.

About 1% of the population in the UK die each year (over half a million), with an average of 20 deaths per GP per year. A quarter of all deaths are due to cancer, a third from organ failure, a third from frailty or dementia (50). Different models to predict PEoLC need and definitions mean between 10 - 20% of the population will have a sudden and/or unexpected death (53) (87).

The considerable benefits of identifying patients in need of palliative care include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need. Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care, are key steps in the provision of high-quality care at the EoL in general practice.

The Quality Outcomes Framework (QOF) indicator is focused on the maintenance of a register (identifying the patients) and on regular multidisciplinary meetings where the team can ensure that all aspects of a patient's care have been assessed, and future care can be coordinated and planned proactively. (52)

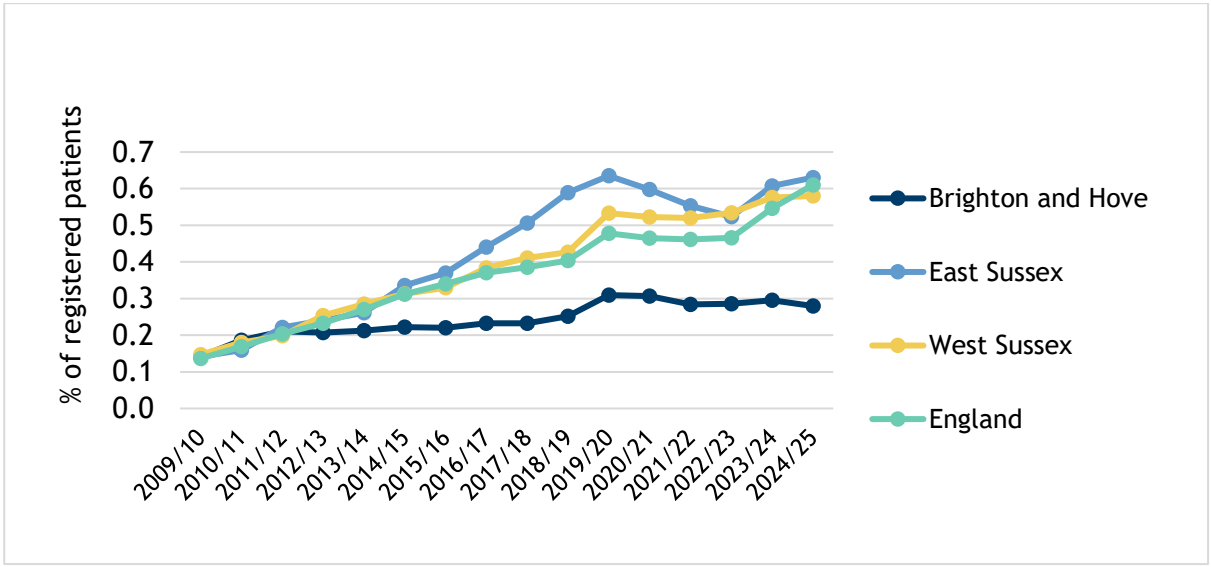
The percentage of patients in need of palliative care/support, is recorded on practice disease registers, irrespective of age. Published Quality Outcomes Framework (QOF)

data shows that for Sussex the prevalence of patients with palliative care codes recorded is 0.54% for year 2024/25. However, there is variation between GP practices, PCNs and other geographies, with one practice in Worthing having 2.2% of its registered patients with a palliative /support care code (PCC) recorded, compared to 0.02% within another Sussex practice (89). It should be noted that the QOF registers are not age standardised therefore we would expect to see variation between localities where there are large populations of older adults.

The England wide distribution of patients on GP palliative and supportive care registers is 0% to 52.73% with a mean value of 0.61%.(89).

Figure 6 shows the increase of registered patients in GP practices that are identified in need of palliative/supportive care over time. East Sussex (O.6), West Sussex (0.5) and England (0.5) are similar, whilst Brighton and Hove (0.3) remain below the national and wider Sussex prevalence.

Figure 6 Long term trends of palliative/supportive care: QOF prevalence and place and England. 2009 – 2025



Published data on Fingertips, a large public health data collection, published by the Office for Health Improvement and Disparities (17), doesn't provide further details on the demographic profile of those with a PCC within their primary care record. Additional analysis has been undertaken relating to patients that have a PCC within their primary care record. Anonymised data has been accessed by a trusted analyst from the Sussex Integrated Dataset (SID) (91). The SID is a primary and secondary health and social care dataset that links routinely collected service user and activity data from health and care providers in Sussex to help plan and improve services for our local population. This data is linked via an individual's NHS Number, so that each contact with a service is traceable. Personal data is pseudonymised and made available for analysis and understanding of which groups are at greatest risk of poor health locally, how services

can be better designed and run and how they can be part of quality improvement and service evaluation of Sussex's integrated health and care system.

This SID data set is not identical to QOF data as not every GP practice shares data with the SID currently. There are other aspects relating to how deaths are reported to the SID and some patients who do not consent to have their data shared with the SID, which will also account for some of the differences with SID and Primary Care/QOF data. However the data is similar enough to explore the profile of those with a PCC recorded in their record. The SID registered population data for Sussex was compared with registered population data reported in the QOF, and after excluding under 18s from the SID data, 1,446,840 patients' records were identified within the SID and used as a basis for the analysis of Palliative Care, Advance Care Planning and ReSPECT plans, recorded in primary care.

Clinical data was extracted from the Encounters data set within the SID. This table is derived solely from data supplied from GP Clinical Systems and reflects data recorded by GPs. Demographic data such as age, sex, ethnicity and Lower Layer Super Output Area (LSOA) came from the SID's Demographic Milestone table. This data set is made up of data supplied by GP clinical systems, secondary care providers, Adult Social Care, Mental Health Services and community providers. The primary source of this data usually comes directly from GP providers as their data is usually the most complete and up to date. However, if any of the demographic data is missing or not up to date, then the SID team will look to fill in the missing data with data from the other SID providers.

SNOMED codes used for analysis were provided by the NHS Sussex ICB lead for Locally Commissioned Services (LCSs) and the QOF Business Rules and these were used to help identify patients within the SID data.

The SID data has highlighted there is variation in the numbers and rates of those on palliative/supportive care registers in GP Practices. Of those with a PCC, the majority were women over the age of 75 years old and in nursing and care homes. There was variation in the recording of ReSPECT plans, and Advance Care Planning, between ICTs in Sussex, and a range of factors will likely influence this. Adur, Rother and Eastbourne ICTs had over 60% of the palliative care patients with a ReSPECT Plan recorded, with the other ICTs having lower.

Sex

Table 27 highlights females are more likely to be registered on the palliative care register. There are likely to be several contributing factors. Females generally have a longer life expectancy than males and therefore make up a larger proportion of the older population. They are also more likely to engage with healthcare services, which may contribute to their greater representation in the data.

Table 27 Number and percentage split of people on the SID - QOF palliative care register by Sex, 2024/25, By Place and ICT.

Location	Males	Females	Males	Females
Brighton and Hove				
Central	115	162	42%	58%
East	162	212	43%	57%
West	168	272	38%	62%
East Sussex				
Eastbourne	268	401	40%	60%
Hastings	214	369	37%	63%
Lewes	196	278	41%	59%
Rother	303	542	36%	64%
Wealden	311	405	43%	57%
West Sussex				
Adur	136	219	38%	62%
Arun	566	908	38%	62%
Chichester	276	399	41%	59%
Crawley	68	98	41%	59%
Horsham	234	374	38%	62%
Mid Sussex	181	310	37%	63%
Worthing	354	659	35%	65%

The size of the populations varies for many reasons. Rother and Worthing have larger populations of older adults and a higher number of care homes.

Age

Figures 7, 8 and 9 highlight the variation in age specific rates by ICT across Sussex. Worthing, Arun and Rother have notably higher rates of the 75+ age group with a PCC on their record. A notable observation would be that Hastings and Eastbourne both have a higher rate of adults in the 65 - 74 age group that have PCC on their record, this could be due to behavioural and socioeconomic factors as these ICT locality areas have lower life expectancies and higher levels of deprivation compared to other areas.

The following figures 10, 11 and 12 also provide the numbers of people by age group and ICT that have PCC on their record. Rother, Arun and Worthing have considerably larger numbers of older people with PCC on their record compared to parts of Brighton and Hove, and Crawley.

Figure 7 SID-QOF palliative care register, age specific rates per 1,000 population in Brighton & Hove ICTs, 2024/25.

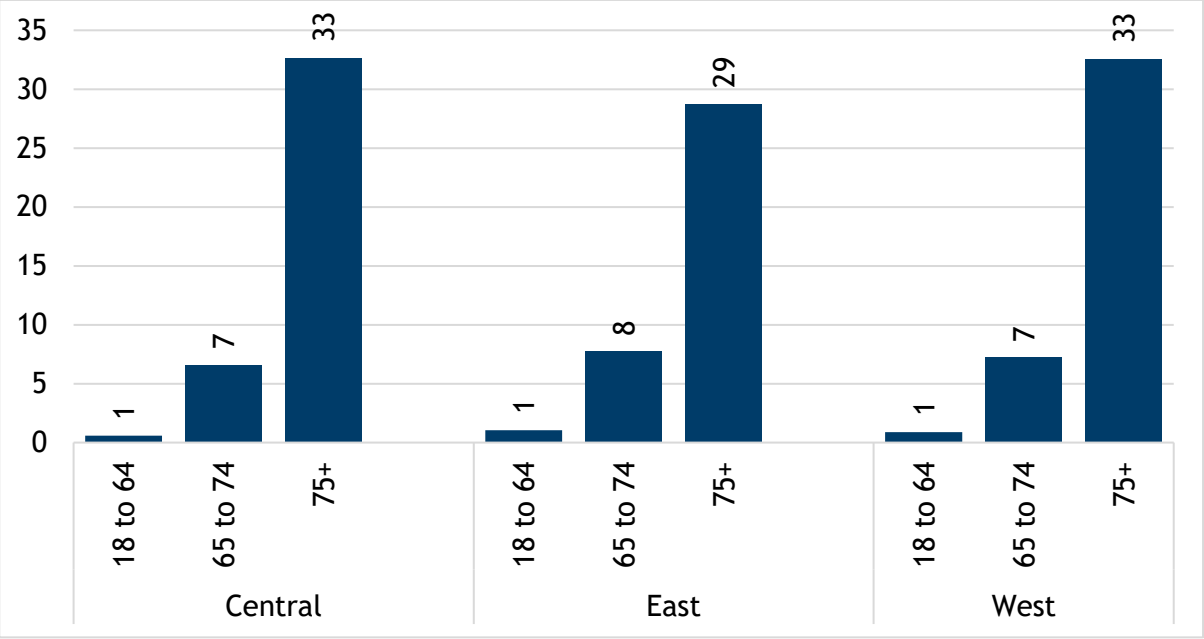


Figure 8 SID – QOF palliative care register, Age specific rates per 1,000 population in East Sussex ICTs, 2024/25.

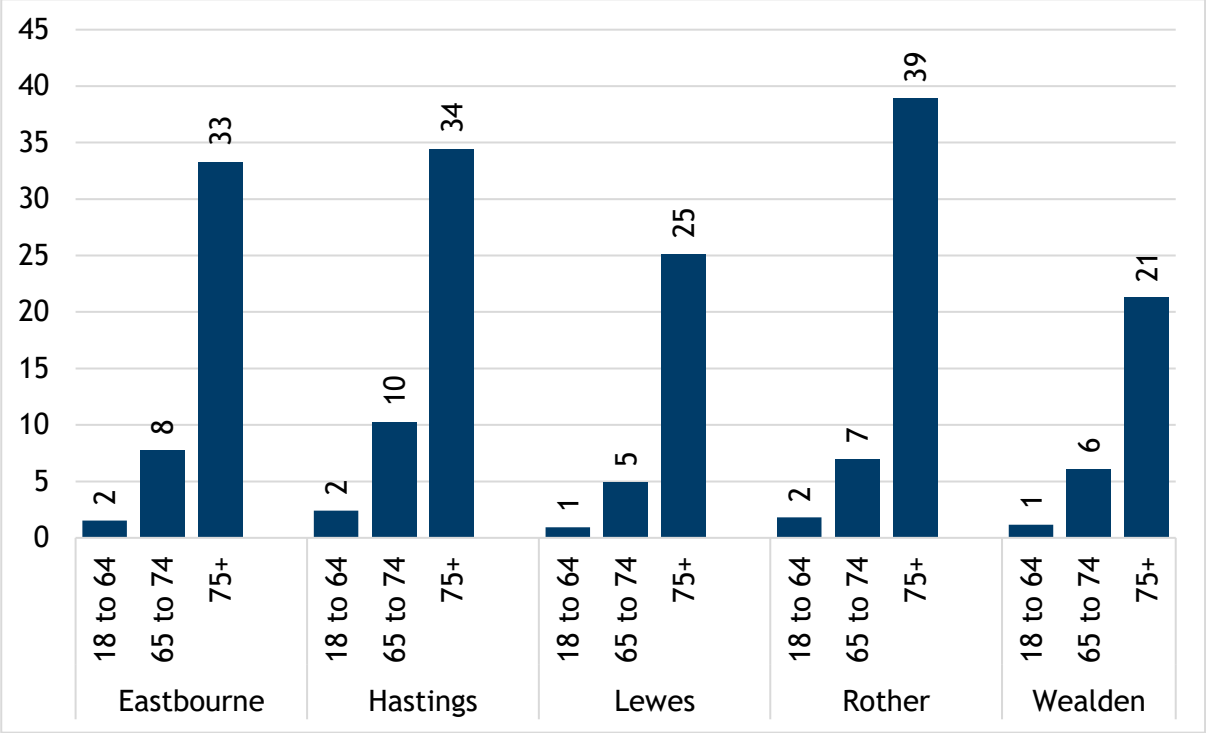


Figure 9 SID - QOF palliative care register, Age specific rates per 1,000 population In West Sussex ICTs, 2024/25.

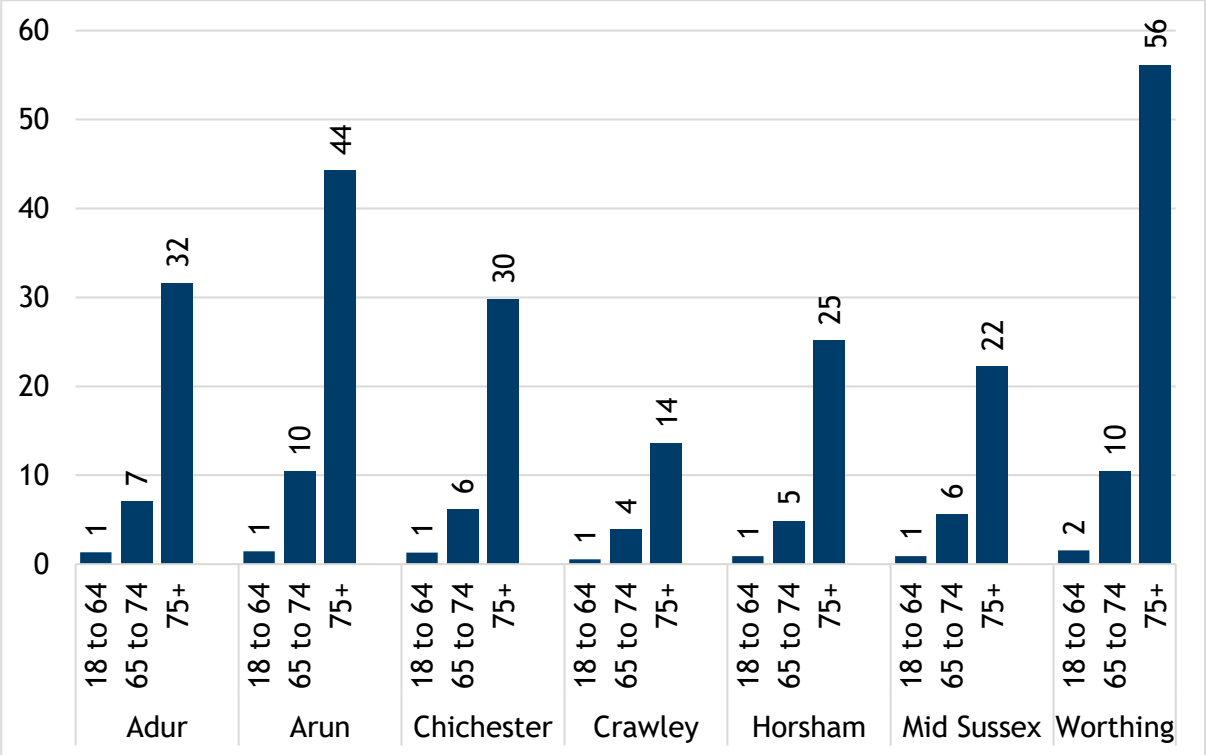


Figure 10: Number on the SID – QOF palliative care register by age group for Brighton & Hove ICTs, 2024/25.

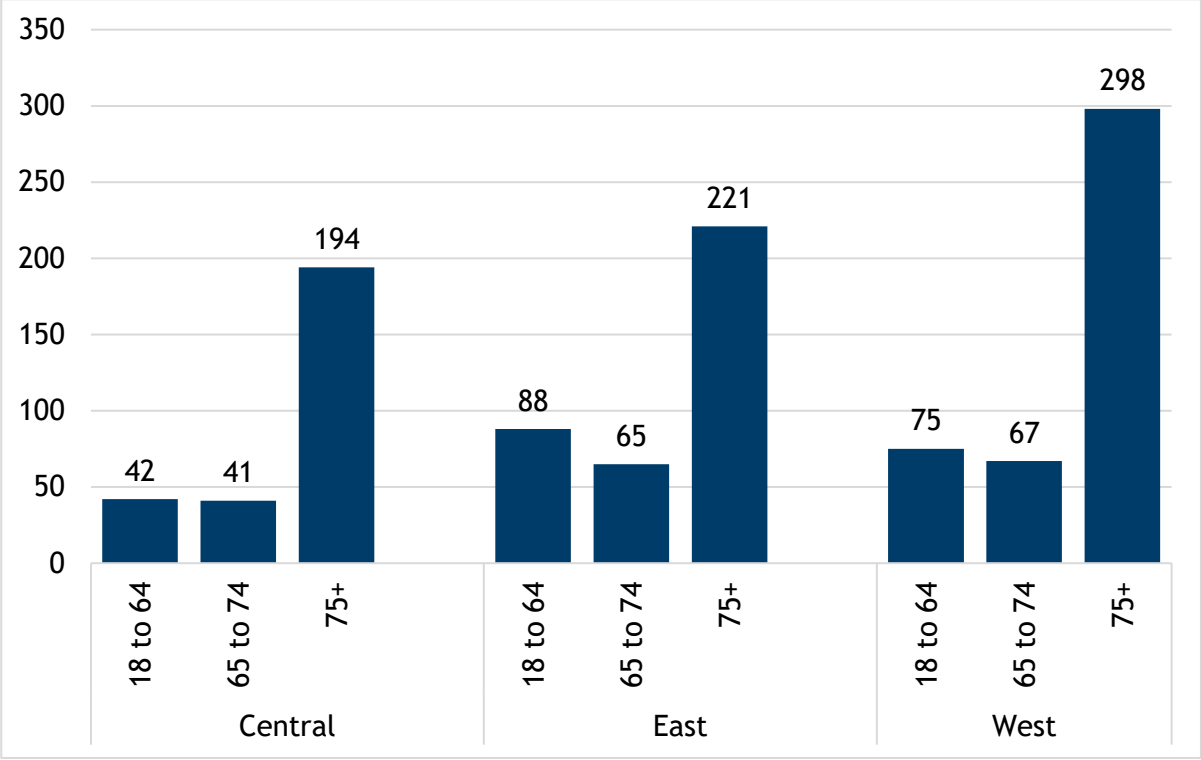


Figure 11 Number on the SID - QOF palliative care register by age group for East Sussex ICTs, 2024/25.

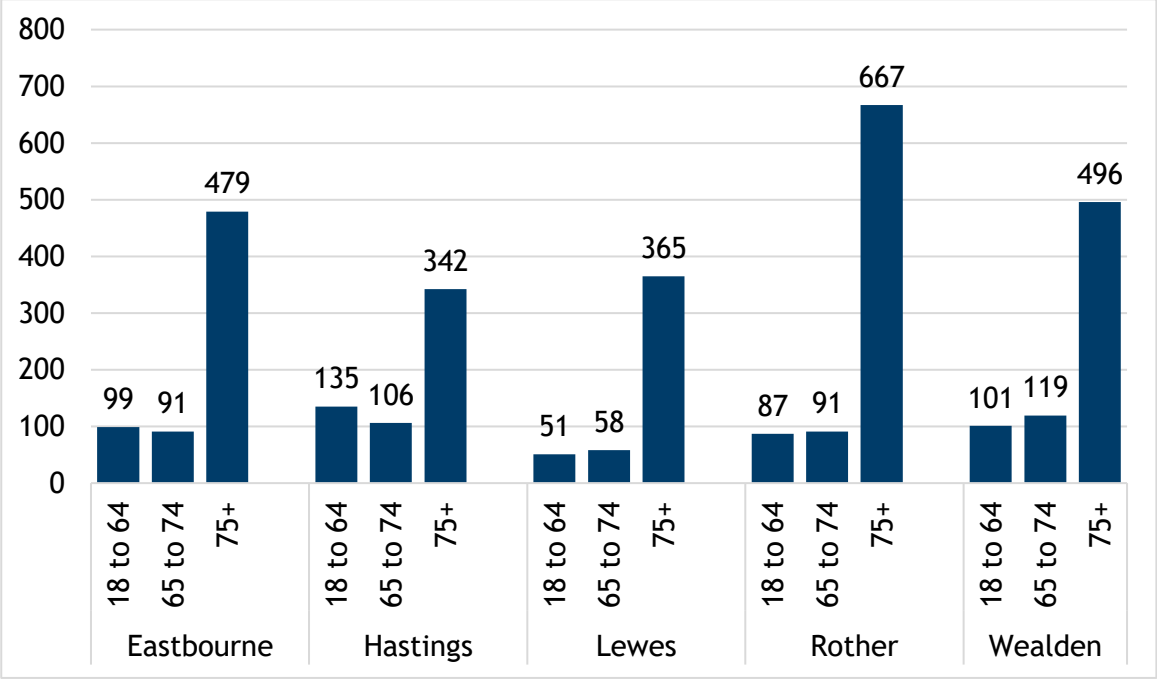
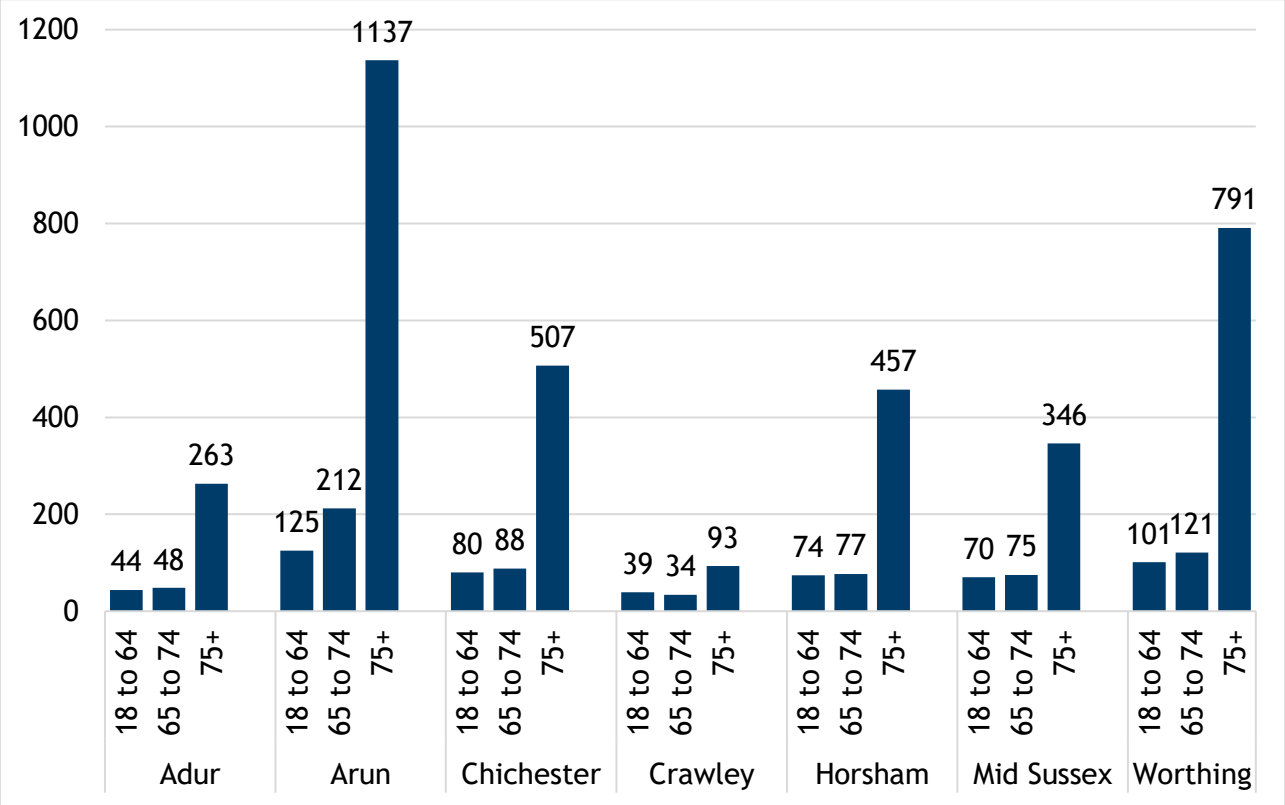


Figure 12 Number on the SID - QOF palliative care register by age group for West Sussex ICTs, 2024/25.



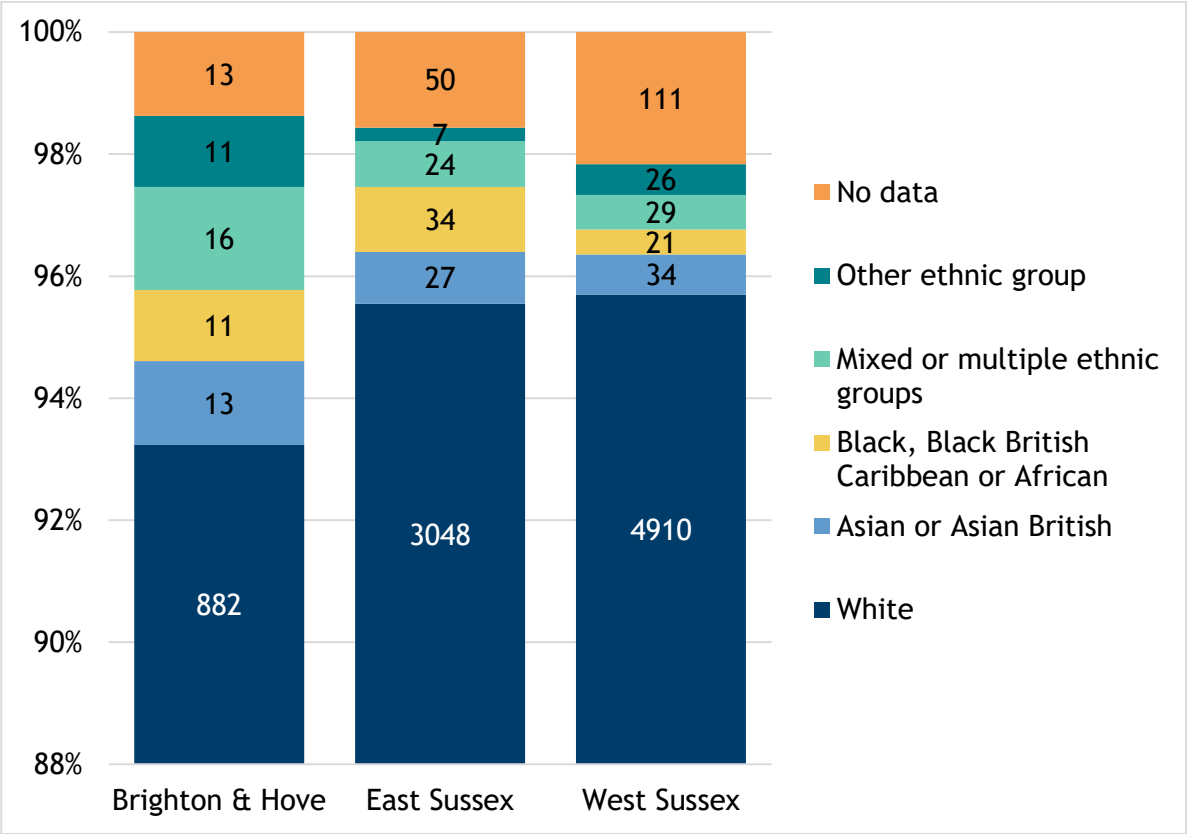
Ethnicity

Evidence demonstrates that nonwhite British populations are more likely to experience barriers in PEoLC (18). The SID data highlights that the ethnicity of people on the Palliative/Supportive Care register was generally recorded. In 2024/25, 9,093 patients with a PCC had their ethnicity recorded.

Only 174 patients didn't have their ethnicity recorded. The percentage of nonwhite populations on the PC register was 5.3% for Brighton and Hove, 2.8% for East Sussex and 2.1% for West Sussex. The nonwhite populations across Sussex do vary considerably, and by population age. More detailed analysis by age and ethnicity would be required to deem if they are underrepresented on the palliative care register in Sussex.

However, other data from 2024/5 relating to accidents and emergency (A&E) attendance shows nonwhite groups are more likely to use A&E in the last 90 days of life in Sussex(64). This may indicate nonwhite groups access primary care services at the EoL less than their white peers and access A&E to engage with services if they require PEoLC.

Figure 13 Ethnicity of people on SID- QOF Palliative Care register, 2024/25.



Sexual orientation and gender identity

Evidence suggests that LGBTQ+ groups may experience barriers and inequalities associated with PEoLC (18). There are less than 15 records of a sexual orientation code for those with a PCC recorded in the SID. Further evidence and insight will be needed to understand how these groups access and experience PEoLC in Sussex.

Accommodation

Understanding where people live is important when planning and considering their healthcare and care. Nationally, most older people do not live in care homes (92). The data analysis of the SID indicates that most adults with a PCC in Sussex don't live in a nursing or residential home. This is an important consideration for wider care and support needs. As residents of care homes may have been assessed for their support, care, treatment and wider needs. Figure 14 shows there is slight variation across Sussex. Brighton and Hove have the highest percentage of people on the Palliative Care register living in their own homes and nursing homes. Whilst West Sussex has the fewest in their own homes and the most in a care home.

Figure 14 Percentage of people on the SID - QOF Palliative Care register who live in care, nursing or residential home or own home/no data, by Place, 2024/25.

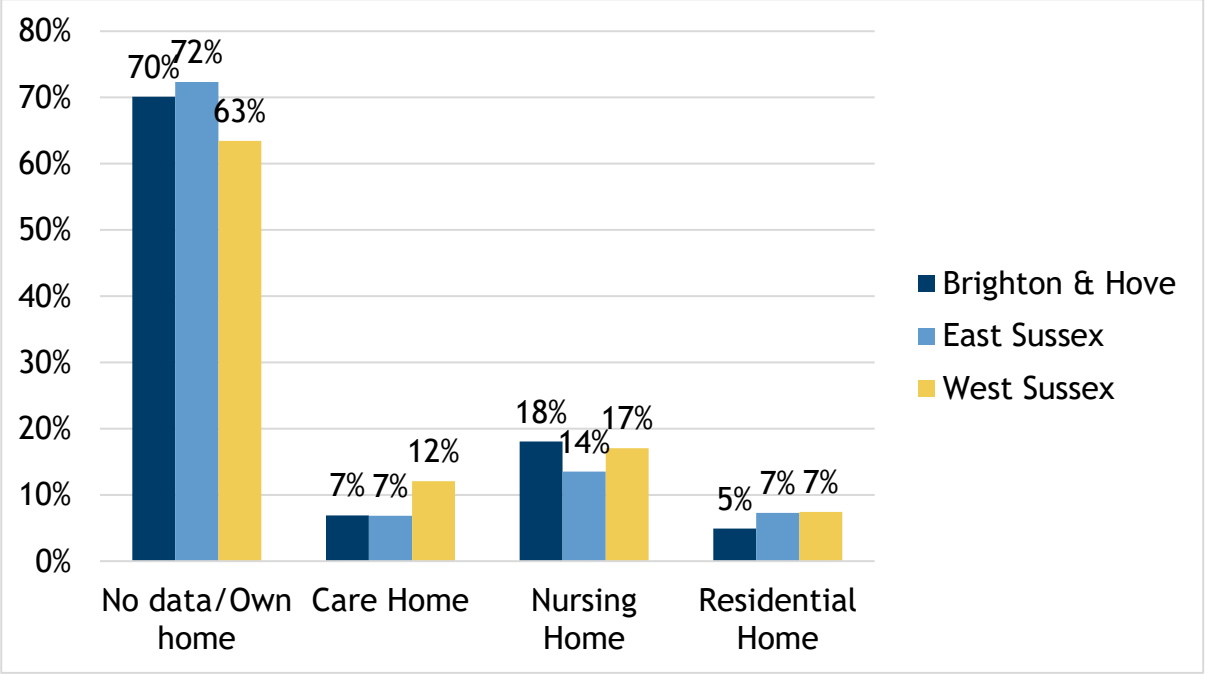
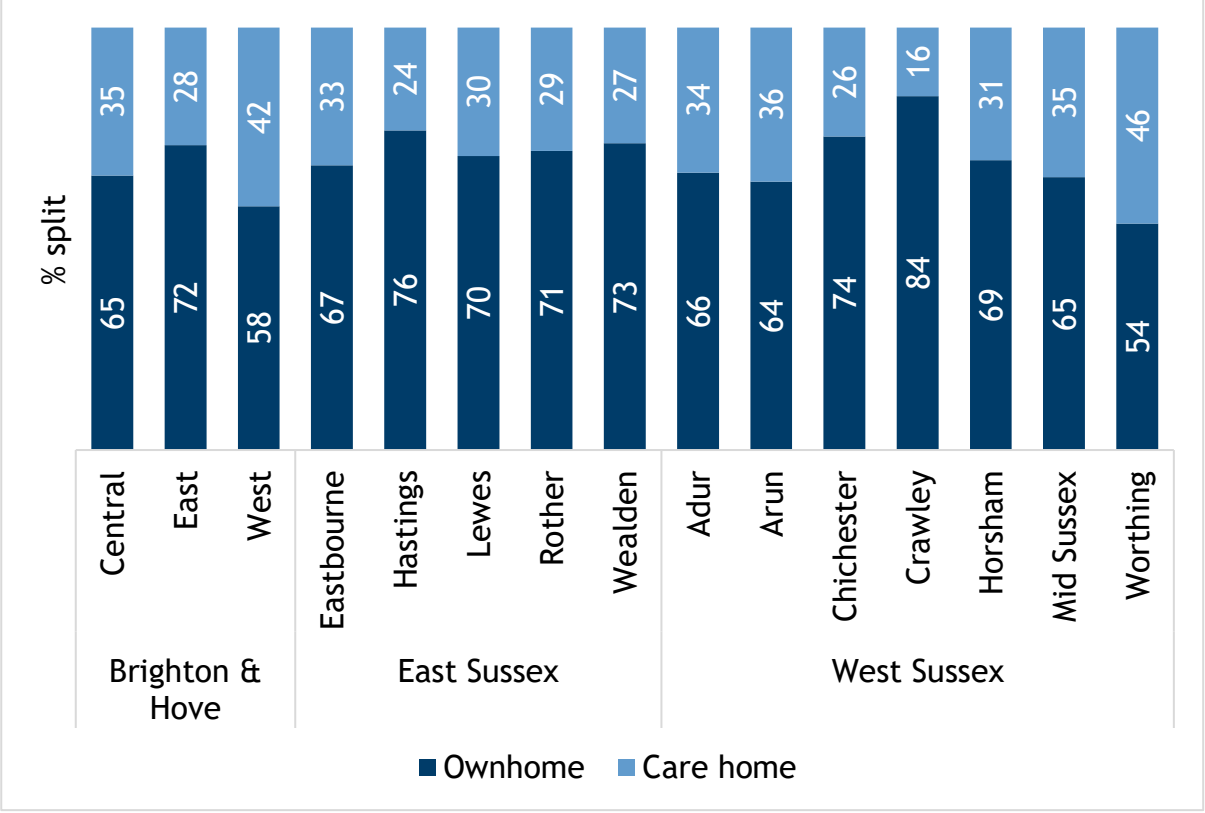


Figure 15 Percentage of people on Palliative Care SID- QOF Palliative Care register who live in care home/hospice, 2024/25.



ReSPECT Plans recorded for those on the Palliative / Supportive Care register.

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. It is a structured process and document used to record a person's preferences and clinical recommendations for emergency care and treatment, especially in situations where they may not be able to express their wishes. (56)

It applies to all age groups, including children and young people. Although it is not limited to EoLC, it includes preferences for treatments that are wanted and those that are not. The plan, and associated document, is designed to be used in emergencies, guiding healthcare professionals when quick decisions are needed. This process is important for the following reasons.

Patient centred planning

- It ensures that care aligns with the individual's values, preferences, and clinical needs especially when they cannot communicate.
- Improved emergency decision making.
- The plan provides a concise summary for clinicians, helping them make informed decisions quickly during emergencies.

Consistency across services

It promotes consistent care planning across hospitals, community services, and care homes.

Legal and ethical clarity

While not a legally binding document, it supports ethical decision making and complements do not attempt cardiopulmonary resuscitation (DNACPR) orders and other legal tools like Advance Decisions.

Supports communication

Encourages conversations between patients, families, and professionals about future care, which can reduce anxiety and conflict.

It should be noted that ReSPECT plans form part of wider discussions about EoL care. Within Sussex, there have been initiatives to promote the discussion and completion of ReSPECT plans. There are specific SNOMED codes related to the recording of ReSPECT plans within the patients record which have been used for this analysis.

Table 28 highlights the range of percentages of registered patients on the Palliative/Supportive Care register that have a ReSPECT plan recorded.

It shows there is variation between Places and ICTs. In areas where there are larger numbers of older people such as Rother and Worthing, larger numbers of people with a PCC have a ReSPECT plan recorded. Adur has the highest percentage with 66%, but a count of 235 with a ReSPECT plan.Whilst Crawley has the smallest number, 58 and percentage 35%.

Table 28 The number and percentage of those on SID - QOF palliative care register and with a ReSPECT Plan recorded, 2024/25.

Place and ICT	Palliative Care Register	Has ReSPECT Plan	%
Brighton & Hove	1,091	557	51%
Central	277	143	52%
East	374	187	50%
West	440	227	52%
East Sussex	3,287	1,822	55%
Eastbourne	669	411	61%
Hastings	583	297	51%
Lewes	474	240	51%
Rother	845	543	64%
Wealden	716	331	46%
West Sussex	4,782	2,474	52%
Adur	355	235	66%
Arun	1,474	852	58%
Chichester	675	245	36%
Crawley	166	58	35%
Horsham	608	265	44%

Place and ICT	Palliative Care Register	Has ReSPECT Plan	%
Mid Sussex	491	227	46%
Worthing	1,013	592	58%
No LSOA recorded/attributable	107	43	40%

Sex

Table 29 shows the difference between females and males on the SID- QOF palliative care register that have a ReSPECT plan recorded. Females make up 55%.

Table 29 Sex of those on the SID - QOF palliative care register that have a ReSPECT plan recorded. 2024/25

Sex	Palliative Care Register	Has ReSPECT plan	%
Female	5,669	3,129	55%
Male	3,598	1,767	49%
Total	9,267	4,896	53%

Age

Table 30 highlights the age groups of those on the SID - QOF palliative care register that have a ReSPECT plan recorded. Older age groups are more likely to have a ReSPECT plan recorded.

Table 30 Age groups of those on the SID - QOF palliative care register that have a ReSPECT plan recorded. 2024/25.

Age Band	Palliative Care Register	Has ReSPECT Plan	%
18 to 64	1,228	258	21%
65 to 74	1,303	459	35%
75+	6,736	4,179	62%

Ethnicity

Table 31 Ethnicity of those on the SID- QOF palliative care register that have a ReSPECT plan recorded. 2024/25.

Ethnicity	Palliative Care Register	Has ReSPECT Plan	%
Asian or Asian British	74	25	34%
Black, Black British Caribbean or African	66	29	44%
Mixed or multiple ethnic groups	69	25	36%
Other ethnic group	44	19	43%
White	8,840	4,720	53%
No data	174	78	45%
Total	9,267	4,896	53%

Deprivation

There are social gradients in health outcomes, associated with deprivation. Table 32 using the national IMD 2019 quintiles, highlights the percentage of those on the SID Palliative care register that have a ReSPECT plan recorded. Among community-dwelling people on the register, 43% in the most deprived quintile had a ReSPECT plan recorded. Further analysis would be needed to understand this, but it could be explained by the higher prevalence of morbidity within deprived populations) and greater use of primary care services by people on the palliative care register.

Table 32 IMD 2019 quintile of those on the SID- QOF palliative care register that have a ReSPECT plan recorded, 2024/25

IMD Quintile (1= most deprived, 5 = least deprived)	Palliative Care Register	Has ReSPECT plan	%
1	668	284	43%
2	944	390	41%

IMD Quintile (1= most deprived, 5 = least deprived)	Palliative Care Register	Has ReSPECT plan	%
3	1,759	699	40%
4	1,511	614	41%
5	1,249	460	37%
No Lower Super Output Areas attributable to East Sussex	86	33	38%
Total	6,217	2,480	40%

Please note, people in care homes (n=3050) have been removed from the data because care home residents often have their address recorded as the care home, not their previous home. This means deprivation scores are linked to the care home's location, not the resident's original socioeconomic context. Many care homes in Sussex are based and located in places that enable providers to provide care in large properties in less affluent areas where property is less expensive. Therefore, including care home residents' deprivation analysis can introduce misclassification bias (94). 79% of Care home, nursing and residential home settings residents with a PPC recorded have a ReSPECT plan recorded. Those living in their own homes or no data recorded (we assume most of which will be living in their own home) were 40%, compared with 79% in care settings, a difference of 39 percentage points.

Table 33 Type of residence of those on the SID - QOF palliative care register that have a ReSPECT plan recorded. 2024/25.

Type of residence	Palliative Care Register	Has ReSPECT Plan	%
No data/own home	6,217	2,480	40%
Care Home	905	718	79%
Nursing Home	1,482	1,174	79%
Residential Home	663	524	79%
Total	9,267	4,896	53%

The data suggest that ReSPECT plan completion is becoming embedded within PEoLC across Sussex, with 53% of people on the palliative care register having a recorded ReSPECT plan.

There is considerable variation by geography, age, ethnicity and deprivation. ReSPECT plans are much more likely to be recorded for older people aged 75 and over (62%) and for care home residents (79%) than for younger adults aged 18–64 (21%) or those living in their own homes (40%). There is also variation between Places and ICTs, with completion rates ranging from 35% of those on a register in Crawley to 66% in Adur, and lower recording rates among most minority ethnic groups compared with the White population.

These findings suggest that opportunities remain to improve advance care planning and ReSPECT discussions, particularly for younger adults, community-dwelling patients, some ethnic minority groups and areas with lower completion rates. Addressing this unwarranted variation could help ensure that more people have their care preferences recorded and respected, supporting personalised care and reducing inequalities in access to advance care planning.

Demographic profile of those with an Advance Care Plan of those on the Palliative/Supportive Care register

Universal Principles for Advance Care Planning (95)

Advance Care Planning (ACP) is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversation about these.

The process, which is likely to involve a number of conversations over time, must have due consideration and respect for the person's wishes and emotions at all times. As a result, the person should experience a greater sense of involvement and the opportunity to reflect and share what matters most to them. The outputs of these discussions may include one or more of the following:

- An advance statement of wishes, preferences and priorities, and may include nomination of a named spokesperson.
- An Advance Decision to Refuse Treatment (ADRT)
- Nomination of a Lasting Power of Attorney (LPA) for health and welfare who is legally empowered to make decisions up to, or including, life sustaining treatment on behalf of the person if they do not have mental capacity at the time, depending on the level of authority granted by the person.
- Context specific treatment recommendations such as emergency care and treatment plans, treatment escalation plans, cardiopulmonary resuscitation decisions, etc.

An advance statement is not legally binding, but it is useful to inform and guide decision making in the future if the person subsequently loses their capacity to make decisions about their care. ADRTs and LPAs are legally binding provided they are valid and applicable. ACP discussions can occur over time, between people and those important to them, such as family, friends, people in their communities as well as with health and care professionals. It should not be assumed that everyone wants to have ACP conversations when offered. Their wishes should be respected. If people decline, this can be sensitively revisited at a later date. Clinician led discussions about treatment preferences, such as 'do not attempt cardiopulmonary resuscitation' (DNACPR), intravenous antibiotics and acute hospital admissions, may be part of these person led ACP conversations, and may also cover other non medical issues which matter to the person.

Table 34 highlights the overall percentage of Sussex residents, within SID, that have a PCC recorded and an ACP recorded. Across Sussex in total, 13% have an ACP recorded. There is variation between places, Brighton and Hove, and East Sussex have 14%, whilst West Sussex is 12%, however West Sussex has the largest number of people with both a PPC recorded and an ACP recorded at 576. There is variation between ICTs. 26% of this Palliative Care cohort that have an ACP recorded reside in Rother and Worthing, compared to 3%, which is 5 patients, in Crawley. There will be many factors that influence this variation. Rother and Worthing, have larger populations of care home residents, with health and care professionals likely familiar with undertaking ACPs with patients and residents requiring care. ACP facilitates person-centred care which is aligned to people's wishes where possible. Those working in care homes may seek to complete ACPs to ensure they are able to provide person-centred care to those residing in the service. This contrasts with the experience of people living in their own homes, where GP consultations may provide limited time to explore a person's healthcare needs, and their wider care and social needs may be less likely to be explored.

This analysis does not explore quality and content of ACP within Sussex, further analysis would be required to understand the content, quality and completeness of ACPs.

Table 34 Place and ICT of those on SID - QOF palliative care register that have advance care plan. 2024/25

Place and ICT	Palliative Care Register	Advance care plan	%
Brighton & Hove	1,091	151	14%
Central	277	55	20%
East	374	32	9%
West	440	64	15%
East Sussex	3,287	473	14%
Eastbourne	669	70	10%
Hastings	583	73	13%
Lewes	474	47	10%
Rother	845	218	26%
Wealden	716	65	9%
West Sussex	4,782	576	12%
Adur	355	69	19%
Arun	1,474	74	5%
Chichester	675	66	10%
Crawley	166	5	3%
Horsham	608	33	5%
Mid Sussex	491	63	13%
Worthing	1,013	266	26%
No LSOA	107	7	7%
Total	9,267	1,207	13%

Age

Table 35 Age profile of people on the SID-QOF palliative care register with a recorded ACP, 2024/25

Age Band	Palliative Care Register	Advance care plan	%
18 to 64	1,228	59	5%
65 to 74	1,303	80	6%
75+	6,736	1,068	16%

Ethnicity

Table 36 outlines the variation between different ethnic groups that are on the SID -QOF palliative care register that have an ACP. The overall numbers of non white groups are quite small so caution should be exercised when interpreting their data. Overall, they are relatively similar percentages of groups that have an ACP recorded.

Table 36 Ethnic group of those on the SID-QOF palliative care register that have a have an ACP recorded, 2024/25.

Ethnicity	Palliative Care Register	Advance care plan	%
Asian or Asian British	74	9	12%
Black, Black British Caribbean or African	66	*	*
Mixed or multiple ethnic groups	69	9	13%
Other ethnic group	44	*	*
White	8,840	1,169	13%
No data recorded	174	9	5%
Total	9,267	1,207	13%

* Small numbers have been suppressed.

Deprivation

As previously outlined, care home residents are removed from analysis when we explore deprivation. When we remove care home residents from this group, there is some small variation between different groups. Our most deprived groups have the smallest percentage of 4%, this is in contrast to our most deprived group having the highest percentage of respect plans recorded. However, these numbers are small. Our second most deprived group has the highest percentage of ACP of 7%. Further analysis would be needed to understand these further.

Table 37 National IMD 2019 quintile of those on the SID-QOF palliative care register that have a ACP recorded. 2024/25

IMD Quintile (1= most deprived, 5 = least deprived)	Palliative Care Register	Advance care plan	%
1	668	30	4%
2	944	64	7%
3	1,759	106	6%
4	1,511	77	5%
5	1,249	77	6%

Accommodation

Table 38 highlights that those residing in residential care settings have higher percentages of those on a PC register who have an ACP. It is those in their own homes that are least likely to have an ACP.

Table 38 Type of residence and the number and percentage of those on the SID- QOF palliative care register 2024/25.

Type of residence	Palliative Care Register	Advance care plan	%
No data/own home	6,217	355	6%
Care Home	905	170	19%
Nursing Home	1,482	455	31%
Residential Home	663	227	34%

Type of residence	Palliative Care Register	Advance care plan	%
Total	9,267	1,207	13%

Referral to PEoLC services

The majority of residents will receive their PEoLC through a GP and other 'generalist' services. This analysis identified small numbers of specialist PEoLC referral codes within primary records. There were only 63 (1%) records of PC patients that had a code relating to the notification to out of hours service and less than 5 recorded referrals to a specialist palliative care physician. However, table 39 outlines that between 9 – 19% have a referral to a PEoLC specialist service recorded.

Table 39 Number and percentage of those on the SID- QOF palliative care register that have a referral to palliative care service recorded. 2024/25.

County	Palliative Care Register	Referral to palliative care service	%
Brighton & Hove	1,091	104	10%
East Sussex	3,287	633	19%
West Sussex	4,782	421	9%
No LSOA	107	6	6%
Total	9,267	1,164	13%

The analysis of palliative and supportive care registers, ReSPECT plans, and Advance Care Planning (ACP) from the 2024/25 SID data highlights significant variation in identification, planning, and recording practices across geographies and demographic groups. While national and local Quality Outcomes Framework (QOF) data suggest a prevalence of around 0.5–0.6%, disparities between practices are stark, ranging from 0.02% to 2.2%. This inconsistency indicates opportunities to improve the systematic identification and proactive care planning for those approaching EoL.

SID data reinforces those older adults, particularly those aged 75+, women, and residents of residential or nursing homes, are most likely to appear on palliative care registers and have ReSPECT plans recorded. However, gaps remain for individuals living in their own homes, where ACP completion is notably lower (6%) compared to residential settings (up to 34%). Recording is limited and observed rates vary between groups, but further analysis is required to determine whether this represents inequitable access or underrepresentation.

Socioeconomic factors also influence outcomes, with higher rates of ReSPECT plans among the most deprived quintiles, though care home location may skew deprivation analysis. Despite these efforts, referrals to specialist palliative care services remain limited, with only 13% of patients having a recorded referral, and very few notifications to out of hours services. Overall, while progress has been made in embedding ReSPECT Plans, the data underscores the need for consistent, equitable approaches across the system in Sussex.

Critical steps to further enhance identification across health and social care, including GPs, include addressing demographic and socioeconomic disparities, and promoting ACP conversations particularly for those outside residential care. Future work should focus on improving data completeness, quality of ACP discussions and documentation, and integration of care planning across health and social care systems to ensure person-centred , proactive EoL care for all.

Protected characteristics

This NA has adopted a strong health inequalities and equity focus, with protected characteristics and inclusion health groups considered throughout the analysis. Key themes about specific groups are explored in subsequent sections. National evidence(18,22,84), local data, and stakeholder insights consistently demonstrate that access to, experiences of, and outcomes from PEoLC are not equitable across all population groups.

Evidence and local data suggest that women are more likely to be represented on palliative care registers, partly reflecting longer life expectancy, while men may be under-identified due to lower engagement with health services.

National and local findings also highlight concerns among LGBTQ+ communities(18,62), some of whom report previous experiences of discrimination within healthcare settings and anxieties about whether their identity, relationships, and care preferences will be respected at the EoL.

Local insight highlighted local communities have concerns about PEoLC not being gender affirming, whilst LGB residents have concerns about how same sex couples would be treated within healthcare settings and services during this distressing time.

There is also evidence of inequalities affecting people from minority ethnic communities. National research identifies(62) differences in PEoLC outcomes, while Sussex service utilisation data indicates that people from non-white ethnic groups are more likely to use hospital-based services during the last 90 days of life, potentially reflecting barriers to accessing primary and community-based care and support.

People with disabilities, including those with learning disabilities and sensory impairments, face additional challenges(62). Local insights identified examples where

the specific needs of people with learning disabilities were not always fully considered during transitions into EoL care settings. Similarly, communication needs associated with hearing or sight loss were not always addressed effectively, highlighting the importance of personalised and accessible care.

A key challenge for understanding and addressing these inequalities is the quality and completeness of demographic data. Improving the routine collection of information relating to protected characteristics and supporting staff to confidently ask about identity and inclusion-related factors will be essential to better understand local need, monitor equity of access, and reduce disparities in PEoLC across Sussex.

PEoLC needs of people with learning disabilities

This section assesses the PEoLC needs of people with learning disabilities, drawing primarily on evidence from the Learning Disabilities Mortality Review (LeDeR) Sussex Annual Report 2024–25. It focuses on identifying needs, inequalities and service gaps relevant to commissioners, providers and system partners responsible for planning and delivering palliative and EoL care.

LeDeR provides a unique, population level source of evidence on the lives and deaths of people with learning disabilities, identifying preventable and avoidable causes of death, highlighting common underlying multiple morbidities and establishing inequalities in access to and receipt of relevant healthcare support in order to inform service improvements inclusive of end of life care.

Sussex has an estimated 41,730 people with a learning disability, equivalent to approximately 2.16% of the population. In addition, a substantial proportion of autistic people also have a learning disability, further increasing the population likely to require reasonable adjustments, specialist support, and coordinated care at the EoL.

During the 2024–25 reporting period, 158 deaths of people with learning disabilities or autistic people were notified to the LeDeR programme in Sussex. This represents a continued year on year increase in notifications. The median age of death was 62 years, with deaths occurring across a wide age range (19–91 years).
People with learning disabilities experience earlier mortality than the general population, meaning that palliative and EoL needs often arise at younger ages, over prolonged periods, and alongside long term social care involvement.

LeDeR identifies that the most common causes of death for people with learning disabilities in Sussex are, diseases of the respiratory system, frailty, dementia, diseases of the circulatory system, infection and sepsis.

Cancer is present but is not the predominant cause of death, contrasting with patterns seen in the general population.

People commonly experience multiple long-term conditions, including respiratory disease, epilepsy, dementia, sensory impairment, incontinence, and severe frailty. These conditions are associated with unpredictable and prolonged trajectories of decline, rather than a clearly defined terminal phase, often making the terminal phase difficult to identify. This creates a need for early, holistic palliative approaches, proactive symptom management, ongoing reassessment of goals of care over time.

A consistent theme across Sussex LeDeR reviews is late recognition of deterioration, driven by, diagnostic overshadowing, symptoms being attributed to learning disability rather than physical illness, missed opportunities in annual health checks and routine monitoring including national screening processes and poor application of the Mental Capacity Act regarding health-related decision making.

Several case studies describe late diagnosis of advanced disease, including cancer.

People with learning disabilities are at high risk of late referral to palliative care. Earlier identification of decline and anticipatory planning is a critical unmet need. Greater integration is required between primary care, learning disability services and palliative teams.

Sussex LeDeR highlights significant system challenges relating to care coordination, particularly:

- unclear ownership of EoL care planning, fragmented pathways between hospital, community services and care settings, limited involvement of specialist palliative care in complex cases.
- The most frequently identified learning themes relate to professional practice and provision of care pathways, DNACPR decisions and EoL care.
- Out of area placements present particular risks, including reduced family advocacy, limited local knowledge of services and unclear accountability for EoL planning.

People with learning disabilities require explicitly coordinated EoL pathways, with clear leadership and accountability. Care homes and supported living services need direct access to palliative expertise and support as people with a learning disability are more likely to die in hospital than the general population.

Sussex LeDeR reviews repeatedly identify gaps in advance care planning, including the absence of documented Advance Care Plans, late or crisis driven DNACPR decisions, lack of documented preferences for place of care and death.

In addition, there are recurring concerns about the application of the Mental Capacity Act (MCA) such as failure to maximise capacity, inadequate best interest decision making, insufficient reasonable adjustments to support understanding and engagement, and a lack of understanding on the legally correct consultation of interested parties and underutilisation of IMCAs.

There is a substantial unmet need for accessible, adapted advance care planning. Palliative services must be equipped to work within MCA frameworks and support best interest decision making. Staff across health and social care require training and confidence in these processes.

Sussex LeDeR case studies illustrate that good EoL outcomes are achieved when discharge planning is well coordinated, care staff are supported by hospice and palliative services, people are enabled to remain in familiar environments.

Conversely, poor outcomes occur when preferences are not recognised or recorded, hospital admission becomes the default, and learning disability expertise is absent from acute decision making.

People with learning disabilities may require additional support and proactive care planning to achieve their preferred place of death. Strong collaboration between community services, hospices, care providers and families is needed to reduce the likelihood of avoidable or unwanted hospital deaths.

LeDeR highlights the central role of families and paid carers, many of whom have supported individuals for decades. Bereavement is often complicated by long term caring relationships, trauma associated with avoidable deterioration or poor care, and lack of accessible bereavement support.

People with learning disabilities themselves may also require bereavement support, particularly in communal living settings where multiple losses may be experienced.

Implications for need

Bereavement services must be accessible, inclusive and adapted. Support for carers should be recognised as a core component of EoL care pathways.

LeDeR Sussex has contributed to improvements by:

- influencing the Palliative and EoL Care Oversight Group,
- supporting the Learning Disability Palliative Care Link Group,
- promoting life story work and accessible advance care planning tools,
- strengthening cross system learning and training.

These initiatives demonstrate that targeted interventions can improve outcomes when learning disability and palliative expertise are brought together. Addressing these needs is essential to reducing health inequalities and ensuring equitable, high quality EoL care.

Faith and religious groups

Faith, spirituality and culture can have a profound influence on people's experiences, preferences and decision-making at the EoL. Sussex is home to an increasingly diverse population, with almost one quarter of residents identifying with an ethnic group other than White and a wide range of faith and belief systems represented across the

population. NHS Sussex ICB launched a comprehensive handbook for health and care staff during Dying Matters Awareness Week 2025 (5-11 May) to help colleagues provide truly personalised EoL care. It outlines rituals and customs of different faiths.

Table 40 Unmet needs/disparities in access to PEoLC and explanatory factors. (Adapted from Respecting Faith and Culture in End-of-Life Care April 2025)

Lower uptake compared to white/majority groups	**Communication**
• Lack of referrals. • Lack of knowledge of services (patients and professionals). • Lack of knowledge about what hospice care involves. • Information not available in different languages/formats for those who do not speak English or cannot read. • Lack of cultural equivalents for words such as hospice and palliative that do not have negative connotations	• Lack of translation resources and advocates. • Problems with using family/friends as translators. • Lack of sensitivity to cultural and religious issues. • Low number of ethnically diverse doctors, nurses and health care professionals. • Scarcity of training to help professionals. • Consequences: mistreatment, unmet religious needs, uncertainty and stress for professionals
Religious and family issues • Hospice care conflicting with religion (hold onto faith in God). • Avoidance of open disclosure due to religious/family values. • Assumptions from patients (care is not available nor accessible) and care providers (family will provide care)	End of life decisions. • Less likely to complete advance care planning documents. • Mistrust from patients. • Influence of religion (God is the one to decide). • Western values of autonomy / right to self-determination not applicable to everyone and contrast with family/community decision-making

Full details and the handbook can be found at Respecting Faith and Culture in End of Life Care Handbook April 2025.

People living with HIV

There are over 3,500 people living with HIV (PLWHIV) in Sussex, who are accessing lifesaving treatment from HIV treatment centres. Many of whom are ageing and experiencing increasing frailty, co-morbidities, and changing social circumstances. Their needs extend beyond clinical management and viral suppression to include emotional, social, and practical support. Many of those living with HIV in Sussex have intersecting identities that overlap with their HIV, compounding the health inequalities for some.

Local engagement, which mainly involved gay, bisexual and other men who have sex with men (GBMSM), found that stigma remains a major barrier to accessing HIV care. This included both stigma experienced from others and stigma felt or anticipated by people living with HIV. It is important to note that many heterosexual people living with HIV also live in Sussex and may experience similar challenges.

For some groups, particularly GBMSM and those diagnosed in earlier decades, past negative experiences of healthcare and loss continue to shape fears about future care, including concerns about entering hospitals, hospices, or care homes. However, engagement also identified that some heterosexual PLWHIV have experienced similar stigma, discrimination, and anxieties about care, demonstrating that these concerns can affect people across different communities and backgrounds. For some, they have not planned for their later life due to their condition, are insecurely housed, and have no children.

Sussex residents consistently emphasise the need for safe, non-judgemental, and trauma-informed healthcare and care that recognises the whole person, beyond their HIV status. Key priorities include continuity of care, advocacy, housing and discharge support, and access to inclusive PEoLC from diagnosis onwards, in line with World Health Organization guidance. Many people living with HIV trust and value HIV organisations within Sussex, such as the Sussex Beacon, Lunch Positive, and Terrence Higgins Trust.

In partnership with Marie Curie, Terence Higgins Trust has published information about EoL care for people living with HIV . Their local engagement work identified three key themes through the project which provide useful insights for the future of palliative care for this population. These themes included how lifelong, intersecting experiences of discrimination negatively impact experiences of healthcare, and ultimately upon access to care and support towards the EoL, the range of priorities for people towards the EoL, and the importance of maintaining a sense of self through life and into death(96).

Research across Sussex (including BHIVA survey data, the UPLIFT Study(97), and BSMS co-design work) further highlights the complex and intersecting needs of this population. Nearly half of people living with HIV are now aged over 50, with many experiencing social isolation, low income, and stigma linked to sexuality, ethnicity, and health status. Around one in five experience cognitive impairment, creating additional challenges for care planning and independence.

At the EoL, priorities for PLWHIV are consistent with the wider population - pain control, dignity, psychological support, involvement in decisions, and being with loved ones - but are compounded by HIV-specific challenges, including fear of discrimination, lack of tailored information, and discomfort accessing generic services.

Evidence suggests that holistic, integrated models of care, such as the Sussex Beacon model, are effective in addressing these needs by combining clinical, emotional, and practical support, improving quality of life and reducing crisis-driven service use.

Carers - The Carers Centre in Brighton and Hove

Family members and carers play a critical role in providing care and support at the EoL. Data related to PEoLC was requested for the three carers charities working across Sussex. All three work with carers that provide care and support for people at the end of life. However, The Carers Centre in Brighton and Hove was the only agency able to provide data for analysis.

The Carers Centre (Brighton and Hove) supports a diverse population of carers, with 157 carers supporting someone at the end of life and a further 649 supporting someone with a life-limiting condition. Most carers supporting someone at the end of life are aged 45–74 years and are women, reflecting the significant caring responsibilities undertaken by middle-aged and older adults.

A snapshot of their data was shared for this NA covering the calendar month of October 2025.

Of the 5,864 active service users recorded, 157 (2.7%) were caring for someone with an EoL condition, and a further 649 (11.1%) were supporting someone with a life-limiting condition. It should be noted that EoL status is often based on referral information and may not always be clinically confirmed.

The data, outlined in the table below, highlights the diversity and complexity of the caring population, with carers of all ages, backgrounds, and circumstances supporting individuals with a wide range of conditions. While not all data fields are complete, the information available provides valuable insight into carers' demographics and needs.

Carers range in age from 12 to 85+, with the majority aged between 45 and 74. Employment status varies widely, including those in full-time and part-time work, self-employment, retirement, and those not in paid work. There is also diversity in gender identity and sexual orientation, as well as a range of health conditions experienced by carers themselves, including mental health conditions, musculoskeletal issues, and sensory impairments.

The conditions of those being cared for are varied, with cancer being the most commonly reported EoL condition, alongside respiratory disease, dementia, neurological

conditions, and organ failure. Caring relationships span partners, parents, friends, and extended family, reflecting the broad social networks involved in care provision.

Table 41 Active carers supporting people with EoL and life conditions. The Carers Centre in Brighton and Hove

Measure	Number	Percentage
Total active carers	5,864	100%
Caring for EoL condition	157	2.7%
Caring for life-limiting condition	649	11.1%

Table 42 Age profile of carers (EoL cohort, n=157). The Carers Centre in Brighton and Hove.

Age Group	Number	Percentage
45–74 years	97	61.8%
Other age groups (12–44 and 75+)	60	38.2%
Total	157	100%

Table 43 Employment status (EoL cohort, n=157 – partial data). The Carers Centre in Brighton and Hove

Employment Status	Number	Percentage
Not specified	47	29.9%
Other categories (not in paid work, retired, employed etc.)	~110	~70.1%
Total	157	100%

Table 44 Gender identity (EoL cohort, n=153 known). The Carers Centre in Brighton and Hove

Gender	Number	Percentage
Women (including trans women)	111	72.5%

Men (including trans men)	42	27.5%
Total (known)	153	100%

Table 45 Ethnicity (partial data), The Carers Centre in Brighton and Hove.

Ethnic Group	Estimated Percentage
White British (majority group)	~79–85%
Asian, Black, Mixed, Gypsy/Traveller, Other	1–8 per group

Table 46 Conditions of people being cared for (EoL cohort, n=125 based on condition totals). The Carers Centre in Brighton and Hove

Condition	Number	Percentage
Cancer	94	75.2%
Non-cancer conditions	31	24.8%
Total	125	100.0%

Due to the small number of responses for individual non-cancer conditions, diagnoses have been combined into a single non-cancer category to reduce disclosure risk and improve interpretation. Conditions reported included Respiratory disease, Dementia, Parkinson's disease, Organ failure, Mobility issues, Heart conditions, Stroke / aphasia, Huntington's disease, Neurological conditions, Muscular dystrophy, Learning difficulties, Mental health conditions.

Family members and carers are a vital part of local PEoLC provision.

The data highlights that EoL caring needs extend across a wide range of ages, backgrounds and circumstances, with carers supporting people with cancer, dementia, respiratory disease, neurological conditions and organ failure. This demonstrates the importance of accessible information, practical support, emotional wellbeing services and bereavement support for carers.

All Age Continuing Care

For individuals that require NHS services due to a rapidly deteriorating condition, which may be entering a terminal phase, a Continuing Healthcare (CHC) Fast Track application can be made by a health professional and sent to the NHS Sussex ICB All Age Continuing Care (AACC) team (98).

If the patient meets clearly defined eligibility criteria, the AACC team arranges appropriate care to meet assessed needs.

Overall Fast Track (Palliative) referral data for Sussex in 2024/25 has been shared. It totals 3,695 eligible patients. The total of domestic care packages commissioned was 3,520 (264,000 hours) with a total spend of £6.8 million.

The Fast Track palliative referral data suggests that people requiring urgent EoL care support in Sussex are most commonly being identified and referred from acute hospital and hospice settings. Acute hospitals accounted for 1,506 eligible referrals, and hospices accounted for 1,457 referrals, together representing around 80% of known referrals. This indicates that many people are being recognised as needing fast-track palliative support at a relatively advanced stage of illness, often once they are already in specialist or hospital-based care.

Referrals from community and other hospital settings were also significant, with 606 referrals, showing an important role for community-based services in identifying need. However, referrals from GPs were very low, with only 22 eligible referrals. This may suggest that opportunities for earlier identification in primary care, secondary care, and community settings could be strengthened. This may indicate late recognition, although referral-source data alone cannot establish timing.

The ethnicity data shows that most Fast Track referral patients were recorded as British: 2,714 people, or 73.5%. Smaller numbers of referrals were recorded across other ethnic groups, including Irish, Any Other White background, Bangladeshi, African, Caribbean, Mixed and Asian backgrounds. There were also 184 patients recorded as ‘Not Known’, which indicates a data quality issue. The relatively low numbers recorded for minority ethnic groups may reflect the local population profile, but it may also raise questions about whether all communities are accessing Fast Track palliative support equitably.

Table 47 Source of AACC referral, all Sussex, 2024/25.

Source of Referral	Number of Referrals (Eligible)
Acute Hospital	1,506
Hospice	1,457

Source of Referral	Number of Referrals (Eligible)
Community/Other Hospital	606
Nursing Home	102
GP	22
Local Authority and Unknown Source	<10

Table 48 Ethnicity of Fast Track (Palliative) referral patients' data for Sussex in 2024/25.

Ethnicity	Number	Percentage
British	2,714	73.5%
Irish	21	0.6%
Any Other White background	42	1.1%
Other ethnic groups* **Other ethnic groups combine all individual categories containing fewer than 10 people: African, Caribbean, White and Black African, White and Black Caribbean, Any Other Black background, Any Other Asian background, White and Asian, Any Other Ethnic Group, Any Other Mixed background, Bangladeshi, Indian and Pakistani**	50	1.4%
Not known	184	5.0%
Not stated	684	18.5%
Total	3,695	100.0%

Table 49 Sexual orientation of Fast Track (Palliative) referral patients' data for Sussex in 2024/25.

Sexual orientation	Number	Percentage
Heterosexual/Straight	2,314	62.6%
Gay or Lesbian/Other	27	0.7%

Sexual orientation	Number	Percentage
Does not know/Unsure	13	0.4%
Not stated	1,075	29.1%
Not known/recorded	266	7.2%
Total	3,695	100.0%

The AACC data shows many eligible clients and significant investment in EoL care across Sussex. However, there are notable gaps in the recording of protected characteristics, particularly sexual orientation as there were less than 1% LGB identities recorded across all of Sussex and the ethnicity data limited, which could mask inequalities.

The incomplete data limits the ability to comprehensively assess equity and identify areas for improvement. However, the available records indicate that some good practice in collecting protected characteristic information is already taking place. This provides an opportunity to review, learn from, and share effective approaches across services to improve the completeness and quality of protected characteristic data collection.

South East Coast Ambulance (SECAmb) Trust

The Ambulance trust plays a vital role in PEoLC, attending patients and families at home via ambulance calls, often during moments of acute crisis. (99)

Research conducted across England (100) highlights critical challenges that hinder their ability to provide effective care to individuals in the last year of life. Key barriers include limited training in palliative and EoL care, poor integration with wider health and social care systems, and restricted access to patient records, essential medicines and clinical advice. These issues can lead to less than adequate care experiences for patients and distress among families and paramedics alike.

South East Coast Ambulance Service NHS Foundation Trust (SECAmb) plays a critical role in responding to people with PEoLC needs, particularly during periods of rapid deterioration, symptom crisis, uncertainty, or when families and carers are unsure who to contact. However, this is not work that the ambulance service are commissioned to provide. Within the local data and national research, there is narrative that suggests the ambulance service picks up non-commissioned workload in place of other services who are struggling to provide capacity in a stretched healthcare system. Therefore ambulance data provides important insight into how well the wider system supports people approaching the EoL. Ultimately, inappropriate use of 999 resources means that

ambulance crews are not able to respond to life-threatening emergencies for patients who need time critical treatment.

SECAmb are commissioned to provide emergency ‘on the day’ escalation of care transport to either hospital or for emergency hospice admission. Equally, they are commissioned to provide care in treatable ‘palliative care emergencies. In both cases, this should result in a patient being conveyed to hospital for onward care and treatment. However this is not what is reflected within the data.

It is important to note that the SECAmb data available for this needs assessment is based on Sussex ICB activity and, where local geographic breakdowns are used, these may be aligned to historic Clinical Commissioning Group (CCG) footprints rather than current Integrated Community Team (ICT), local authority, or neighbourhood geographies. This limits direct comparison with some of the other datasets used in this needs assessment and should be considered when interpreting variation across Sussex. It also means that the data is best used as an indicator of system pressure, service use and potential gaps in care, rather than as a precise measure of need by current local planning area.

For the purposes of this section, ‘See & Convey’ refers to an ambulance attendance where the patient is transported by ambulance to another care setting, most commonly an emergency department or hospital. A non-conveyance means the person was physically attended by ambulance clinicians, with assessment and management at the scene without being transported to hospital. In ambulance terminology this is often described as ‘See and Treat’. A virtual response, or “Hear and Treat”, refers to patients managed remotely, usually by telephone or clinical triage, without an ambulance crew attending in person.

SECAmb data for Sussex ICB for the period 1 April 2025 to 31 March 2026 recorded 2,522 attendances for patients coded as EoLC by an ambulance clinician within clinical record keeping software. This is a known underreport of numbers, but the current best data available. Ambulance clinicians are more likely to code a patient by the symptom presented rather than ‘EoLC’ and therefore presents an underreport, however the data provided is still concerning. Of these 2522 999 ambulance calls, 76.2% were non-conveyed, meaning they were assessed and managed without transport to hospital; 1.8% received a virtual response; and 22% were conveyed. Crews spent an average of 1 hour and 28 minutes on scene. The longest recorded on-scene time in Sussex was 5 hours and 17 minutes, while the shortest duration within the top 50 longest on-scene times was 3 hours and 42 minutes.

Table 50 SECAmb EoL care activity, Sussex ICB, 2025/26

Measure	SECAmb data	Interpretation
Total attendances coded as EoL care by an ambulance clinician	2,522	Indicates substantial ambulance involvement in PEoLC across Sussex.
Peak time for a 999 EoLC call	9am. Highest call volume is seen between 9-11am.	This data does not evidence the assumption that ambulance services are only being called in the out of hours period. Peak call time is 9-11am. Lowest 999 call volume is between midnight and 6am.
Non-conveyed / 'See and Treat'	76.2%	Most patients coded as EoLC were managed without transport to hospital. This indicates a significant burden of non-commissioned activity on the ambulance trust. On the other hand, this demonstrates effective clinical decision-making by ambulance clinicians and/or that many people's needs could be met in the community when appropriate support is available. It also suggests that ambulance services are often operating as part of the routine community EoLC response. The system should aim for significantly lower See & Treat rates. This would represent appropriate use of ambulance resources only being required for emergency care with onward treatment and conveyance.
Virtual response / 'Hear and Treat'	1.8%	A small proportion of EoLC contacts were managed virtually. This may indicate limited use of remote ambulance response for this cohort, though the data does not explain whether this reflects patient acuity, triage thresholds, coding, or availability of alternative advice pathways.
Conveyed to hospital or	22%	Around one in five patients coded as EoL care were transported by ambulance. Conveyance is not inherently inappropriate, as some patients

Measure	SECAmb data	Interpretation
another care setting		will require hospital-based assessment, treatment, symptom control or admission. However, in the context of wider evidence on preferences for home/community care, this may also reflect occasions where community support, care planning, medication access or out-of-hours response was insufficient to safely maintain care at home. The system should aim for significantly higher 'See & Convey' rates over the coming years in combination with a significantly lower overall call volume to 999. This would represent appropriate use of ambulance resources and adequate community provision of care.
Average ambulance crew on-scene time	1 hour 28 minutes	Long average on-scene times suggest that EoL care calls can be clinically, emotionally and operationally complex. An overall average on scene time would be 30 minutes for 'generalist' patients. Therefore, EoLC presents a significant resource burden for the ambulance trust.
Longest recorded on-scene time in Sussex	5 hours 17 minutes	Very long on-scene times may indicate complexity, difficulty accessing onward clinical advice, delays in arranging community support, uncertainty about care plans, or challenges in making safe decisions in the absence of shared information. All of the extremely long on scene times involved one ambulance and two members of staff. Therefore 5 hours and 17 minutes represents 10hours and 34 minutes of clinician time and essentially half a shift this crew were not able to respond to other patients. This is a very significant operational burden for the trust which is unique to EoLC. The 'top 50' longest on scene times have been audited by the trust. The outcomes show that the main contribution to extremely long on scene times is ambulance clinicians managing conflict

Measure	SECAmb data	Interpretation
		between services, often being bounced from one provider to another and needing to make multiple phone calls. It also showed that there is often conflict between providers, patients and families. All of the cases audited ended in a conveyance, with around half conveyed directly to a hospice. 26 cases happened in hours. 33 patients were already known to EoLC services. Ultimately, this showed that ambulance clinicians attempting to navigate a complex system and trying every option to keep people out of hospital.
Shortest duration within the top 50 longest on-scene times	3 hours 42 minutes	The fact that the top 50 longest attendances all exceeded 3 hours 42 minutes suggests EoL care responses place significant time demand on ambulance crews and a system failure.
25% of all 999 Cardiac Arrest calls have a DNACPR in place (101)		This means that the treatment of CPR was not required for those patients and a care plan was already in place. SECAmb are commissioned to provide the treatment of resuscitation. They are not commissioned to provide verification of death when CPR is not required. 25% equates to 1827 calls across the SECAmb regional footprint. For every cardiac arrest call, two ambulances and a rapid response car would be dispatched. This is due to the high acuity nature of the calls and the demands of CPR treatment. 20% (377) of those patients went on to receive CPR treatment with a DNACPR decision in place. This is largely due to clinicians being unaware of the DNACPR decision. However, 51 of those resuscitation attempts happened in nursing homes.

Measure	SECAmb data	Interpretation
		There were statistically significantly less inappropriate 999 calls for CPR within Coastal West Sussex.

The SECAmb data suggests that ambulance clinicians are frequently required to manage PEoLC crises in Sussex. Often supporting people without conveyance, representing a significant non-commissioned workload for the ambulance trust. Historically, non-conveyance has been seen as a strength, enabling people to remain in their usual place of residence and avoid unnecessary hospital attendance. However, the volume of attendances, the proportion conveyed, and the long on-scene times indicate unmet need in the wider system, particularly around proactive planning, shared care records, timely access to medication, and consistent community alternatives to hospital.

Table 51 Number and percentage of EoL Incidents by historic clinical commissioning Group (CCG) for Sussex ICB. SECAmb 2025/26

Historic CCG locality for Sussex ICB	Count of Incidents	% of Incidents
NHS Coastal West Sussex CCG	**918**	**35.4%**
NHS Hastings and Rother CCG	**409**	**15.8%**
NHS Eastbourne, Hailsham and Seaford CCG	**405**	**15.6%**
NHS Horsham and Mid Sussex CCG	**301**	**11.6%**
NHS Brighton and Hove CCG	**245**	**9.5%**
NHS High Weald Lewes Havens CCG	**224**	**8.6%**
NHS Crawley CCG	**89**	**3.4%**
Total	**2,591**	**99.9%***

* Percentages may not total 100% because of rounding.

Table 51 suggests that EoLC need, pressure or risk is not evenly distributed across areas. Coastal West Sussex has the highest number of incidents, with 918 incidents, accounting for 35.4% of the total 999 call volume. This suggests a particularly high level of EoLC activity, need, or system pressure in that area. Hastings and Rother and Eastbourne, Hailsham and Seaford also show relatively high numbers, with 409 incidents and 405 incidents respectively. Together, these areas account for around 31% of all incidents, indicating significant need across parts of East Sussex.

The data may point to variation in access, planning, coordination or service capacity across local areas. Higher incident numbers could reflect greater population need, higher levels of frailty or deprivation, more people dying with complex needs, or gaps in EoLC provision.

Areas with lower numbers, such as Crawley CCG with 89 incidents, may have lower recorded need, but this should be interpreted cautiously. Lower figures may also reflect differences in reporting, population size, service pathways, or identification of EoL care needs.

The data therefore supports the need for Sussex to strengthen integrated PEoLC pathways between ambulance services, primary care, community nursing, hospices, urgent care, care homes and social care. Priorities should include improving access to ReSPECT and ACP information for ambulance crews, expanding single point of contact or care coordination models, ensuring timely access to anticipatory medicines and specialist advice, and reviewing the reasons behind longer on-scene times and conveyances to identify avoidable 999 escalation. This would support more people to receive care aligned with their needs and preferences, while reducing distress for families and avoidable pressure on emergency services.

Separate analysis and reports by the Ambulance Trust, highlights examples of inappropriate resuscitation across the regional trust wide footprint., Their data from cardiac arrest registry for 2024 calendar year includes 1,827 patient cardiac arrests with DNACPR in place but 377 (20%) of those patients receiving a resuscitation attempt. 87% of attempts were initiated over the phone. 36% of those patients went on to have resuscitation given by crews. 68% of the calls were taken ‘out of hours’ with still a significant number in hours. The most common place of inappropriate resuscitation is home – where patients are three times more likely to receive inappropriate resuscitation.

The second group is Nursing Homes, with 51 of 378 patients given inappropriate CPR in a nursing home. This should be a never event.

The report shows significantly fewer inappropriate resuscitations in the Coastal West Sussex area, notably an area with dedicated EoLC Single point of access. SECAmb staff conclude that improvements should be made in relation to access to shared care records, to help reduce this problem.

Palliative and EoL Care in Acute Trusts in Sussex

Acute hospitals play a significant role in PEoLC by managing complex clinical needs and providing care for a large proportion of people in their final days. Across England 42% of all deaths occurred in a hospital, with Frailty (48%), and cancer (19%) being the leading cause of death. Those aged 75+ accounted for over 50% of all deaths. (30,64)

However, while they can meet important physical and some holistic needs, they often face barriers including late recognition of dying, limited specialist palliative care involvement, workforce constraints, and inconsistent use of structured care planning, which contribute to high levels of unmet need.

A National, multi-centre study, that included Sussex hospitals, found that unmet need at the EoL in hospitals is systemic, multi-dimensional and closely linked to failures in early recognition, care planning and service coordination. (30)

A key issue identified is the presence of a population of patients with unmet need who are not known to specialist palliative care services. The study specifically examined patients without prior specialist palliative involvement, yet many were found to require specialist input when assessed. This suggests that current systems are not reliably identifying patients who would benefit from additional support, leading to late or missed opportunities for intervention.

Care is often reactive rather than proactive, with needs only becoming apparent late in the disease trajectory or after formal review(102). The study also highlights significant variation in unmet need across different hospital settings, suggesting inequity in how care is delivered. Patients in district general hospitals were more likely to experience unmet needs than those in teaching hospitals or cancer centres. (30)

National Audit of Care at the EoL

The National Audit of Care at the EoL (NACEL) is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient providers in England, Wales and Jersey. (33)

NACEL measures the performance of hospitals against criteria relating to the delivery of care at the EoL which are considered best practice. These criteria are derived from national guidance, including ‘One Chance To Get It Right’, 2014, and NICE Quality Standards and guidance. Specifically, the audit was designed to capture information on the Five priorities for care of the dying person as set out in One Chance To Get It Right, 2014. The priorities make the dying person themselves the focus of care in the last few days and hours of life and specifically cite outcomes which must be delivered for every dying person. The Five priorities for care of the dying person are as follows:

1. This possibility (that a person may die within the next few days or hours) is recognised and communicated clearly, decisions made, and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

The audit is also closely aligned with NICE Quality Standards and guidelines. NICE Quality Standard 13 EoL care for adults covers care for adults (aged 18 and over) who are approaching the end of their life. It 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 and includes care provided by health and social care staff in all settings. It describes high quality care in priority areas for improvement.

In March 2017, this quality standard was updated and statement 11 on care in the last days of life was removed and replaced by NICE's Quality Standard 144. More specifically, there are two publications from NICE which outline standards which should be expected for the dying person and people important to them in the last few days of life. NICE Clinical Guidelines NG31 Care of dying adults in the last days of life covers the clinical care of dying adults (18 years and over) in the last few days of life. It aims to improve care for people by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity.

The guideline covered how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life. NICE Quality Standard 144, Care of dying adults in the last days of life, identifies priority areas for quality improvement for the same group of people as in NG31.

In Sussex our NHS Trusts that provide acute healthcare in hospitals participate in NACEL audits and have a NACEL report published. These Trusts are University Hospitals Sussex NHS Foundation Trust (UHSx) which provides hospital services for people in Brighton, Hove and parts of East and West Sussex. East Sussex Healthcare NHS Trust (ESHT) which is an integrated provider of acute and community care in East Sussex, and Surrey and Sussex Healthcare NHS Trust (SaSH) which is an acute trust providing care to Sussex residents in the north of West Sussex and Surrey residents.

Table 52 National Audit of Care at the EoL – Sussex NHS Trusts and National Clinical Audit Benchmarks

Indicator	National aggregate	SaSH East Surrey Hospital	UHSx Royal Sussex County, Worthing, St Richard's & Princess Royal Hospitals	ESHT Conquest Hospital	ESHT Eastbourne District General Hospital
Death recognised as likely ('Expected') during final admission	83%	79% — within expected limits; 80 cases	81% — within expected limits; 42 cases	83% — within expected limits; 90 cases	78% — within expected limits; 90 cases
Communication about hydration documented, or reason why not	62%	54% — below national rate; 80 cases	33% — below national rate; 40 cases	34% — below national rate; 90 cases	31% — below national rate; 90 cases
Anticipatory medication prescribed for likely symptoms in last days of life	87%	83% — below national rate; 76 cases	89% — above national rate; 37 cases	88% — above national rate; 81 cases	79% — below national rate; 87 cases
Emotional/psychological needs assessed, or reason why not	82%	85% — above national rate; 78 cases	51% — below national rate; 41 cases	82% — above national rate; 89 cases	72% — below national rate; 90 cases
Bereaved people rating overall care/support as excellent or good	72%	52% — below national rate; 23 cases	N/A — no data; 0 cases	N/A* — suppressed due to low numbers	N/A* — suppressed due to low numbers

Indicator	National aggregate	SaSH East Surrey Hospital	UHSx Royal Sussex County, Worthing, St Richard's & Princess Royal Hospitals	ESHT Conquest Hospital	ESHT Eastbourne District General Hospital
Face-to-face specialist palliative care service available 8 hours/day, 7 days/week	61%	Yes — 8 hours/day, 7 days/week	No — not 8 hours/day, 7 days/week	No — not 8 hours/day, 7 days/week	No — not 8 hours/day, 7 days/week
Bereaved people agreeing staff communicated sensitively	83%	70% — below national rate; 23 cases	N/A — no data; 0 cases	N/A* — suppressed due to low numbers	N/A* — suppressed due to low numbers
Individualised plan of care addressing end-of-life needs	84%	67% — within expected limits; 63 cases	68% — within expected limits; 31 cases	77% — within expected limits; 75 cases	77% — within expected limits; 70 cases
Ethnicity documented in clinical records	87%	74% — below national rate; 80 cases	76% — below national rate; 42 cases	81% — below national rate; 90 cases	80% — below national rate; 90 cases
Staff agree there is a culture prioritising compassion and support	88%	81% — below national rate; 21 cases	N/A — no data; 0 cases	84% — below national rate; 141 cases	84% — below national rate; 154 cases

The NACEL data highlights several areas of good practice across Sussex hospitals, alongside significant opportunities to improve the quality, consistency, and equity of EoL care.

The audits found that most patients who died during their final admission were recognised as likely to die before death occurred. Across the Sussex hospitals included in the audit, 78% to 83% of deaths were identified as expected, broadly in line with the national average of 83%. However, this measure does not capture how far in advance of death the approach of end of life was recognised and may therefore include cases identified only shortly before death. While recognition of dying is an important prerequisite for timely communication, personalised care planning and symptom management, performance in line with the national average does not in itself demonstrate that recognition was consistently timely or that it resulted in the delivery of all elements of high-quality end of life care.

The most consistent area of unmet need relates to communication about hydration at the EoL. All Sussex hospitals performed below the national average of 62%, with documented discussions ranging from only 31% to 54%. This indicates that many patients and those important to them may not be receiving, or having documented, conversations about hydration and related decision-making during the dying phase.

Acute hospital PEoLC evidence of unmet need in Sussex

Analysis undertaken and presented by Dr Suzanne Ford-Dunn, Medical Examiner and Palliative Care Consultant, UHSx NHS Foundation Trust, on behalf of the Palliative Care Teams and EoL Leads in Acute Hospitals across Sussex, provides important insights into unmet PEoLC needs within acute hospitals across Sussex.

There are complex challenges faced by patients and families who require specialist palliative care in acute hospital settings. Patients often present with complex needs alongside acute changes in health, new diagnoses associated with shock and uncertainty, and active treatments that must be balanced with symptom management and EoL care planning.

Specialist palliative care teams also support situations involving conflicts or difficult decision making between clinical teams and patients or families. Additional challenges include limited access to hospice services, a lack of wider specialist multidisciplinary support such as social work and psychology, pressures within the hospital environment including corridor care and escalating demand, and unmet expectations regarding the role and availability of hospital palliative care services.

Table 53 Key facts – Sussex acute hospital palliative care services

	UHSx	ESHT	SaSH
Number of beds	1,780	765	740
Number of patients referred to hospital palliative care team per year	5,160	2,230	1,980
Number of deaths per year (% with EoL care plan)	3,500 (75%)	1,970 (61%)	1,400 (62%)
Size of hospital palliative care team	3.5 Consultants 14 CNS 3 Support staff	1.6 Consultants 8 CNS 2 Support staff	1.5 Consultants 10 CNS 1 Support staff

Table 54 UHSx Specialist PEoLC patients identified as needing and wanting hospice inpatient bed. Mar-Oct 2025.

Outcome for patients placed on waiting list for hospice bed (n=194)	Percentage	Approximate number of patients
Transferred to hospice inpatient unit (IPU)	57%	111
Died in hospital while waiting for a hospice bed	34%	66
Discharged home once symptoms were managed	5%	10
Discharged to a care home	4%	8
Total	100%	194

% may not sum because of rounding.

Average wait for hospice bed before transfer	**4 days (range 0–17 days)**
Average time from being placed on waiting list until death in hospital	4 days (range 1–16 days)
Average number of patients identified as needing and wanting a hospice bed	2 patients per week per hospital

Local data demonstrates the pressure on local hospice inpatient capacity across Sussex. While most patients identified as needing a hospice bed were eventually transferred (57%), over one-third (34%) died in hospital while waiting for a hospice bed. Patients who died while waiting did so, on average, within four days of being added to the waiting list, suggesting that referrals are often made very late in the final stages of life. This indicates unmet need for timely access to specialist hospice beds and highlights the importance of earlier identification, advance care planning, and strengthening community and hospice capacity to ensure people can access their preferred place of care and death.

The findings from the Pan Sussex Hospitals Single Day Survey (October 2025) highlights the extent to which acute hospitals continue to act as the default setting for people approaching the EoL.

As part of the survey, patients were categorised;

1. Hospital admission inappropriate/avoidable (eg actively dying on admission / symptom control and known to Community Palliative Care Team).
2. Active treatment necessitating hospital admission appropriate (eg pleural drain / optiflow).
3. Active treatment with potential for community delivery (Eg bisphosphonates, IV antibiotics).
4. Completed hospital-based active treatment and now awaiting discharge placement (NH, PoC, Hospice).
5. Completed hospital-based active treatment and now unfit to move from hospital
6. Other – free text.

Table 55 SPC Sussex Hospitals Single Day Survey All NHS Trusts: combined results

Category and description	Number of patients (%)	Average length of stay (Days)	Total bed days	Average length of stay after no criteria to reside (Days)	Total bed days after no criteria to reside
1. Avoidable admission	17 (12%)	13	216	13	216
2.Appropriate admission – ongoing active treatment	55 (38%)	N/A	N/A	N/A	N/A
3.Community treatment could have been instigated	6 (4%)	8	32	N/A	N/A
4.Appropriate admission, now No Criteria to Reside (NCTR)	49 (34%)	22	1,073	8	382
5.Missed opportunity for discharge, now dying	17 (12%)	25	400	11	187
6.Other (Preferred Place of Death hospital)	2 (1%)	N/A	N/A	N/A	N/A
	145 (100%)		1,721		785

Across East Sussex Healthcare NHS Trust (ESHT), SaSH and UHSx 145 patients were under the care of hospital palliative care teams on the survey day. The review found that 57% of patients could potentially have been supported outside an acute hospital setting, while 785 bed days were occupied by patients who were no longer receiving active hospital treatment.

Almost half (49%) of these bed days related to patients who were medically fit for discharge and waiting for community, hospice or continuing care arrangements, while a further 24% related to patients who deteriorated and died while waiting for discharge arrangements to be completed.

These findings suggest substantial unmet need within community and discharge pathways, resulting in avoidable hospital stays for people approaching the EoL.

Of particular concern were the 17 patients identified as having potentially avoidable admissions, accounting for 216 acute bed days. The detailed review of these patients suggests opportunities for earlier intervention in the community, improved care planning and stronger community responses. Seven of the seventeen patients (41%) were already known to community palliative care teams, indicating that hospital admission occurred despite existing specialist support. 11 patients (65%) had a ReSPECT form in place; however, in seven cases the documented plan was not followed. Furthermore, twelve patients (71%) arrived at hospital following a 999 call.

Clinical review suggested that many admissions may have been prevented through access to a senior clinical decision maker in the community, responsive palliative care assessment, improved access to medications, and timely community-based support.

ESHT audit of quality of ReSPECT Plans

A clinical audit of the quality of ReSPECT forms was repeated in October 2023. The audit data suggests that ReSPECT Forms (RFs) in the trust are primarily being used to document DNACPR decisions and consequently RFs are not being used to their full potential in guiding personalised care. In terms of compliance to national standards, the trust is good at completing the basics of a RF: adequate legibility, complete patient demographics, health summary, clinical recommendations, DNACPR decisions, and the details of clinician who wrote the form. However, although these sections are being completed, there is room to improve the quality of information included. For example, whilst 98% of the RFs had something written in the summary of information section, almost a third (32%) of this information was regarded as poor. This was because clinicians simply listed medical conditions (not all of them relevant) and used acronyms that other members of the health multidisciplinary team may be unfamiliar with. Only 12% of RFs met the criteria for an excellent summary of information, making this is a clear area for improvement. The same picture is reflected in the clinical recommendation section of the RF. Whilst 93% of clinicians are writing a clinical recommendation, 13% of these recommendations were judged poor and only 28% excellent. Furthermore, only 48% of RFs had recommendations that would be useful to a community practitioner if the patient was discharged from hospital. The RF is meant to be a tool for patient

care across all areas of healthcare, not just hospital treatment. There were some outstanding RFs which had clearly involved the patient and attempted to make truly personalised plans. However, these were the exceptions. This is well illustrated by the fact only 28% of RFs listed the patients preferred name: indicating that patients had not been fully engaged with the ReSPECT discussion. Indeed, it was felt that less than half (48%) of RFs had any evidence of patient involvement in the RF process – despite the fact 61% of RFs said patients had capacity to be involved with the process. A major area for improvement is the emergency contact section of the form. Only 33% of forms had the full details of an emergency contact. In cases where patients lack capacity, only 33% of RFs had evidence an emergency contact was involved in planning. This is particularly worrying as when patients lack capacity, those closest to them should be consulted to get a sense of what mattered most to a patient. It such situations it is also important to inform the family about clinical decisions made about relative, as per past legal precedent.(103) An action plan is being developed to improve completion of RFs.

Community NHS Services End of Life Care

Sussex is supported by two NHS trusts that provide community services. In East Sussex, East Sussex Healthcare NHS Trust provides both acute and community-based services. In Brighton & Hove and West Sussex, Sussex Community NHS Foundation Trust provides a wide range of community-based services.

The following sections outline key highlights from these services and describe how they are helping to meet palliative and end of life care (PEoLC) and bereavement support needs across Sussex.

Sussex Community NHS Foundation Trust (SCFT)

SCFT is a major provider of PEoLC across Sussex, delivering care through community nursing teams, intermediate care units, care home support services and specialist end of life care leadership programmes. The Trust has placed end of life care as a strategic priority, focusing on earlier identification of patients approaching the EoL, improving ACP, strengthening multidisciplinary working and supporting more people to remain and die in their preferred place of care.

Community nursing services provide substantial EoL care activity across Sussex. Between June 2025 and May 2026, SCFT recorded over 23,000 referrals relating to PEoLC patients, with referral numbers increasing steadily throughout the reporting period. The Trust notes that this upward trend is continuing, reflecting both growing demand and improved identification of patients with PEoLC needs.

Community nurses work collaboratively with a wide range of services, including general practice, specialist hospice providers, adult social care, care and nursing homes, SECAmb, specialist nursing services, frailty teams, virtual wards, remote monitoring services and voluntary sector organisations. This multidisciplinary approach is essential for supporting people with complex needs in their own homes and reducing avoidable hospital admissions.

The scale and complexity of community-based EoL care activity are further illustrated by syringe pump management and mortality data.

During 2025-26, community nursing teams managed between 711 and 927 patients with syringe pumps each quarter, with the highest activity occurring during winter pressures in Quarter 3. During the same period, 4,145 deaths were recorded on community nursing caseloads. Overall, 67% of patients achieved their preferred place of death.

Advance Care Planning and ReSPECT Implementation

A major area of development within SCFT has been the implementation of the ReSPECT plan. ReSPECT aims to support ACP and guide emergency treatment decisions when individuals are unable to participate in decision-making. The programme has been implemented across intermediate care units and wider community services as part of a structured quality improvement programme.

A published evaluation, in British Journal of Nursing, (104) undertaken between 2022 and 2023 demonstrated a 43% increase in ReSPECT conversations within participating community hospital wards and improvements in the quality of documented care planning. The programme highlighted the importance of organisational leadership, local champions and implementation support in embedding advance care planning into routine practice. The implementation plan is informing wider rollout across community hospital wards for adults with frailty and multiple conditions.

SCFT has also invested significantly in workforce capability through the creation of an EoLC and ReSPECT Champion network. By 2026, the Trust had developed a network of 110 EoLC and ReSPECT Champions representing teams across the organisation. Champions participate in quarterly development events that focus on sharing best practice, strengthening clinical confidence and supporting continuous improvement.

In care home settings, audit findings demonstrated generally high-quality ReSPECT documentation. A review of 132 ReSPECT forms completed during August 2022 found strong compliance across most sections, with 53% rated as good and 36% rated as outstanding.

Table 56 Summary of SCFT ReSPECT Care Home Matron Audit September 2022

132 ReSPECT forms completed during August. (an increase of 60/ month since April)

Section	Question	% Completed
1	Preferred Name	50%
2	Summary of relevant information (Diagnoses, communication)	100%
	Details of other relevant planning documents	53%
	Legal Proxy information	100%
3	Continuum (Personal preferences)	100%
	What is Valued/ Feared	100%
4	Clinical recommendations	93%
	CPR Status	97%
5	Capacity Assessment	100%
6	Involvement in making plan	100%
7	Designation	100%
	Clinician Name	100%
	Registrant Number	98%
	Signature	97%
	Date & Time	90%
8	Emergency Contacts & others	90%
Overview	Correct template	99%
	Template issues	0%
	Are all entries in a language that can be easily understood by the patient and other HCPs	92%

Particular strengths were noted in recording what matters most to patients and identifying fears and preferences, while areas for improvement related mainly to documentation completeness and recording of DNACPR decisions.

Quality Improvement and EoLC Governance

EoLC has been identified as a Quality Account priority for SCFT between 2026 and 2028. A baseline clinical audit focusing on recognition of dying, use of the Comfort Tracker and ReSPECT documentation demonstrated variation in implementation across services. The audit found that 72 (85%) of reviewed patients had a ReSPECT document in place, 70 (82%) had Comfort Tracker interventions recorded and 64 (71%) had palliative triage documentation. However, notable variation remained in the use of SPICT4All identification tools, palliative observations and prescribing of EoL medications.

The Trust has also strengthened governance through improvements to mortality review processes, including the introduction of independent review for all inpatient deaths led by the Deputy End of Life Care Lead. SCFT is also participating in the National Audit of Care at the End of Life (NACEL), providing additional opportunities for benchmarking and service improvement.

Digital Innovation: The Comfort Tracker

One of the most significant recent developments within SCFT has been the development and testing of the Comfort Tracker, a digital tool designed to support proactive management of patients approaching the EoL. The tool was developed collaboratively by Lisa O'Hara (SCFT Nurse Consultant in Palliative and End of Life Care), Suzanne Ford-Dunn (Palliative Consultant, UHSx) and Rachel Melsom (Macmillan and SSCN Transformation Lead).

The Comfort Tracker enables patients and carers to record observations using their own devices, helping clinicians identify deterioration earlier and provide timely intervention. The programme was developed in response to increasing demand for home-based end of life care and aimed to:

- Improve patient care through earlier identification of deterioration.
- Support carers through better information and guidance.
- Facilitate proactive clinical intervention.
- Reduce clinician moral distress associated with delayed recognition of deteriorating patients.
- Support the wider shift of care from acute settings into community-based care.

During the pilot period between July 2025 and March 2026, 141 patients were supported using the Comfort Tracker. Clinician feedback demonstrated positive outcomes:

- 61% reporting improvements in arranging timely clinical care,
- 53.8% reporting improved relationships with patients before the active dying phase,
- 38.5% reporting that patients required fewer face-to-face visits.
- 35% reduction in clinicians reporting distress linked to not reaching patients earlier.

Economic evaluation suggests potentially substantial system-wide savings.

Comparison with a baseline cohort of 68 known palliative care patients found average costs of approximately £11,883 per patient during the final nine months of life. For patients supported through the Comfort Tracker, estimated costs over an equivalent nine-month period were approximately £5,624 per patient, generating an estimated saving of £6,259 per patient. Average monthly costs reduced from £1,320 to £625 per patient.

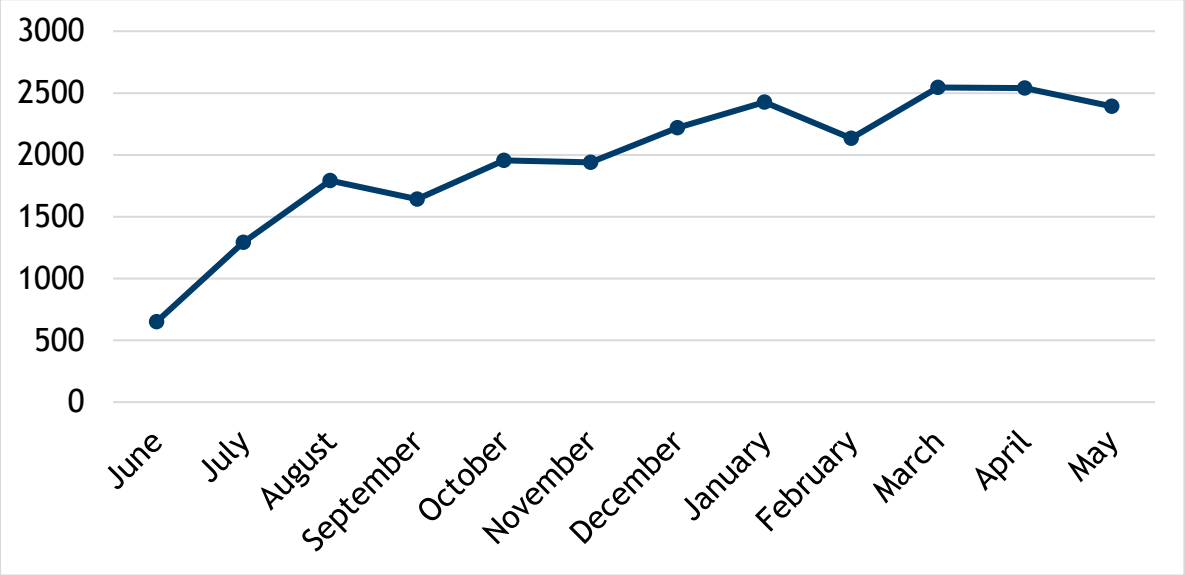
SCFT Community Nursing EoLC activity.

There are significantly more patients who are identified as being in the last year of their life in the Coastal West Sussex area where we have the ECHO end of life care hub. ECHO holds a central caseload of patients who have consented to the service which stands at approx. 2,800 at any one time. This is expected as services work collaboratively to identify patients earlier in their trajectory to receive support via the ECHO coordination service.

Community Nurses work collaboratively with a range of health care professionals including, GP's, Specialist hospice providers, Adult social care, Care and nursing homes, SECAmb, specialist nurses and teams such as Falls, frailty, Tissue viability, dementia, AHP's, Remote monitoring hub, one call, ECHO, learning disabilities, voluntary sector, care home matrons UCR and Virtual wards to deliver care in the patient's own home. This list is an example and is not exhaustive.

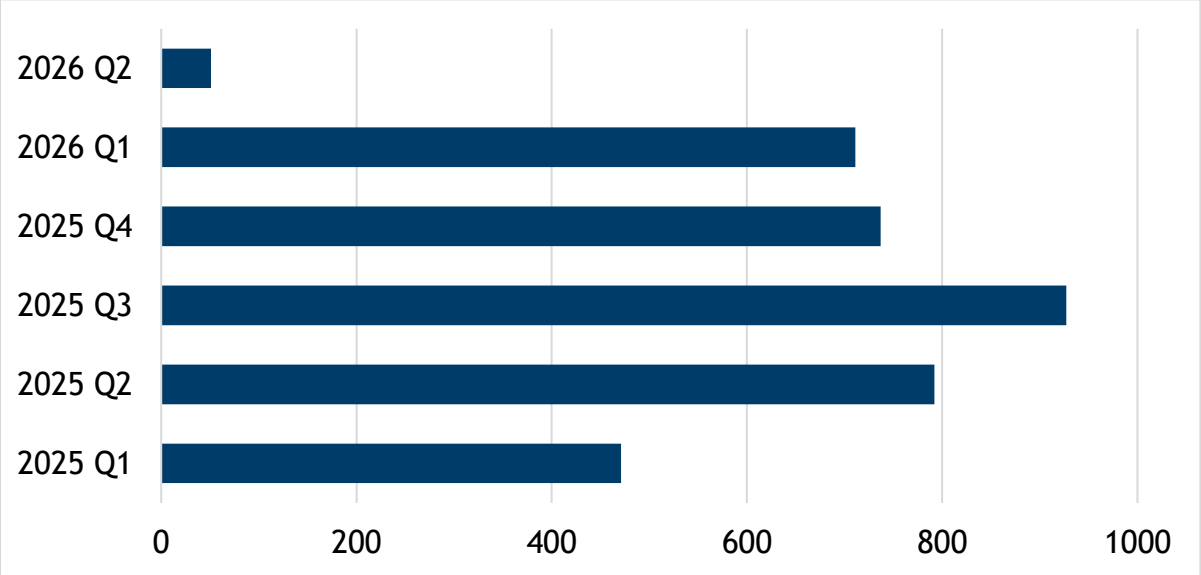
SCFT Nursing Service activity data is presented below for the required period from June 2025 to May 2026.

Figure 16 Number of EoLC referrals received and being supported by community nursing team, from June 2025 to May 2026.



There was a total of 23,520 referrals for PEoLC patients between June 2025 – May 2026. There is a steady increase in referrals and this trend continues.

Figure 17 Number of syringe pumps managed June 2025-May 2026. Q2 2026 presents partial data.



There was a peak in numbers of patients with a syringe pump in Q3 at 927 patients being managed by community nursing teams during the winter period.

In Q2, Q3 and Q4 the numbers/activity remained consistent between 927 – 711 patients being managed by Community nursing teams across SCFT. This remains consistent with winter pressures and increased complexity of patients who are at the EoL.

Number of deaths.

There were 4,145 deaths between June 2025 to May 2026. 67% of patients achieved their preferred place of death.

The number of deaths is higher than average (green line below) peaking in Q3 in alignment with the number of patients being managed with a syringe pump in the same Q.

Figure 18 Weekly deaths reported to SCFT specialist PEoLC services, June 2025 to May 2026.

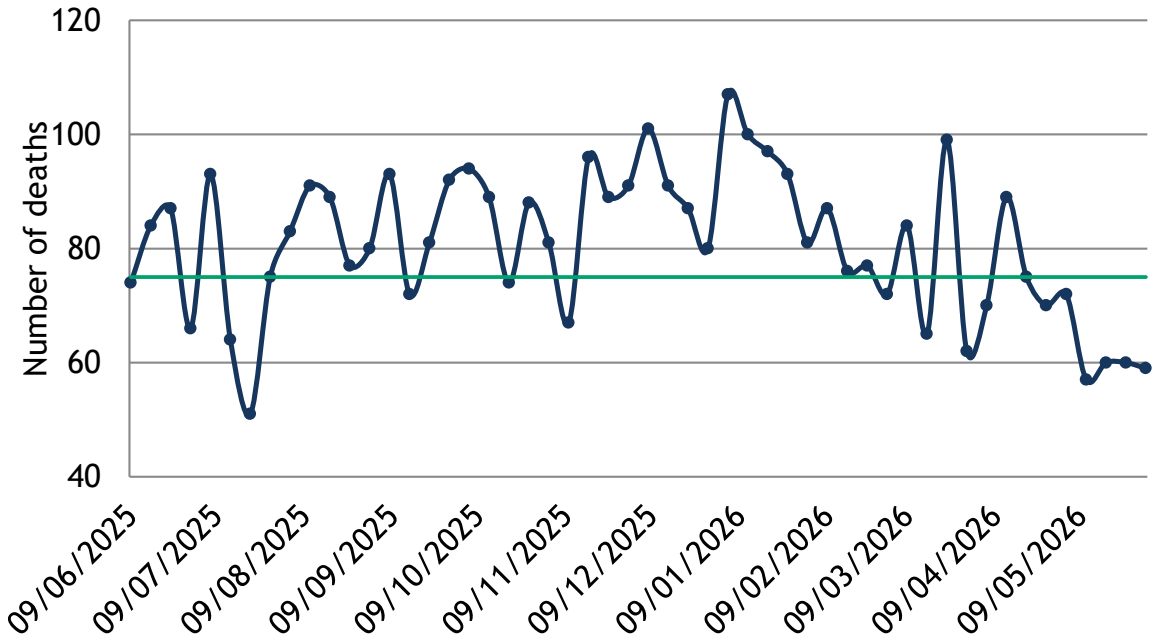
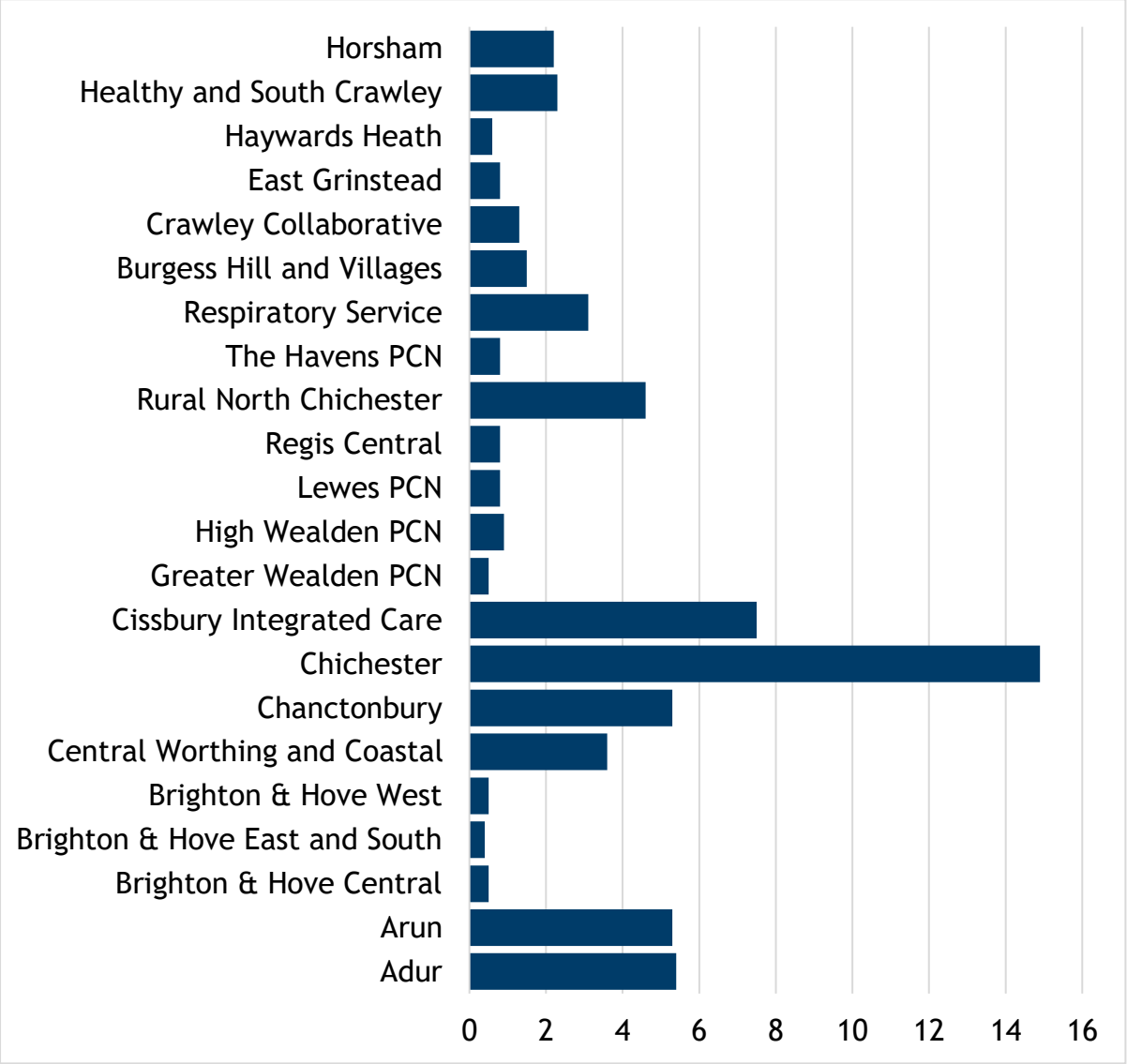


Figure 18 shows weekly deaths fluctuating considerably between June 2025 and May 2026, generally around the overall average (green line) of approximately 75 deaths per week.

Deaths increased through late 2025, reaching a peak of just over 100 around January 2026, before generally declining during spring 2026. Although there were several sharp short-term increases and falls, the final months show deaths below the period average, at around 60 per week.

Figure 19 Average weekly deaths by Community Nursing Team (PCN) or service, SCFT, from June 2025 to May 2026.



The highest number of deaths by area was in the Chichester area in West Sussex. With the lowest in Greater Wealden and Brighton Central & Brighton West Teams. This high number of deaths in community setting have a high impact of moral distress of staff managing the patient and their families. It should be noted that a proportion of SCFHT patients are registered with or resident in East Sussex localities.

A research study conducted (105) into the contributions of community nursing to PEoLC show:

- Referrals to community and district nursing services are increasing, while length of time on caseload has markedly reduced.
- In England, we show that community and district nursing teams spend about one in ten of all their care hours providing PEoLC.

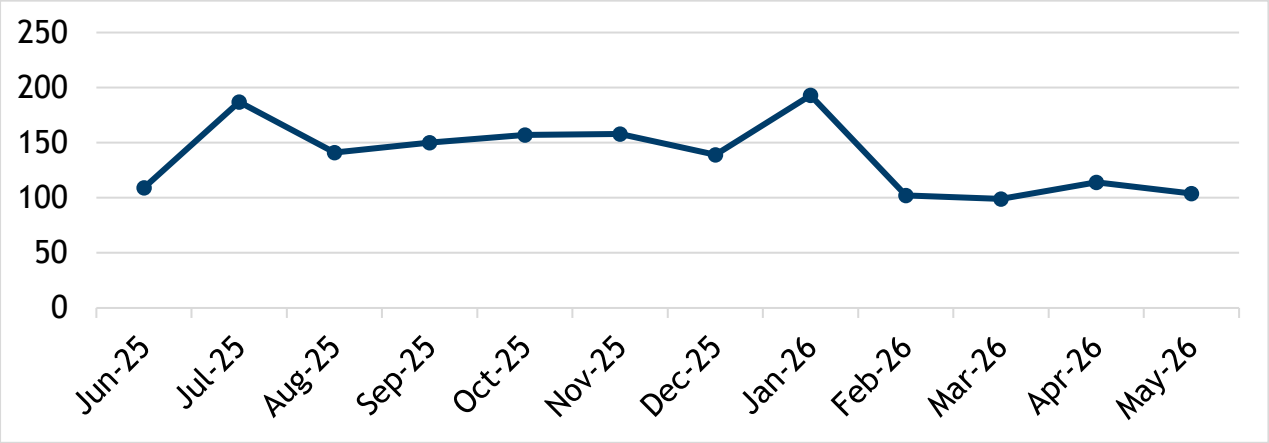
- Models of community nursing care are changing; from longer-term relational care to shorter episodes of care.
- There has been a 50% increase in referrals for palliative & end of life care over the last 10 years.

ESHT community nursing EoLC activity data

District Nurses work in partnership with General Practitioners (GPs), Hospitals, Health Visitors, Specialist Nurses and Social Services to deliver skilled patient-focused nursing care and support to individuals and their carers in a variety of non-hospital settings including patients' homes. To demonstrate the level of activity provided by the ESHT district nursing service for PEoLC patients, service activity data are presented below.

The data cover the 12-month period from June 2025 to May 2026 and include three key measures: the number of EoLC referrals received and currently being supported by the service; the number of EoLC patients currently receiving care with a syringe pump in place; and the number of deaths recorded among patients on the district nursing caseload.

Figure 20 Number of EoLC referrals, Jun 25 – May 26.



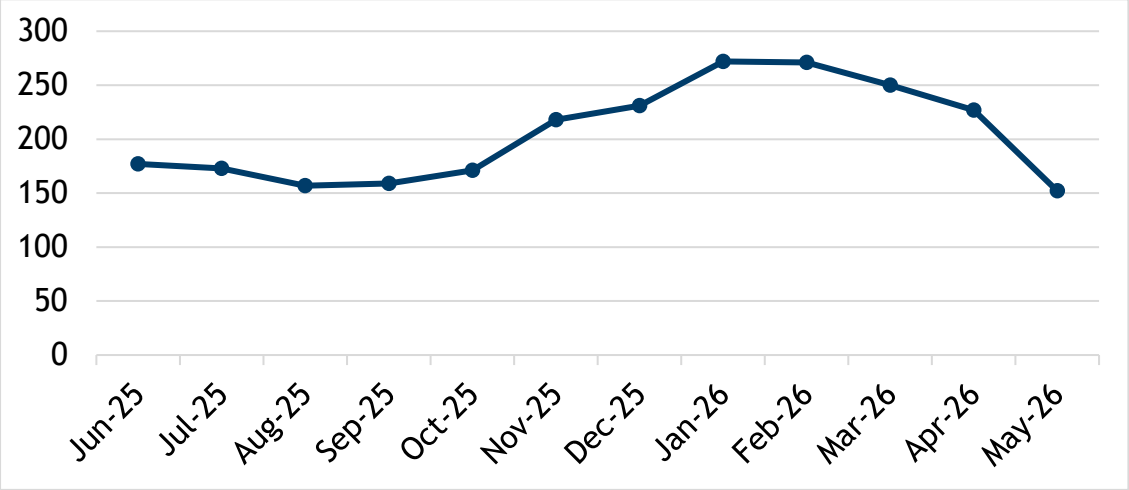
Monthly referrals ranged from approximately 95 to 195 referrals.

Referrals peaked twice:

- July 2025 (around 190).
- January 2026 (around 195).

Referrals fell substantially after January, reaching approximately 100 per month during February and March.

Figure 21 Number of "Control of symptoms via syringe pump" care plans performed, June 2025 - May 2026.

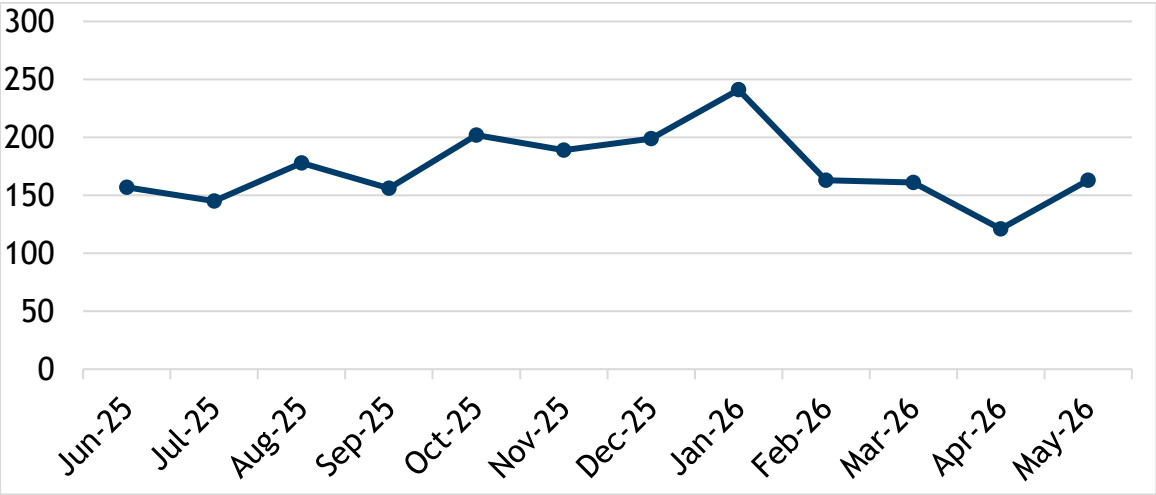


The number of care plans involving symptom control through syringe pumps increased steadily during autumn 2025 and remained elevated throughout winter 2025/26, peaking in January and February 2026. This suggests increased demand for intensive symptom management and potentially greater complexity among patients receiving EoLC. Activity reduced during spring 2026 but remained above levels seen earlier in the year for several months.

The number of deaths among patients on the ESHT Community Nursing EoLC caseload varied throughout the year but increased markedly during autumn and winter, reaching a peak in January 2026.

Activity subsequently fell through spring 2026. This pattern suggests that community nursing teams experienced heightened EoLC demand during the winter period, reflecting seasonal increases in mortality and illness severity.

Figure 22 Number of deaths on caseload, Jun 25 – May 26.



Sussex Hospice Alliance Data

Every year Hospice UK (HUK) collates activity and demographic data about hospice services across the country. The collection forms a key part of the work they carry out to promote and fight for hospice care. Participation from all hospices is crucial so that HUK can have meaningful and robust data to evidence the vital work going on at local and national level.

As described in previous sections of this report, the Sussex Hospice Alliance (SHA) members, along with hospices nationwide, attend webinars throughout the year to agree and align on the various data points so that they can ensure they are all recording and reporting the same thing. An agreed data set is shared with HUK, this data set has been analysed for this report.

It should also be noted that half of the patients supported by St Catherine's originate from within Surrey ICB. Data from Hospice in the Weald is not included, despite having a small site in East Sussex, and approximately 20% of their patients being East Sussex residents.

The following data covers the period April 2024 to March 2025

The data suggests there is substantial and sustained need for hospice and palliative care across Sussex, not only for people who die in hospice inpatient beds but also for those supported in the community, at home, in care homes and through outpatient services. Although 1,240 deaths occurred in Sussex hospices, the Sussex Hospice Alliance supported 10,622 people, indicating that hospice services are playing a much wider role in enabling people to receive PEoLC outside hospice settings.

Table 57 Capacity and utilisation Sussex Hospice Alliance Hospices, 2024/25.

Capacity of staffed Beds (Available bed days)	**Total occupied bed days**	**Actual occupancy (of staffed beds)**
23,680	23,099	97.5%

Referral source

Over half of SHA patients were referred from the hospital. With nearly a third from GP practices.

Table 58 Referral source Sussex Hospice Alliance Hospices 2024/25.

Referral source	Percentage
Hospital	55%
GP Practice	28%
Other	9%
District Nursing	5%
Care Home	2%
Family	1%

The ‘Other’ referral category used by hospices in the SHA captures a broad range of referral routes that are not recorded elsewhere. It does not represent a single referral route but rather a mixed group of professional, organisational and individual referral sources.

Table 59 highlights the age distribution of hospice patients, showing that patient numbers increase with age, particularly in the 45–64 and 65–74 brackets, suggesting a greater need for hospice services among older populations.

Table 59 The patient age group Sussex Hospice Alliance Hospices, 2024/25.

Patient age group	Percentage
19–25	0.2%
26–44	2.1%
45–64	13.9%
65–74	18.6%
75–84	32.6%
85+	32.4%

Length of stay – bedded care

People tend to be cared for as hospice inpatients for short periods either for symptom management or at the EoL. The unpredictability of demand can lead to

peaks and troughs and waiting times for a bed when a patient is referred. Any additional bed capacity isn't open because of a lack of sustainable and recurrent funding, to be able to staff these beds.

Table 60 Lengths of stay Sussex Hospice Alliance Hospices, 2024/25.

Metric	Value
Alliance Average LOS	14.5 days
Alliance Median LOS	9.7 days

Community and care activity

Table 61 outlines the number of visits and contacts that SHA hospices provided over the year. Many of these services would have enabled patients to receive PEoLC in a setting of their choosing.

Table 61 Number of visits and contacts, Sussex Hospice Alliance Hospices, 2024/25.

Activity Type	Number of contacts
Specialist Community Visits. Defined as no. of visits to a residence (NOT nursing / care home) for new or follow up patients, including in person visits or 'remote' consultations by the specialist community team.	26,387
Non-Specialist Community Visits. Defined as no. of visits to a residence for new or follow up patients including in person visits or 'remote' consultations.	15,602
Domiciliary Care Visits. Defined as no. of visits to a residence for new or follow up patients (this should be only for visits as part of an official domiciliary care or, home care service)	14,568
Outpatient Contacts. Defined as no. of assessments / consultations / treatments / therapies on hospice site (or by hospice staff at a non- residence site or virtually) for new or	10,867

Activity Type	Number of contacts
follow up patients including individually, as part of a group, via social prescribing, etc	
Care/Nursing Home Visits. Defined as separate specialist visits specifically to patients in nursing / care homes.	1,129

Ethnicity

Table 62 outlines the ethnic breakdown of SHA Hospice patients, over a fifth of patients have no ethnicity recorded. This makes it difficult to assess if different ethic groups experience barriers in accessing SHA hospices and their services.

Table 62 Ethnic breakdown of patients, Sussex Hospice Alliance Hospices 2024/25.

Ethnicity	Number	%
Asian / Asian British	57	1%
Black / Black British / Caribbean / African	42	0%
Mixed / Multiple ethnic groups	762	7%
White	6,751	64%
Other ethnic group	179	2%
Prefer not to say	124	1%
Not recorded	2,707	25%
Total	10,622	100%

Note: The 0% for Black / Black British / Caribbean / African is due to whole-number rounding. The actual proportion is approximately **0.4%**.

Religion

Table 63 outlines the religious identity of SHA Hospice patients, almost half of patients had no religion recorded. This makes it difficult to assess if different religious groups access these hospice services.

Table 63 Religious identity breakdown of patients, Sussex Hospice Alliance Hospices 2024/25

Religion	Number	Percentage
Buddhist	23	0%
Christian	2,830	27%
Hindu	25	0%
Jewish	19	0%
Muslim	26	0%
No religion	2,019	19%
Not recorded	5,067	48%
Other religion	384	4%
Prefer not to say	223	2%
Sikh	6	0%
Total	10,622	100%

Percentages are rounded to the nearest whole number.

Sexual Orientation

Table 64 outlines the recorded Sexual Orientation of hospice patients. The majority were not recorded. Where it is recorded this is below the expected population profile of LGBTQ+ people. There is evidence of some good practice for collecting this information within Sussex hospices, which could be explored to support improve recording across other hospices.

Table 64 Sexual Orientation breakdown of patients, Sussex Hospice Alliance Hospices 2024/25

Sexual Orientation	Numbers of patients
Bisexual, Gay or Lesbian	39
Not recorded	5,181

Other sexual orientations	21
Prefer not to say	61
Straight / Heterosexual	3,331
Grand Total	8,633

Friends and family members

Table 65 outlines support that these six Hospices provided to patients, carers and loved ones. The 'Bereavement Only' are the bereaved that accessed bereavement support services.

Table 65 Count of support provided, Sussex Hospice Alliance Hospices 2024/25

Bereavement ONLY sub section	**2,316**
Total Contacts Care for Carers / Loved ones	24,036
Total Unique Carers / Loved ones All Services	4,089

The tables 66 and 67 provide an overview of Sussex hospice patients in the Sussex Hospice Alliance hospices and their primary diagnosis or life-limiting condition. Out of a total of 10,622 patients, 6,433 (61%) had cancer as their primary diagnosis, 3,192 (30%) had a non-cancer life-limiting condition, and for 9% the diagnosis was not recorded.

Among the non-cancer group (3,192 patients), the most frequent conditions were chronic respiratory disease (678), dementia including Alzheimer's (459), heart failure and other heart/circulatory diseases (473), and neurological conditions (210).

Other non-cancer diagnoses included chronic renal failure, motor neurone disease, liver failure, and HIV/AIDS, though these were less common. This breakdown highlights that while cancer remains the predominant diagnosis in hospice care, a significant minority of patients are admitted for a wide range of other serious illnesses.

Table 66 Number and percentage of hospice patients and primary diagnosis / life-limiting condition Sussex, Hospice Alliance Hospices 2024/25

	Numbers of hospice patients and primary diagnosis / life-limiting condition	%
Not recorded	997	9
Total Cancer	6,433	61
Total non-Cancer	3,192	30
Grand Total	10,622	100

Table 67 All other non-cancer, Sussex Hospice Alliance hospices patients 2024/25

Non-cancer conditions	Number
Dementia including Alzheimer's	459
Chronic renal failure	99
Not recorded as one primary diagnosis	9
Motor neurone disease	131
Neurological conditions	210
Heart failure, stroke and other heart & circulatory	473
Chronic respiratory disease	678
Liver failure, chronic/non-malignant liver disease	37
All other non-cancer (inc HIV, Diabetes mellitus)	1094
Grand Total	3192

Most referrals come from hospitals (over half), this may indicate missed opportunities to identify PEoLC needs in primary care and wider community services.

The largest patient age groups are 75–84 and 85+, together making up about 65% of patients. There is a high occupancy rate (97.5%), suggesting strong bed utilisation across Sussex. The occupancy is only for those beds that the Hospices are able to fully staff/resource and open for patients. If all registered beds were staffed/resourced the hospices could provide a further 8440 bed days per year.

There is minimal spare capacity in the system. Community visits (specialist and non-specialist) are significant, indicating a strong emphasis on care at a person's usual home.

Learning from deaths, complaints and prevention of future deaths: Sussex Overview

Across Sussex, NHS system partners are continuing to strengthen how they learn from deaths, with a clear focus on improving patient safety, experience, and the quality of PEoLC. Data from NHS Sussex ICB and the Learning from Deaths Quality Improvement Network (QIN) highlights both progress and ongoing challenges.

Between November 2021 and July 2024, the NHS Sussex ICB Palliative and End of Life Care Oversight Group reported 46 complaints relating to PEoLC, with poor coordination and communication identified as the most consistent themes. The introduction of the Medical Examiner system in September 2023 has strengthened governance, ensuring all non-coronial deaths are reviewed and that learning is more systematic and incorporates family perspectives, including whether individuals experienced a "good death."

The Learning from Deaths QIN expanded its scope in 2025 to include expected deaths and broader system representation, meeting quarterly to improve the identification and analysis of themes relating to PEoLC, including across complaints and compliments. Between April and December 2024, 14 PEoLC complaints were upheld or partially upheld, most commonly relating to communication and funding arrangements, particularly Continuing Healthcare (CHC) processes. Notably, very few compliments were recorded during this period, suggesting limited sharing of positive feedback at a system level. At the time of writing, the Sussex Learning from Deaths Quality Improvement Network had been paused and was under review following the formation of NHS Surrey and Sussex in April 2026.

Further system learning is drawn from the Sussex Prevention of Future Death (PFD) reports. These are formal documents issued by a coroner in England and Wales which highlight systemic risks or dangers discovered during an inquest, and urge organisations or government agencies to take action to protect public safety. The volume of PFDs issued nationally increased significantly in 2024–25, continuing a multi-year upward trend. These highlight recurring themes including:

- Communication failures.

- Delayed recognition of deterioration.
- Governance and documentation issues.
- DNACPR decision-making issues.
- Discharge planning challenges.
- Delays in accessing treatment or beds.

Many PFD notices relate to individuals with multiple compound needs or belonging to inclusion health groups, including people experiencing substance misuse, mental health conditions, involvement with the criminal justice system, or other forms of vulnerability. System-level challenges include limited access to specialist services, gaps in care planning and transitions, and capacity pressures, particularly around bed availability. Ligature deaths also remain a significant concern, reflecting wider national patterns.

A wider review of approximately 150 complaints and compliments (2020–August 2025) provides further insight into people's experiences. While around 20,000 people die in Sussex each year, the relatively small number of complaints should be interpreted cautiously, as this dataset does not include complaints held by individual providers. Within these cases, only nine compliments were identified, often highlighting positive experiences of the AACC service, particularly around facilitating care packages.

However, complaints consistently raised concerns about:

- CHC Fast Track processes, including delays, lack of clarity, and funding decisions being withdrawn or disputed.
- Coordination of care, including communication between services and across settings.
- Access to GP support, particularly home visits and timely prescribing.
- Quality of care in community and care home settings, including equipment and medication availability.
- Delays in care provision and discharge.

Encouragingly, all complaints have been formally addressed, and NHS Sussex ICB provides publicly available information to support people in accessing funding and navigating the system.

These datasets point to a system where many of the core components of EoLC are in place, but where people's needs are not always met in a timely, coordinated, or person-centred way. Persistent themes around communication, coordination, and access to services indicate gaps in joined-up working, particularly at transitions between hospital, community, and care settings. Delays in Fast Track funding, alongside confusion about eligibility, suggest unmet need in timely access to care

packages and support at the EoL, which may contribute to distress for patients and families.

The prominence of issues related to recognition of deterioration, DNACPR decisions, and discharge planning also suggests that opportunities for anticipatory care and early planning are sometimes missed, leading to reactive and potentially avoidable crises. Furthermore, the overrepresentation of people with multiple and complex needs highlights ongoing inequalities in access and outcomes, particularly for more vulnerable groups.

At the time of writing, the Sussex Learning from Deaths Quality Improvement Network had been paused. NHS Surrey and Sussex ICB have transitioned in April 2026 and are currently aligning to a Strategic Commissioning organisation and ways of working. A review of learning networks is in progress through Autumn/Winter 2026.

Evidence of unmet need reported by Healthwatch East Sussex and Brighton and Hove

In September 2020, Healthwatch Brighton and Hove produced 'A Good Send-Off' based on conversations with 15 patients who were at the very end of their life - and with their families. 'A Good Send-Off?" Patients' and Family's Experiences of EoLC. One year on (March 2021)' The report acknowledged that some progress had been made through new initiatives, care planning developments, improved discharge processes and work to strengthen community services. However, many of the key unmet needs identified in the original report remained unresolved and were still in the early stages of implementation rather than embedded in practice. The report found that patients and families continued to experience difficulties accessing coordinated support in the community, particularly out of hours, with ongoing concerns about avoidable hospital admissions, delays in discharge, limited access to specialist palliative care seven days a week, poor communication between services, and inadequate support for families caring for people at home. Advance care planning and ReSPECT discussions were still not consistently understood by patients and families, while carers continued to report a need for clearer information, a single point of contact, and better coordination across health and social care services.

Healthwatch concluded that although EoL had become a strategic priority and a number of promising pilots had been introduced, the system still lacked fully integrated community support, consistent 24/7 access to specialist advice and

effective care coordination, and sufficient community resources to consistently enable people to die in their preferred place of care, usually at home.

Healthwatch East Sussex feedback also highlights unmet need across the PEoLC pathway, particularly relating to timely access to support, care coordination and communication between services. Families frequently reported difficulties accessing urgent help, especially out of hours, with many describing confusion around NHS 111 pathways, delayed referrals, slow responses from community services, and uncertainty about who to contact when a patient's condition deteriorated. Several people called for a single point of contact for palliative care, reflecting a wider perception that care pathways are fragmented and difficult to navigate.

A recurring theme was poor coordination between GPs, hospices, community nursing teams, pharmacies, hospitals and social care services. Families often found themselves acting as care coordinators, chasing referrals, arranging medication, and communicating between different organisations. There were numerous examples of referrals being delayed, lost or declined without explanation, as well as concerns that professionals were not effectively sharing information about patients' needs, leading to avoidable crises and distress during the last days and weeks of life.

Many accounts highlighted unmet needs in symptom management and end-of-life comfort. Families described delays in obtaining pain relief, setting up syringe drivers, accessing anticipatory medicines and receiving specialist palliative care advice. Reports of unmanaged pain, agitation, breathlessness and distress were common, particularly during evenings, weekends and overnight periods when specialist support was perceived to be less available.

Difficulties, associated with the prescribing of medications, the receipt of timely prescriptions at the pharmacy, and accessing essential medications from pharmacies further compounded these issues and, in some cases, led to prolonged suffering for patients and families.

The feedback also suggests a need for greater workforce capacity and support within community services. Delays in nurse visits, shortages of staff, limited specialist knowledge among some care providers, and challenges maintaining continuity of care were frequently cited. These issues often affected people wishing to remain and die at home, with families reporting difficulties accessing equipment, obtaining practical support, arranging urgent reviews, and securing the level of care needed to achieve a comfortable and dignified death in their preferred place of care. Concerns about reductions to hospice-at-home services have heightened anxieties about the future availability of community-based support.

Carers described significant emotional, physical and practical burdens. Many felt unsupported, uninformed and overwhelmed, particularly when caring for someone with complex needs at home. Experiences of trauma, exhaustion, isolation and prolonged distress were common themes. Collectively, the feedback indicates unmet needs for better carer support, clearer information, more responsive services, stronger integration between organisations, and equitable access to high-quality PEoLC regardless of where or when support is needed.

EoL and service use patterns NHS Sussex ICB and England

ICB Palliative EoL Dashboard[8]

The ICB Palliative EoLC report provides an overview of the profile, and hospital services accessed by patients in their last 90 days of life. The dashboard displays service utilisation across multiple years to enable users to assess changes in activity over time. The dashboard has been developed to allow users to switch the focus of the report views by selecting chosen criteria, including ICB, financial year, and specific sub-groups such as age group, cause of death, place of death, ethnicity and deprivation.

The aims of the dashboard report are to:

1. Review and identify disparities based on patient characteristics and deprivation, to enable ICBs to put plans in place to address and track the effectiveness of these plans.
2. Provide information to understand whole patient journeys and develop new funding currencies.
3. Standardise reports for every Integrated Care System (ICS) and ICB.
4. Provide the benefits of scale and automation, producing analyses once and using them many times, providing much better value than individual ICSs and regions producing separate analyses.

Data for NHS Sussex ICB for the year 2024/25 has been compared to all ICBs in England for the same period.

[8] **ICB Palliative EoL Dashboard** utilises the following activity datasets via, NCDR: Mortality, SUS+ Emergency Care Dataset, Admitted Patient Care, Critical Care and Outpatient Datasets. In addition, the Palliative Care Register is derived from the GP QOF.

In 2024/25, the dashboard recorded 18,936 deaths across Sussex, with people being known to services for an average of 69 days before death, similar to the national average of 70 days.

The place of death profile in Sussex differs from the national picture. A greater proportion of deaths occur in care homes (29% compared with 22% nationally) and hospices (7% compared with 6%), while a smaller proportion occur in hospital (37% compared with 42%). This suggests a greater reliance on community, residential and hospice-based models of EoL. While this may reflect success in supporting people to remain outside acute hospital settings, it also highlights the importance of ensuring that care homes, community health services, primary care and hospice providers have sufficient capacity, workforce skills and specialist palliative care support to meet complex end-of-life needs.

The age profile of deaths further demonstrates the importance of services for older people. Almost half of all deaths in Sussex occur among people aged 85 years and over (45.7%), higher than the national average of 40.2%. In contrast, Sussex has a lower proportion of deaths in younger age groups than England overall. This reflects Sussex's older population and suggests increasing demand for services that support people with frailty, dementia, multimorbidity and complex social care needs.

The data from the service utilisation dashboard reinforce this picture, showing that people aged 85 years and over have lower planned care and outpatient activity, whereas those aged 65–84 have the highest levels of emergency and unplanned care utilisation prior to death. Hospital service utilisation in the last 90 days of life is consistently lower in Sussex than across England. Sussex residents approaching the EoL are less likely to attend A&E, experience an emergency admission, or have outpatient appointments than the national average.

Considerable variation exists between population groups. People living in more deprived areas, some ethnic minority groups and those dying from cancer experience different patterns of service utilisation. Cancer patients have substantially higher levels of planned care, outpatient appointments and follow-up activity than those dying from frailty, organ failure or other terminal illnesses, suggesting that established cancer pathways may facilitate access to coordinated care more effectively than pathways for non-cancer conditions.

Table 68 ICB Palliative EoL Care Dashboard data for NHS Sussex ICB and All ICBs in England 2024/25

Measure	NHS Sussex ICB	All ICBs
Total deaths (reported on dashboard)	18,936	528,526
Average days known to services	69	70
Average contacts per person in last 90 days	2.5	3.4
Palliative Care Register 2023/24	9,894	345,261
Palliative Care Register prevalence	0.54%	0.55%

Table 69 Place of death: ICB Palliative EoL Care Dashboard data for NHS Sussex ICB and All ICBs in England 2024/25

Place of death	NHS Sussex ICB	All ICBs	Difference between NHS Sussex ICB & all ICBs in England
Care home	29%	22%	+7 %
Elsewhere / other	2%	2%	-
Home	26%	28%	-2%
Hospice	7%	6%	+1%
Hospital	37%	42%	-5%

Table 70 Age at death: ICB Palliative EoL Care Dashboard data for NHS Sussex ICB and All ICBs in England 2024/25

Age group	NHS Sussex ICB	All ICBs	Difference
Under 18s	0.2%	0.6%	-0.4 %
18-49	3.0%	3.7%	-0.7 %
50-64	8.8%	10.6%	-1.8 %

Age group	NHS Sussex ICB	All ICBs	Difference
65-74	13.3%	15.2%	-1.9 %
75-84	29.0%	29.8%	-0.8 %
85+	45.7%	40.2%	+5.5 %

Table 71 Contact with hospital services in the last 90 days: ICB Palliative EoL Care Dashboard data for NHS Sussex ICB and All ICBs in England 2024/25

Service contact	NHS Sussex ICB	All ICBs	Difference
A&E attends	57.2%	62.2%	-5.0 %
Inpatient emergency	54.1%	60.3%	-6.2 %
Inpatient day case	10.1%	10.3%	-0.2 %
Inpatient elective	3.6%	4.7%	-1.1 %
Regular day admission	2.5%	4.3%	-1.8 %
Outpatient first appointment	22.4%	30.5%	-8.1 %
Outpatient follow-up	33.1%	40.0%	-6.9 %

Figure 23 Service utilisation by deprivation quintile ICB Palliative EoL Care Dashboard data for NHS Sussex. 2024/25

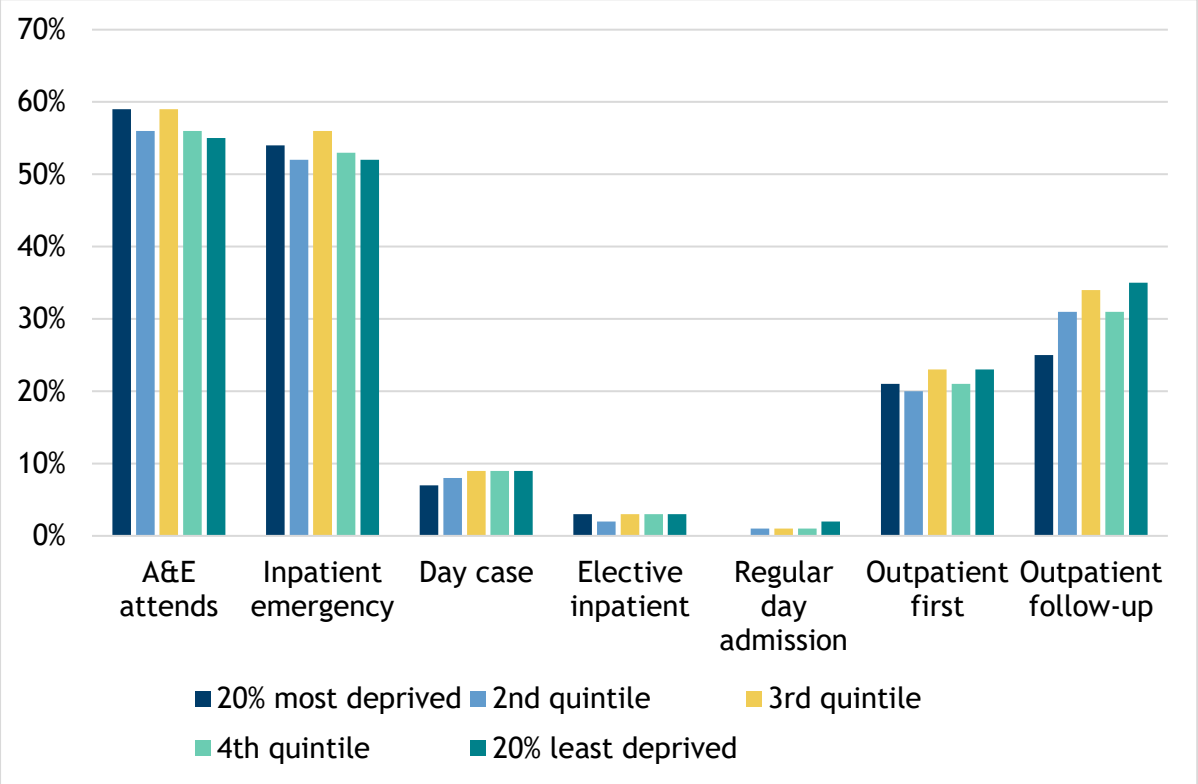


Figure 24 Service utilisation by age group ICB Palliative EoL Care Dashboard data for NHS Sussex ICB, 2024/25

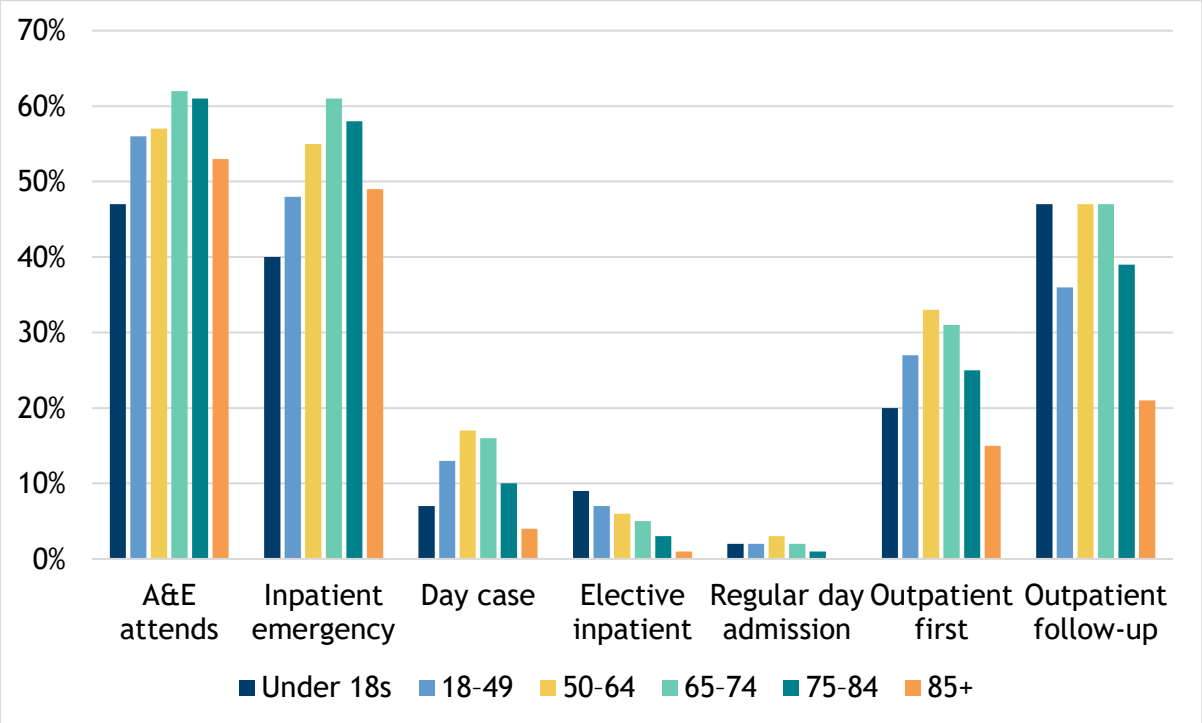


Figure 25 Service utilisation by condition, ICB Palliative EoL Care Dashboard data for NHS Sussex ICB, 2024/25

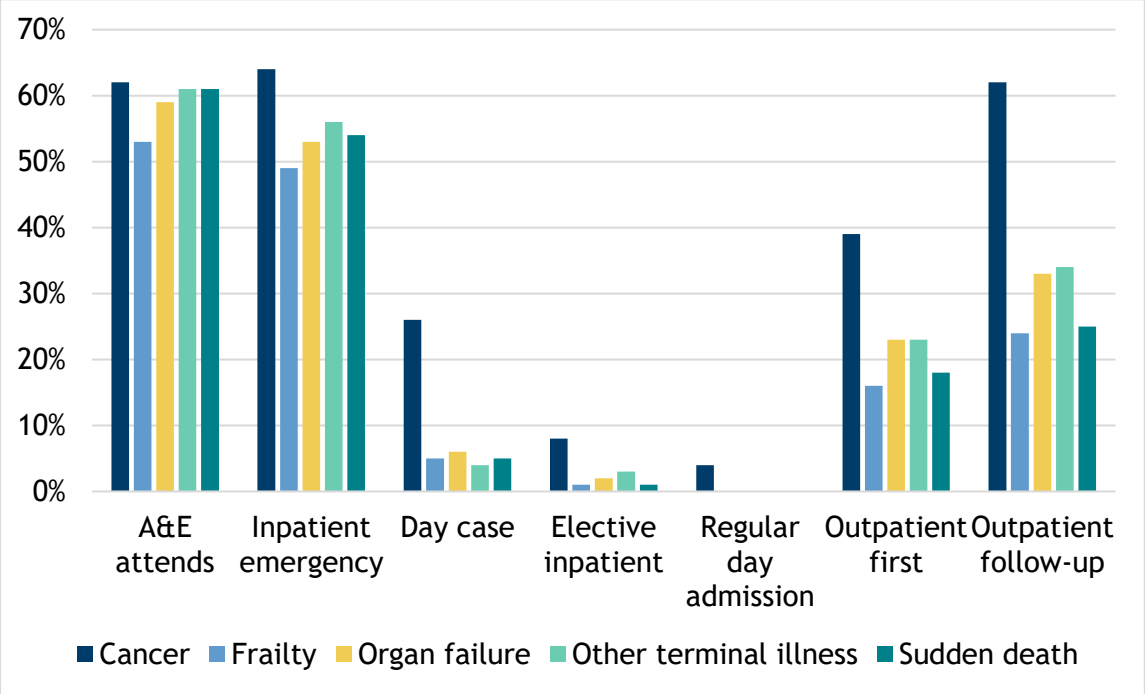
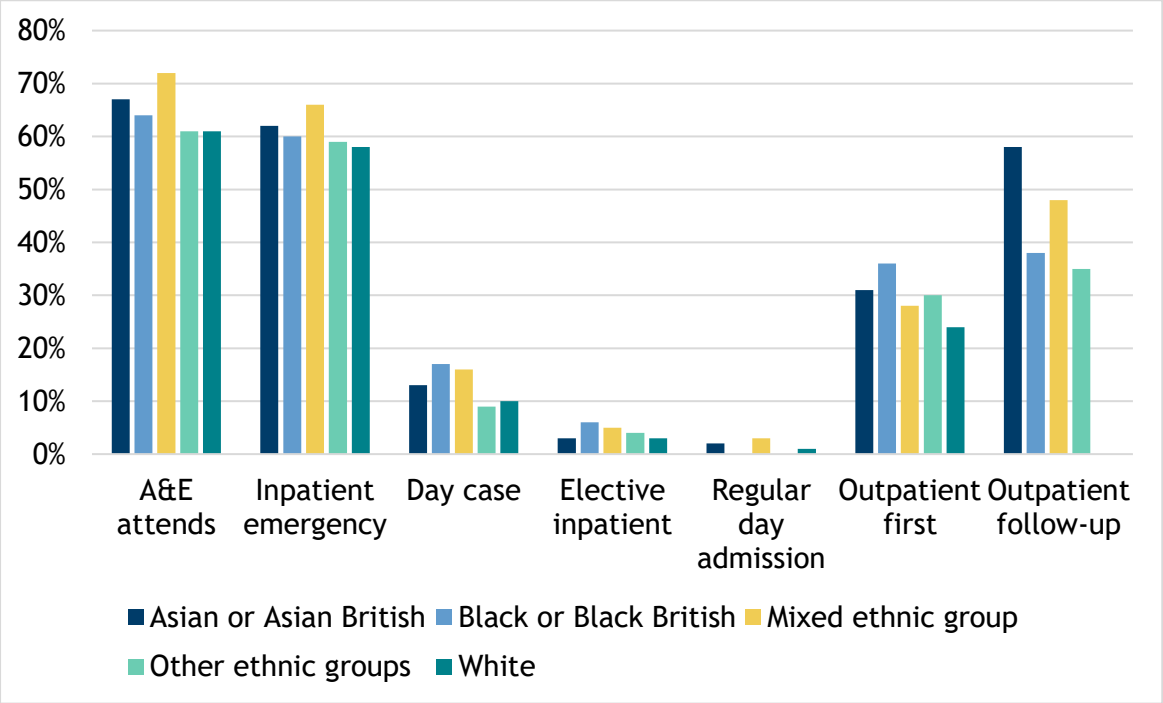


Figure 26 Service utilisation by ethnic group, ICB Palliative EoL Care Dashboard data for NHS Sussex ICB, 2024/25



These findings indicate that future PEoLC needs in Sussex will be increasingly shaped by population ageing, frailty, dementia and rising demand for community and care home-based support. There is likely to be growing need to strengthen provision outside hospital settings, improve earlier identification of people who

could benefit from palliative care, support care home staff and community services, and address inequalities in access and service utilisation.

While the NHS Sussex ICB level data provide a valuable strategic overview, they can mask important geographical variation in health outcomes, service use and inequalities. The subsequent sections therefore explore mortality patterns and EoLC needs at smaller geographical levels to better understand local variation and identify population groups with the greatest unmet need.

The following later sections explore the mortality data, and smaller geographies.

Chapter 3 Conclusion – What does this mean for Sussex?

Need

Adult PEoLC need in Sussex is driven mainly by an older population living with frailty, dementia, cancer, organ failure and multiple long-term conditions. The Sussex Integrated Dataset identified 9,267 adults on the palliative/supportive care register, with most aged 75 and over. In 2024/25, the ICB Palliative EoL Dashboard recorded 18,936 deaths in Sussex, with a higher proportion of deaths occurring in care homes and hospices, and a lower proportion in hospital, than the national average. This demonstrates that Sussex utilises primary care, community services, care homes, hospices, social care and carers to enable people to receive care and support outside hospital, including in more familiar settings.

Sussex also has substantial hospice activity. Sussex Hospice Alliance services supported more than 10,000 people in 2024/25, demonstrating that hospices provide much more than inpatient EoLC, including community support, outpatient care, carer support and bereavement services.

Unmet Need

The chapter shows that many adults who could benefit from PEoLC are not being identified early enough, particularly people with frailty, dementia, organ failure, learning disabilities and other non-cancer conditions. Late identification reduces opportunities for symptom management, carer support, more coordinated care, holistic Advance Care Planning and ReSPECT plan discussions.

Advance Care Planning remains under-recorded compared to ReSPECT plan discussions. Only 13% of people on the palliative/supportive care register had an ACP recorded, falling to 6% among people living in their own homes. This suggests that people living at home may be less likely to receive timely conversations about their wishes, priorities and future care needs. However, there is variation between Places and ICTs relating to ResPECT, in areas where there are larger numbers of

older people such as Rother and Worthing, larger numbers of people on the palliative care register have a ReSPECT plan recorded. Adur has the highest percentage with 66%, but a count of 235 with a ReSPECT plan recorded. Whilst Crawley has the smallest number, 58 and percentage 35%.

There is also evidence of unmet need in urgent and crisis response. Healthwatch feedback, complaints data and SECAmb intelligence highlight difficulties accessing timely support, especially out of hours, with families often left to coordinate between services themselves. Ambulance data show 2,522 attendances coded as EoLC in Sussex ICB during 2025/26, indicating that ambulance clinicians frequently respond to PEoLC crises in the community.

Variation

There is significant variation across Sussex in palliative care register prevalence, ReSPECT completion, Advance Care Planning, specialist palliative care referral and service use. QOF data show palliative care register prevalence ranging from 0.02% to 2.2% between GP practices. Some variation is expected because populations differ, but the scale of difference suggests inconsistent identification and recording.

ReSPECT planning is more established than ACP, with 53% of people on the palliative/supportive care register having a ReSPECT plan recorded. However, completion varies across localities, from 35% in Crawley to 66% in Adur, and is much higher among people living in care, nursing or residential homes than those living at home.

Variation is also evident in acute hospital care. NACEL data demonstrates broad alignment with national benchmarks in recognising expected deaths and prescribing anticipatory medication, but gaps remain in documented communication about hydration, individualised care planning and access to face-to-face specialist palliative care seven days a week. For example, the Conquest Hospital NACEL report recorded 83% of deaths as expected during the final admission, but only 34% had documented communication about hydration, compared with a national aggregate of 62%.

Inequalities

The chapter identifies inequalities affecting people with non-cancer diagnoses, frailty, dementia, learning disabilities, sensory impairment, HIV, minority ethnic backgrounds, LGBTQ+ identities, homelessness experience, substance use needs and other inclusion health characteristics. These groups may face barriers to timely identification, care planning, communication, access to specialist support and culturally appropriate care.

People with learning disabilities experience earlier mortality than the general population, with LeDeR evidence showing a median age of death of 62 years in Sussex. Their PEoLC needs often occur earlier and may be complicated by diagnostic overshadowing, communication needs, Mental Capacity Act practice, reasonable adjustments and gaps in coordinated care planning.

People living with HIV in Sussex have specific needs shaped by ageing, frailty, multimorbidity, stigma, social isolation and previous experiences of discrimination. The evidence highlights the importance of safe, inclusive, trauma-informed and non-judgemental care that recognises identity, relationships, housing, advocacy and trusted support networks.

Data quality limits understanding of inequalities. Sexual orientation was rarely recorded in the SID QoF data, and hospice data show high levels of missing information, with ethnicity not recorded for 21% of patients and sexual orientation not recorded for 60%. Improving protected characteristic and inclusion health data is essential for monitoring equity and improving access.

Future demand

Future adult PEoLC demand in Sussex will increase as the population ages and more people live with frailty, dementia and multiple long-term conditions. In Sussex, 45.7% of deaths occur among people aged 85 and over, compared with 40.2% nationally. This means future need will be shaped not only by the number of deaths, but by longer, more complex and less predictable care trajectories.

Rising demand will place further pressure on primary care, community nursing, care homes, social care, hospices, specialist palliative care teams, ambulance services, carers and bereavement support. As Sussex already has a higher proportion of deaths in care homes and hospices than England overall, strengthening non-hospital care will be central to future sustainability.

What this means for Sussex

Sussex has strong adult PEoLC foundations, including committed primary care, community services, hospices, acute palliative care teams, social care providers, ambulance clinicians, VCSE organisations and carers. Many people receive compassionate, person-centred support. However, the evidence shows that care is not yet consistently delivered at the right time, in the right place, or with the same level of coordination and equity across Sussex.

The main priorities are to improve earlier identification, reduce unexplained and unwarranted variation between services and localities to strengthen Advance Care Planning and ReSPECT plan use, and improve support for people living at home. Integrated community-based models should be strengthened across general

practice, community nursing, hospices, ambulance services, care homes, acute trusts, social care and the VCSE sector. Shared care records, visible ACP and ReSPECT plans, access to anticipatory medicines, and consistent single points of coordination will be important enablers.

Adult PEoLC improvement must also be equity-focused. Services should be designed with people with learning disabilities, HIV, sensory impairment, minority ethnic communities, LGBTQ+ groups, people experiencing homelessness or substance use, carers, rural communities and people living in deprivation. This will require better data, targeted engagement, reasonable adjustments, culturally competent care and partnership with VCSE organisations and people with lived experience.

Chapter 4 Patient, public and professional voice

Key takeaways from chapter 4

People need earlier access to information, advice and conversations about PEoLC. Awareness of palliative care, Advance Care Planning and ReSPECT processes remains low, with discussions often occurring only after a crisis.

People need greater choice, control and involvement in decisions about their care. Residents want to understand their options, have their wishes respected, and retain autonomy over treatment, care and place of death, where possible.

There is a need for better coordination and communication across services. Patients, carers and professionals reported fragmented pathways, poor information sharing and uncertainty about who is responsible for coordinating care.

Unpaid carers need greater recognition, support and inclusion as partners in care. Carers frequently experience isolation, emotional strain and responsibility for navigating services, while often feeling overlooked in decision-making.

More people need timely identification and proactive support before reaching crisis point. Professionals highlighted that people with frailty, dementia and non-cancer conditions are often recognised too late, limiting opportunities for planning and support.

There is a need to reduce inequalities in access to PEoLC. Several groups, including people with learning disabilities, LGBTQ+ communities, minority ethnic groups, people experiencing homelessness, rural populations and those with complex conditions, experience additional barriers to care.

People need stronger community and bereavement support networks. Social connection, voluntary sector support and compassionate communities play a vital role in reducing isolation, supporting wellbeing, and helping people live well until death and to cope with bereavement.

Palliative and EoLC Focus Groups

PEoLC Focus groups were used as part of the corporate approach to this needs assessment to capture lived experience, explore felt and expressed need, and understand how services are perceived and/or experienced in practice.

The insights are not intended to be generalisable, noting that those who attended were self-selecting, often had a keen interest in the topic and/or had recently

experienced the death(s) of a loved one and responded to the questions with examples of their experience. However, these qualitative insights complement the epidemiological and service level data and strengthen the assessment's equity focus.

Focus groups were conducted over the course of a week in late March 2026. The topic discussion guide was developed and reviewed with feedback from the multi-agency steering group. A pilot focus group was conducted with public health colleagues to refine processes.

Focus groups were recruited with the support of several VCSE and statutory partners. The Trans, Non Binary and Intersex focus group was recruited through The Clare Project, The LGBTQ+ Group was promoted via Switchboard, The Sussex Research Engagement Network and Switchboard, whilst Hastings Voluntary Action (HVA) supported recruitment to the in person focus groups in Hastings.

The 24 participants had an average age of 66 (median 69, range 36–83), and reported sex assigned at birth as Female (67%), Male (29%), and Other (4%). Most said their gender identity matched sex at birth (20 of 23 non-blank responses), while gender was most commonly Female (including trans woman) (13 of 23).

The most frequently selected ethnic group was English British (50%), the most common religion/belief was No religion (10/42%), 7 (29%) were Christian, with 5 (20%) stating they were Hindu, and the most common sexual orientation was Heterosexual/Straight (15/63%), following gay/lesbian (6/25%), marital/civil partnership was most often Married (9 of 20 non-blank responses).

Regarding health and caring, 58% reported a long term physical or mental health condition (with most of those indicating it reduced day to day activities "Yes, a little"), and 25% reported providing care or support, most commonly for another family member, typically for 9 hours a week or less (though a small number reported 50+ hours).

Thematic analysis was completed following discussion with the facilitators.

1. What does a 'good death' look like?

1.1. Theme: Comfort, dignity, and freedom from suffering

Across all focus groups, participants consistently defined a good death as one in which pain and physical discomfort are minimised, and the person is treated with dignity. Participants spoke in practical terms about effective pain management being in place. Other comments related to avoiding unnecessary suffering such dehydration and unmanaged symptoms associated with the EoL. Other participants described feeling physically cared for at the EoL also formed part of a good death.

Others shared how a good death is described to others, as one that was peaceful and painless.

> "Being free and comfortable… pain free and comfortable."
>
> Hastings focus group 2 participant

> "It was a good passing… it was peaceful and painless."
>
> Hastings focus group 1 participant

1.2. Peace, calm, and emotional safety

A good death was also described as an emotionally peaceful experience, characterised by calm surroundings, reassurance, and a sense of safety. Participants contrasted peaceful deaths with experiences of stress, noise, or confusion, drawing on experiences of hospital settings, noting the emotional impact this can have at the EoL.

> "A good death is peaceful… the person is at rest."
>
> Hastings focus group 1 participant

> "It's about feeling safe and held."
>
> LGBTQ+ group 1 participant

1.3. Not dying alone but with the *right* people

While participants often said they did not want to die alone, this was strongly qualified by who was present. Across all groups, there was a clear rejection of assumptions that 'family' automatically means biological relatives. Some LGBTQ+ participants expressed that the presence of biological family wasn't enough, dignity and emotional safety depended on *who* was there, such as their chosen family and friends.

> "Not alone, not alone."
>
> Hastings focus group 1 participant

> 'Nobody should die on their own."
>
> LGBTQ+ group participant

> "It's not just about not being alone...it's about having the people you trust there."

> "Family doesn't always mean blood… it can be chosen family."
>
> LGBTQ+ group participant

> “People want the people they trust around them at the end.”
>
> LGBTQ+ group participant

> “It’s about having the people you want with you, not who others think should be there.”
>
> LGBTQ+ group participant

2. What do people need to have a good death?

2.1 Information, choice, autonomy, and control

Information, choice, autonomy and control emerged as a central theme across all discussions. Participants described the need for information at this stage of life, that enables and empowers people to have a choice and control over the place of death, who is involved in care and decision making, and the treatments and interventions offered and accepted. A lack of information, which reduces autonomy and choice, particularly late in the illness trajectory, was associated with distress and feelings of powerlessness, meaning a less good death.

Illustrative quote:

> “It’s about being allowed to decide what matters to you, not what other people think should matter.”
>
> LGBTQ+ group participant

> ‘If I don’t decide, somebody else will decide… so why not have what I want?’
>
> Hastings focus group 1 participant

> ‘He wanted to know what the prognosis was… how much longer would he last. He wanted to know what it meant’
>
> Hastings focus group 2 participant

2.2 Being seen as a person first, not a diagnosis

Participants repeatedly stressed the importance of being treated as a whole person, rather than being defined by diagnosis, age, or perceived vulnerability. This was particularly strong in discussions involving dementia, where participants described being spoken about rather than spoken to.

Illustrative quote

> ‘See the person first, not the illness’
>
> Hastings focus group 1 participant

2.3 Being seen as a person first, inc. respect for identity, culture, religion, and belief

Participants described being seen a person first with respect for cultural, spiritual, and belief-based needs was identified as essential to a good death.

Participants described their faith-based needs (e.g. Catholic last rites), specific cultural practices around death and bereavement with some faith groups and non-religious and humanist identities. Several participants emphasised that not having a religion should be respected equally.

Illustrative quote:

> "According to my faith, Catholic, I don't fear death."
>
> Hastings focus group 1 participant

> "People really wanted their priest to come and say prayers at the end – that was very important to them."
>
> Hastings focus group 2 participant

> "It matters that your beliefs are respected – that what you believe in is part of how you die."
>
> Hastings focus group 2 participant

2.4 Psychological and physical safety, respect for LGBTQ+ and Trans, Non-Binary, and Intersex (TNBI) people

Participants described psychological and physical safety as inseparable from respect for LGBTQ+ and TNBI identity, highlighting the importance of being recognised, not having to educate staff, feeling free from discrimination, and knowing that both they and their 'chosen family' would be treated with dignity and respect.

> "I worry about being put somewhere where there might be discrimination because of my sexuality."
>
> LGBTQ+ focus group 2 participant

> "There's a real fear that you'll be treated differently because of who you are, especially in places where you don't get to choose who's caring for you."
>
> LGBTQ+ focus group 2 participant

> "I don't want to worry about the people I love being made uncomfortable while I'm dying."
>
> LGBTQ+ focus group 2 participant

> “If the people around you feel safe, then you feel safe.”
>
> “If I want to hold my partner’s hand at the EoL, that should be allowed, without judgement or looks”

LGBTQ+ focus group 2 participant

> “You shouldn’t have to educate people while you’re dying.”

TNBI focus group 2 participant

3. Perceptions of palliative and EoLC services

3.1 Compassionate care exists, but experiences are inconsistent

Participants recognised that compassionate, person-centred care does exist within local palliative and EoL services, however, experiences were described as inconsistent, with quality often dependent on individual staff, service capacity, or location rather than a reliable standard of care. Those that shared fewer positive experiences related to primary care and acute hospital experiences. A separate theme relating to General Practice also emerged and is described.

This inconsistency contributed to anxiety about what care might look like in the future. Some participants were unaware of the services available and how to find out more information.

> “The staff were compassionate… I felt the compassion from the whole team.”

Hastings focus group 2 participant

> “I can’t fault the care – they were just brilliant.”

Hastings focus group 2 participant

> “You can have one really good experience, and then the next one is completely different.”

Hastings focus group 2 participant

> “It shouldn’t come down to luck, but sometimes it feels like it does.”

Hastings focus group 1 participant

3.2 Hospices: valued but misunderstood

Participants spoke very positively about hospices as places of compassionate, person-centred care. However, many also described widespread misunderstanding about what hospices do, who they are for, and how to access them, alongside concerns about limited capacity and inconsistent eligibility decisions.

Illustrative quote:

> “The hospice was very good – they were kind, supportive, and made a really difficult time easier.”
>
> Hastings focus group 1 participant

> “People think hospices are just places you go to die – they do much more than that.”
>
> Hastings focus group 1 participant

> “Some people get hospice care and others don’t, and it’s not always clear why.”
>
> Hastings focus group 1 participant

> “It feels like a bit of a lottery – who gets hospice support and who doesn’t.”
>
> Hastings focus group 1 participant

3.3 General Practice perceived as a barrier and bottleneck

General Practice was frequently described as a barrier and bottleneck within the system. Difficulties accessing appointments, complex gatekeeping processes, reliance on reception triage, and assumptions that everyone is registered with a GP contributed to delays and disengagement. For some groups particularly LGBTQ+ and TNBI people with previous negative experiences, GP access was actively avoided, increasing the risk of late presentation and crisis-based care.

Illustrative quote:

> ‘You phone at 8 in the morning and you’re number 24 in the queue – every single time.”
>
> Hastings focus group 1 participant

> “Sometimes you just give up ringing because you know you won’t get through.”
>
> Hastings focus group 1 participant

> “Everything goes back through the GP, even when you’ve been under hospital care – and I didn’t realise that.”
>
> Hastings focus group 1 participant

> “There’s an assumption that everyone has a GP – and that’s just not true.”
>
> Hastings focus group 1 participant

4. Planning: ReSPECT, Advance Care Planning, and conversations

4.1 Planning is empowering but poorly normalised

Participants consistently described planning for EoL as empowering, bringing reassurance, clarity, and a sense of control, however, planning was widely viewed as poorly normalised, rarely initiated by services, culturally avoided, and often only undertaken after crisis or personal experience.

Illustrative quote:

> "It helps you feel more in control, rather than waiting for things to happen to you."
>
> Hastings focus group 1 participant

> "People just don't want to talk about it – it's still a taboo."
>
> Hastings focus group 2 participant

> "Nobody talks about this stuff until you're already in a crisis."
>
> Hastings focus group 1 participant

> "It's not something that's ever really explained or encouraged."
>
> Hastings focus group 2 participant

4.2 Low awareness of ReSPECT and ACP

Participants consistently reported low awareness of ReSPECT and Advance Care Planning, with many unaware these options existed until late in illness or crisis. For those who had experienced 'Planning conversations', these were described as poorly signposted, inconsistently offered, and often delayed, leading to confusion about purpose and use. However, where ReSPECT and ACP were understood, participants described them as empowering, providing reassurance, clarity, and a sense of control—particularly important for those without family or trusted advocates.

Illustrative quote:

> "I'd never heard of ReSPECT before coming to something like this."
>
> Hastings focus group 1 participant

> "Nobody ever mentioned an advance care plan to us."
>
> Hastings focus group 2 participant

4.3 Start conversations earlier in life

Participants consistently emphasised the need to start conversations about EoL earlier in life, describing current discussions as reactive, crisis driven, and culturally avoided. Earlier, routine conversations were seen as key to reducing fear, supporting choice and control, and ensuring wishes are known—particularly for those without family or traditional support networks.

Illustrative quote:

> "It shouldn't be something that only gets discussed when you're dying."
>
> "You don't know when you're going to die – why wait?"
>
> "Everybody should have an idea of what they would like, because you don't actually know when you're going to die."
>
> "When you don't have family, it becomes even more important to talk about these things early."

5. Community support, loneliness, and social connection

5.1 Community connection as part of EoLC

Participants consistently highlighted community connection as a vital part of EoLC, particularly for people without close family. Faith groups, voluntary organisations, chosen family, and local community spaces were described as reducing isolation, providing emotional support, and offering continuity of care before and after death. Participants emphasised that EoLC should support living well until death, not simply managing symptoms.

Low barrier community activities were seen as vital for reducing isolation.

Illustrative quote:

> "You're alive right up until the moment you die."

6. Cross cutting themes

6.1 Men / males and engagement with EoL discussions

Participants consistently noted lower engagement by men in EoL discussions, with men perceived as more reluctant to attend groups, talk about death, or engage in advance planning. This avoidance was linked to discomfort with emotional conversations and a tendency to engage through practical or activity based settings

rather than discussion led forums, contributing to late or crisis driven decision making.

Illustrative quote:

> "There's no men here – men just don't talk about this."
>
> Hastings focus group 2 participant

6.2 Access to information

Participants consistently described EoL information as difficult to find, poorly signposted, and rarely offered proactively. Information was often received late, during crisis, or via informal routes, contributing to confusion, anxiety, and unequal access—particularly for people without strong service or community connections.

Illustrative quote:

> "There is a lot of information out there, but you don't know where to get it.
>
> "If professionals don't bring it up, people don't know to ask."
>
> "You only find out about these things when you're already in the middle of it."
>
> "By the time you get the information, you're already in crisis."
>
> "There used to be leaflets you could just pick up, but that's gone."
>
> "If you're not already connected, you miss out on information completely."

The themes and insights from the focus groups provide valuable qualitative insight into how PEoLC is experienced and understood by local residents. While not representative of the wider population, the findings consistently highlight what matters most to people at the EoL and where current systems fall short.

Participants described a 'good death in clear' and consistent terms, one that is comfortable, peaceful, and dignified, where individuals feel safe, are treated as whole people, and are surrounded by those they trust. This includes recognition of chosen family, respect for identity, culture, and beliefs, and assurance that care environments are inclusive and free from discrimination.

Across discussions, the importance of information, choice, and autonomy was central. People want to understand their options, make decisions about their care, and retain control wherever possible. However, these needs are often unmet due to late conversations, limited awareness of planning tools such as ReSPECT and Advance Care Planning, and a wider cultural reluctance to discuss death.

Experiences of services were mixed. While compassionate, high-quality care was widely recognised, particularly within hospices, participants described a lack of consistency, with care often dependent on individual staff, circumstances, or geography. Access to General Practice was frequently seen as a barrier, contributing to delays in support and reinforcing crisis-driven care pathways.

A strong and consistent message was the need to normalise earlier conversations about death and dying, supported by accessible information and proactive engagement from services. Participants also highlighted the critical role of community networks, social connection, and voluntary sector support, particularly for those without traditional family structures.

Views of unpaid carers on planning ahead for future health and care

Carers Support West Sussex (CSWS) Engagement Team gathered the views of unpaid carers on planning ahead for future health and care. This was done through a survey and follow-up phone interviews with a selection of respondents. The purpose was to inform the Sussex-wide PEoLC and bereavement needs assessment, recognising that carers bring a distinct and often underrepresented perspective on planning, decision making, and support needs. Carers can also experience increased vulnerabilities, both emotionally and practically, which makes their insight essential to understanding local need and shaping equitable services.

A sample of 150 carers, evenly distributed across West Sussex, were contacted, alongside members of the Carer Voice Network. The survey was promoted through social media and partner networks, including Healthwatch. The survey ran from 19 March to 29 April 2026 (41 days). Fourteen carers completed the survey, and five took part in follow-up interviews.

Respondent Profile

Respondents were predominantly older carers, with most aged 64+. The majority were female (71%) and identified as White British. All participants were caring for family members, most commonly a partner or spouse (64%).

Key findings

Positive experiences:

Positive experiences were linked to professionals taking time to listen and involve carers. Ten out of the fourteen participants described positive experiences with individual clinicians, including GPs, specialist services and district nurses. Positives drawn from this included being treated as a partner in care, professionals

recognising their carer expertise, consistent care (named individuals) and time and space to be listened to.

> "Doctors made special amendments to cater for my son's needs."
>
> "There was one doctor who was great. It felt like we had all the time we needed to speak. It made a real difference compared to other appointments where you feel rushed or not listened to."
>
> "When caring for mum at home, the district nurses would include me and offer advice… the head district nurse… helped to get mum into respite so I could rest."
>
> "The stroke doctor at East Surrey has consistently involved me, and I feel respected by her when I ask questions."

Negative experiences

However, some carers felt overlooked or unsupported, particularly during times of crisis. Carers described needing to advocate strongly to be heard and noted that their involvement often depended on individual professionals. Conversely, lack of recognition of the carer role remained a concern. Common negative experiences included:

- Being excluded from decisions (7/14, 50%)
- Poor communication (8/14, 57%)
- System rigidity / bureaucracy (6/14, 43%)
- Lack of support for carers (9/14, 64%)

> "Everything decided well before I was involved."
>
> "We might as well be invisible."
>
> "When I was admitted to casualty and informed nurses and doctors that I was a carer, they did nothing. My son suffered because of this—he was left on his own at home."
>
> "I did tell them I was a carer and showed my carer card, but nothing really happened… it made me feel like that role just wasn't recognised."

Carers also reported burnout, stress and isolation. Six of the fourteen respondents described providing 24/7 care, often with little support. Carers spoke about constant responsibility, emotional strain, and the impact on relationships. Many felt indispensable yet unsupported, with systems assuming they would "fill the gaps" without providing the authority or resources to do so.

> “24/7 caring is a lonely business.”
>
> “You cannot go anywhere without planning everything.”

Being involved in care decisions: feeling heard

Carers reported mixed experiences of being involved in care decisions. Most felt their voice was heard but there was a gap between being heard and having their views acted upon. Some carers reported that important decisions had happened without them. In follow-up conversations, carers emphasised that although professionals may listen, empowerment and system flexibility were often lacking. Many felt that being included depended on their own persistence rather than on consistent practice across services:

> “If I’m forward in advocating.” “I make sure I am [involved].”
>
> “I am always listened to but… the system is geared to assist my partner and not me.”
>
> “I am able to express my concerns but the system restricts those listening from doing anything.”
>
> “Communication is abysmal… everything happens at a snail’s pace… The entire system feels designed to create maximum stress.”

Talking about hopes, wishes and worries

When asked what “planning ahead” meant, carers most commonly referred to preparing for future care scenarios, alongside legal and administrative processes such as Lasting Power of Attorney, future care planning, including “what if” scenarios and funeral planning.

Carers reported a wide range of experiences when discussing future plans. Some had open conversations, while others struggled due to emotional burden, uncertainty or lack of support. Structured tools were seen as helpful in enabling these discussions.

> “(discussing how to have advance care planning conversations) I think you need something to fill out, somewhere to write things down about what you want and how you feel about the future (in a clear, structured way). And someone to guide you through it…(just) knowing it exists and having help to complete it would make these conversations much easier (less overwhelming)”

Some described reassurance from proactive planning:

> “We talk about things quite openly as a family… we’ve already thought about what might happen… and that does give a sense of reassurance.”
>
> “Planning for all eventualities.” “Ensuring action plan in place for our passing.”

Carers also reflected that these topics can be emotionally loaded, with top concerns including:

- Causing distress.
- Burden and responsibility.
- Making the wrong decisions
- Professionals not following wishes
- Timing of decisions
- Emotional difficulty

Other concerns included financial and practical worries and losing control. Many carers also selected all of the concerns.

Future Planning Conversations

Planning ahead was associated with reassurance, control and preparedness. Carers emphasised the importance of both practical and formal planning (e.g. wills, Lasting Power of Attorney, DNACPR decisions). Many described themselves as the central coordinator of care, acting as the “hub” between services and family members. Some carers reported they were unsure about who should initiate these conversations, meaning they did not happen. Legal forms, often with paid legal support, such as LPAs or ReSPECT forms were seen as practical ways to ensure wishes were respected.

> “I’m the one who holds everything together really… I’m the hub between the doctors, the carers and the family.”
>
> “I call it my safety net appointment because they talk to both of us and go through everything properly. I can ask questions, even things that aren’t really part of the appointment, and I come away feeling like I’ve got some useful information.” (describing an appointment with a health professional where she always feels included).

Carers described a lack of consistent, coordinated approaches across services. Many said that planning conversations rarely happened or happened too late. A persistent concern around this was, what would happen if the carer was not there, and how would their loved one's wishes be respected.

> “We’ve never really had those conversations with professionals… there’s no plan in place… I don’t even have a plan.”

> “What worries me is what would happen to my son if I wasn’t here… you just want to know there’s something in place.”

Planning was often informal and led by carers themselves rather than supported through structured systems. Carers reported that having clear action plans written down helped them feel more in control and cope both practically and emotionally. Planning in advance also reduced the overwhelm that can come with making decisions during a crisis. Carers also reflected that preferences and wishes can change over time, and because of this, digital versions of any documents, that can be easily updated and shared were preferred.

Carers highlight several needs:

- Consistent recognition of carers as partners in care and inclusion in any future care planning
- Proactive and structured support for planning ahead for carers and those they care for.
- Accessible tools and guidance to support conversations.
- Clear contingency planning for emergencies and future care.
- Opportunities for peer support to reduce isolation.

Carers identified the following priorities:

1. Allowing time for meaningful conversations: Recognising carers’ expertise, including them within conversations and allowing space for discussion.
2. Better coordination between services: To reduce repetition, improve accessibility and improve continuity. If possible named points of contact and clear pathways were felt to be valuable.
3. Practical tools and resources: Increased awareness and use of care planning tools.
4. Peer support opportunities: Spaces for carers to share experiences, advice and reduce isolation.
5. Accessible and inclusive formats to tools: A mix of digital, face-to-face, and printed resources.
6. Building on strengths of listening, empathy and flexible conversations: having the conversations in a proactive and supported way.
7. Carers wanted to be able to make plans for “what if” scenarios, with discussions on how to ensure wishes are respected and who would provide care if they were unable to.

This engagement demonstrates that unpaid carers play a vital but often under-recognised role in coordinating care. While there are examples of good practice, many carers experience inconsistent inclusion and limited support, particularly in planning for the future. Strengthening coordinated, proactive approaches to engagement is needed to meet carers' needs and improve outcomes for both carers and those they support.

Professional voice

Workforce survey

A staff and volunteer survey was developed with the project steering group to capture their views on needs, current provision, identify areas for improvement, and highlight current good practice. Respondents could respond as individuals, teams or as an organisation. The survey was extensively promoted to the local health and care system in early 2026, included professionals from statutory and voluntary sectors, as well as people with direct experience of palliative care and bereavement.

226 responses were received, 160 responses were received by individuals, 18 from teams and 48 were organisational responses. The following sections present the qualitative analysis of responses to the workforce survey. The survey captured perspectives from a wide range of stakeholders across health, social care, the voluntary and community sector, independent providers, and people with lived experience. The analysis draws on free text survey responses and reflects views from the following settings:

- Hospices (inpatient, hospice at home, community and education teams).
- Acute hospitals.
- General practice and primary care networks.
- Community health services (district nursing, urgent community response, community pharmacy).
- Ambulance services.
- Adult social care and children's services.
- Residential and nursing care homes.
- Voluntary, community and faith sector organisations.
- People with lived experience, unpaid carers, and volunteers.

Table 72 Number and percentage of workforce survey respondents by service and setting.

Respondents could select more than one service or setting; therefore, counts and percentages exceed the total number of respondents and do not sum to 100%.

Service and/or setting of the responder	Total	Percent
Bereavement Support Service	16	7.08%
Children's Hospice	13	5.75%
Community Pharmacy	6	2.65%
Domiciliary/Home Care	8	3.54%
General Practice Surgery	11	4.87%
Hospice	80	35.40%
Hospital	16	7.08%
Nursing Home	6	2.65%
Residential Care Home	8	3.54%
Voluntary/Charity Sector (Non hospice)	35	15.49%
Other (please state below)	61	26.99%
Not Answered	7	3.10%

Settings and services in the other category included 23 responses from the ambulance trust, 15 from adult social care.

Table 73 Number of workforce survey respondents by locality

Respondents could select more than one service or setting; therefore, counts and percentages exceed the total number of respondents and do not sum to 100%.

Locality	Total
Brighton and Hove	88
East Sussex	96
West Sussex	140

Locality	Total
Other (please state if you cover a smaller area such an ICT, PCN etc.)	16
Not Answered	2

Question: What is working well in PEoLC

Theme: High quality hospice care working in partnership

Across responses from hospice staff and volunteers, acute clinicians, and people with lived experience, hospices were consistently described as providing compassionate, holistic and person-centred care. Respondents highlighted they provide expertise, skilled symptom and pain control, and time to support patients and families. Others described hospice care as enabling calm, supported deaths.

> 'Palliative and EoLC needs are being met by hospital, hospice and GP services, Care and Care Home services, and other voluntary support services, however, they can be improved'
>
> 'The Palliative Care Team and The Martlets Hospice have been fantastic with a client of mine recently. The Palliative Care Team went out to assess the day after getting the referral and gave advice to her family and did the Fast Track CHC form and visited again to monitor things'

Social Care, Brighton and Hove

> '**Current** hospice services for residential adults and the hospice in the community really work well in EoLC, supporting the person and their friends and family.'

Social Worker East Sussex

Theme: Effective partnership working in some localities between providers and services

Respondents from community nursing, GP practices, ambulance services, and hospice community teams described areas where strong informal and formal relationships enabled rapid advice and escalation, and joint decision making to avoid hospital admission where possible. Coordinated responses during EoL crises examples included MDT working, direct phone access to hospice clinicians, and collaboration between ambulance clinicians and hospice or community teams. Good outcomes were often reported to be dependent on local relationships rather than system-wide design, leading to inconsistency across Sussex.

> ‘Being part of enhanced services improves access to urgent medicines, including out-of-hours supply. Regular communication with primary care teams and local hospice services supports coordinated care and quicker problem-solving’

Community Pharmacy

> ‘Generally, palliative arrangements are made in good time via either GP or hospital assessment, and palliative team and/or hospice involvement is subsequently organised. Usually when an ambulance arrives to a palliative patient, Just In Case (JIC) medications are already in place, so we can give these as necessary. If these arrangements have not been put in place and we think a patient would benefit from palliative review and management, we can usually make referrals through the GP or palliative teams via 111, and this often works very well.

Ambulance Service

Theme: Specialist coordinated and out of hours services

Respondents stated they believe the local telephone service which provides support and advice 24 hours a day, 7 days a week (ECHO EoLC Hub) in Coastal West Sussex, is particularly valued for Out of hours clinical advice and Support for non-specialists managing dying patients and navigation of complex systems for families. The model aligns strongly with population preference to remain at home but is not consistently available across all Sussex geographies.

> ‘The ECHO service works well coordinating the care of patients registered with it for palliative and EoLC.

Ambulance Service

> ‘ECHO are a very beneficial service and support ourselves when we are with EoL patients. Generally with patients I have attended, their needs are being met.’

Ambulance Service

> ‘Having a combination of ECHO, JIC meds accessible to ambulance crew and hospice at home allows a dignified and safe death, this also takes pressure off the hospitals by preventing unnecessary admissions for EoL patients and preventing extra pressures on hospitals.’

Ambulance Service

Question: What is working well in bereavement support

Theme: Hospice led bereavement support

Respondents from hospice services and voluntary organisations described hospice bereavement support as trusted and highly valued. This included counselling and therapeutic support, peer and group based programmes and follow up contact after death. However, access was often perceived or restricted to families who's relative had been known to a hospice.

> 'The local hospice to me provides an utterly fantastic service. They support patients, families, carers - both professional and volunteer. The only limitation to their work is the lack of central funding.'
>
> 'The hospices locally offer a lot of support in many different ways to reach all sorts of people. Could be more support through age related death bereavement - Age UK bereavement support for example. Think this could be advertised better.'
>
> Social Worker

Theme: Role of the Voluntary and Community Sector (VCSE organisations, carers)

VCSE organisations were frequently described as filling significant gaps in bereavement support, particularly where statutory provision was limited. These organisations provide long term and community-based support, identity specific and culturally specific services, and flexible peer led service models. Voluntary organisations also consistently reported high demand, long waiting lists and insecure funding.

> 'VCSE seem to be meeting these needs in the main. All other services offer short term only. Again as with many VCSE, there is chronic underfunding so service provision is impacted.'
>
> 'There are now several Bereavement Peer Support groups in the city and these are increasing continuously - including the Death Cafe, Dying To Share and other EoL and Bereavement support groups run by groups and grief counsellors. Some funeral directors have post bereavement support in the form of peer groups or 1:1 support'
>
> 'It's great that Switchboard's LGBT+ Grief Meets and the Queer Death Cafe exist.'

Question: What could be done differently to improve current local provision and support for palliative, EoLC, and bereavement support needs in Sussex

Theme: More financial resources for services and staff

Across nearly all roles and sectors, respondents identify chronic underfunding as the primary factor influencing current local provision and support for palliative, EoLC, and bereavement support.

This issue contributes to staff shortages and burnout, closure of hospice beds and reduced community services, prolonged waiting times for palliative care and bereavement support, and an excessive dependence on charities and volunteers for essential service delivery.

The consensus from the majority of survey respondents highlights the current funding frameworks are unsustainable, and influence scale, quality, equity, and choice at the EoL locally.

> ‘Hugely increased funding (from Government) so that there are more staff to provide more support 24/7.’
>
> ‘Funding is always an issue. If more money was available, more nurses/counsellors etc could be employed thus extending the scope of the services offered.’
>
> ‘Better resources for supporting in EoLC, more nurses to assess patients within their homes when families are calling with concerns rather than it being passed to ambulance service to attend. Better multidisciplinary team communication or ability to view care folders.’

Theme: Late identification and crisis driven care

Respondents across primary care, hospital teams, ambulance services and adult social care highlighted that many people are identified as dying too late, particularly those with frailty and dementia. This leads to poor or absent advance care planning, Emergency ambulance attendance, Out of Hours need, and deaths in hospital that do not reflect people’s wishes.

> ‘Increase training and development of frailty services across Sussex to manage to identify patients early, support advance decision making and availability of frailty and/or elderly provisions, avoiding acute hospital admission, especially focusing on MDT decisions as frequently in the out of hospital setting patients are on multiple medications prescribed through various specialities without supported frequent medication and health reviews’

Ambulance Service

> ‘I meet and hear about lots of people who have a palliative diagnosis and are going into or in a dying stage. It appears that there is little in the way of forward planning or specialist support offered. Often people are incorrectly

> referred to us rather than health services or funded CHC; this causes a delay and distress to adults. It also means that there is a delay in getting specialist appropriate care to people and they often end up admitted to hospital when they do not wish to be'
>
> 'A recognition from professionals that, though this is a commonplace situation for them, it is new and extremely distressing for the person dying and their family and friends around them- sometimes explanations of what is happening/likely to happen don't get explained properly leading to misunderstandings and distress- this is particularly a problem in the community. It seems to be handled better in hospital and hospice settings.'

VCSE Worker

Theme: Insufficient and variation in relation to community capacity (Community health, hospices, care homes)

A dominant theme across community nursing, hospice teams, care homes, and carers was insufficient capacity to support people at home, particularly overnight and out of hours support, capacity to issue rapid symptom control and access to medications and equipment. Respondents described long waits, staff burnout, and increasing reliance on families and carers to manage complex care.

> 'Better funding of social care - relatives are often desperate trying to support their loved one without a package of care. Discharges from hospital usually delayed by having to wait for a package of care- this sometimes results in a patient not being able to go home prior to their death even for a short time. Or in a patient being unable to access a hospice bed because it is occupied by someone waiting for a POC'

Dr, Hospital

Theme: Communication and system fragmentation (Hospitals, GPs, social care, ambulance)

Across settings, respondents described poor communication and information sharing, including discharge from hospital without adequate planning for the care. Ambulance services reported a lack of shared electronic records. This fragmentation increases distress and undermines otherwise skilled care.

> 'Better communication between hospices, GPs and patients. Improving communication between all professionals involved in care'

Social worker

> ‘As ambulance clinicians we often experience issues with JIC meds not being available, mostly due to poor communication between Hospice and GP practices or the meds are available but there is no paperwork’
>
> Ambulance Trust staff

> ‘Clearer communication between all members of the MDT who are trying to support the palliative client and their family.’
>
> Social Worker

Theme: Understanding, support and access for groups experiencing unmet need

Several respondents felt that older people, frail people, and their carers are not having their needs met well. Death and frailty were sometimes described as being treated as a ‘normal’ part of ageing, leading to poorer recognition of palliative need, delays in planning, and inadequate bereavement support.

> ‘Tons of support in primary care is unrecognised and underfunded. Most deaths in my service are not supported by the palliative care team as the people are severely frail with complex needs’

People with learning disabilities were also stated as a group with specific needs. Some also noted limited specialist bereavement support and poor accessibility of information and environments.

> ‘Learning Disabled people have difficulty in understanding this, and find it difficult to talk about it, and express their feeling’
>
> Adult Social care

People experiencing homelessness, insecure housing, addiction, severe mental ill health, or social exclusion were frequently identified as having unmet need. Respondents described difficulties accessing GPs and mainstream palliative care, stigma in hospice settings, complex needs that do not fit traditional models, and lack of tailored services for these groups. Trust in services was also raised as a barrier.

> ‘Our client group can often be difficult to engage - clients can feel ashamed and judged because of their situation / substance misuse etc’

Several responses highlighted a lack of culturally sensitive care, including poor understanding of different faith practices, cultural preferences around death and bereavement, and language barriers. Minority ethnic communities were seen as less likely to access services and more likely to face mistrust, stigma, or services that do not reflect their needs. Some respondents also noted that hospice branding, history, or assumptions may unintentionally create barriers.

> ‘Bias and unfair prejudice. Language difficulties, fear, cultural expectations, care and EoL beliefs are likely to discourage engagement’
>
> Hospice

> ‘Hospices are often seen by communities as being only for certain types of people. More work is needed to reach out to and engage with people of different ethnic backgrounds and faiths / no faith. The Christian origins and naming of some Hospices is potentially a barrier. In addition, the needs of queer and transgender people are not being met, as the legislative and societal shifts of recent years have made the world increasingly unsafe for them and healthcare is a key environment in which their needs are likely to be unmet and where they risk facing ignorance and hate.’

A clear theme was that LGBTQ+ people, especially trans and non-binary people, may experience unmet need due to lack of staff knowledge, gendered services/facilities, heteronormative assumptions in bereavement support, and fear of discrimination. Some respondents noted progress through staff training, but many felt services still do not adequately understand or affirm people’s identities and relationships.

The survey responses suggest that people with frailty, dementia, liver disease and HIV may experience particular unmet need where palliative care models remain oriented towards cancer, rely on self-advocacy or family navigation, or lack specialist pathways for complex, socially marginalised or less common conditions.

> ‘People in rural communities receive a substandard response during night times, and often during the day times’
>
> Ambulance service

> ‘Emergency ambulance cover is threadbare at night times and people in rural communities receive a substandard response during night times, and often during the day times’
>
> Ambulance service

Sussex includes a mix of coastal, rural and urban populations. Ensuring consistent access to hospice-at-home, specialist palliative advice, and bereavement services, regardless of postcode, should be a central priority.

Question: Outside of budgetary constraints, what if any blocks exist in your role which prevent you from delivering palliative and EoLC, and bereavement support, in the way you would wish to?

Respondents identified a wide range of non-financial barriers to delivering good palliative, EoL and bereavement care, although most noted that funding still underpins many of these problems such as access to training. The most common issues were lack of time, workforce pressure, staff shortages and competing demands, which reduce the ability to provide compassionate, person-centred care.

A second major theme was poor coordination across services, including silo working, unclear roles, inconsistent communication, weak information sharing, and lack of joined-up pathways between hospitals, primary care, hospices, community services and social care. Several respondents described problems with handover, referral pathways, access to records, and lack of a single point of access.

Many responses also highlighted training, confidence and knowledge gaps. These included limited understanding of the dying process, lack of confidence in having EoL conversations, limited knowledge of available services, and insufficient training for staff, volunteers, families and the public.

There were also important cultural and organisational barriers, such as overly medicalised approaches, reluctance to talk openly about death and dying, bureaucratic processes, risk aversion, and attitudes that prevent flexible, person-centred decision making. Some respondents felt that fear, stigma and misunderstanding about hospice and palliative care continue to delay referrals and access to support.

Chapter 4 Conclusion – What does this mean for Sussex?

Need

The engagement undertaken as part of this NA provides valuable insight into the experiences, priorities and expectations of Sussex residents, carers, volunteers and professionals. Across all groups, there was strong consensus about what matters most at the EoL; being treated as an individual, maintaining dignity and comfort, receiving compassionate support, being involved in decisions, and having care that reflects personal preferences, values, relationships, culture and beliefs.

Participants consistently described a good EoL experience as one that extends beyond clinical care alone. Emotional wellbeing, trusted relationships, effective communication, support for families and carers, and the ability to remain connected to communities and social networks were identified as equally important aspects of high-quality care.

Unmet Need

The engagement findings highlight several areas of unmet need across Sussex. Public awareness of palliative and EoLC, Advance Care Planning (ACP), ReSPECT processes and available support services was generally low. Many participants reported that conversations about death, dying and future wishes often occurred too late, frequently following a crisis, deterioration in health or emergency admission.

Carers described difficulties accessing timely information, practical support and clear guidance about what to expect as a person's condition deteriorated. Many reported uncertainty about who to contact during periods of crisis and felt inadequately prepared for the practical and emotional challenges associated with caring for someone approaching the EoL.

Professionals also identified unmet need relating to earlier identification, particularly for people living with frailty, dementia and non-cancer conditions, where opportunities for proactive planning and support are often missed.

Variation

Variation in people's experiences was a consistent theme throughout the engagement. Whilst many participants described excellent, compassionate and coordinated care, others reported fragmented pathways, inconsistent communication and difficulties accessing support.

Experiences often differed depending on where people lived, which services they accessed and how effectively care was coordinated between organisations. The findings suggest that whilst examples of excellent practice exist across Sussex, access to coordinated, person-centred care is not yet consistent across all settings or localities.

Variation was also evident in awareness and understanding of PEoLC services, ACP and care planning processes, indicating opportunities to improve consistency in information, communication and support across the system.

Inequalities

The engagement highlighted important inequalities affecting access to and experiences of palliative and EoLC. People supporting and those people with learning disabilities, LGBTQ+ communities, people experiencing homelessness, minority ethnic communities, rural populations and those living with dementia or frailty described barriers to accessing services that meet their specific needs.

Participants reported concerns relating to discrimination, stigma, culturally inappropriate care, inaccessible information and services that do not always recognise diverse identities, family structures or support networks. LGBTQ+

participants, for example, emphasised the importance of recognising chosen families and ensuring that care is inclusive, respectful and affirming.

These findings reinforce the need for future service development to place equity, inclusion, accessibility and cultural competence at the centre of commissioning, workforce development and service delivery.

Future demand

Although engagement focused primarily on people's experiences and priorities, participants consistently recognised that demand for PEoLC is likely to increase in the future. Professionals highlighted growing complexity of need, increasing numbers of older people, workforce pressures and rising demand for community-based support.

The findings suggest that future services will need to support larger numbers of people living with complex conditions over longer periods, whilst also responding to increasing expectations around personalised care, care coordination, carer support and equitable access.

There was widespread recognition that health and care services alone will be unable to meet future demand without stronger partnerships with communities, carers, voluntary organisations and local support networks.

What this means for Sussex

The engagement findings provide a clear message that improving people's experiences of PEoLC is not solely about expanding services, but about delivering care that is personalised, coordinated, proactive and equitable.

The evidence suggests that Sussex should prioritise earlier conversations about future wishes and preferences, improve public awareness of ACP and ReSPECT processes, strengthen care coordination and ensure patients and carers know who to contact when support is needed. Better information sharing, clearer pathways and improved continuity of care would help address many of the issues described by residents, carers and professionals.

The findings also highlight the critical role of unpaid carers. Future service development should recognise carers as equal partners in care, ensuring they have access to information, practical support, emotional support, contingency planning and involvement in decision-making.

Chapter 5 Mortality data, trends and life expectancy for Sussex, Brighton and Hove, East Sussex West Sussex, and England.

Key messages from chapter 5

Demand for PEoLC will continue to grow. Sussex recorded 18,927 deaths in 2024, equivalent to 1.08% of the population, with demand expected to rise as the population ages and more people live with frailty, dementia and multiple long-term conditions.

Most people who die in Sussex are likely to require PEoLC. Analysis suggests around 80% of deaths are 'expected deaths', with models estimating 90% of all deaths will require some form of PEoLC, highlighting the importance of earlier identification, advance care planning and coordinated support.

Dementia and frailty are becoming major drivers of need. Dementia was the leading cause of death among people aged 75+, accounting for 6,761 deaths between 2022 and 2024, reflecting the growing impact of an ageing population.

Health inequalities remain significant. Life expectancy varies by up to 14.5 years for men and 12.2 years for women between different Sussex communities, with areas such as Hastings experiencing higher mortality and lower life expectancy than many parts of West Sussex.

Hospitals remain the most common place of death across Sussex, yet increasing numbers of older people with complex needs will require greater investment in community-based care, care homes, hospice support and support for unpaid carers to meet future demand.

Mortality statistics are gathered and published by the Office for National Statistics (ONS) using information from death certificates registered in England and Wales. They include counts of death registrations (the date a death is registered with a local authority) and occurrences (the date a death happened) (106).

The latest Deaths registered in England and Wales Office for National Statistics release was on 27 May 2026.

Number of deaths

In 2024, there were 568,613 deaths registered in England and Wales; this was 12,750 (2.2%) fewer deaths than in 2023, and 8,547 (1.5%) fewer deaths than 2022.

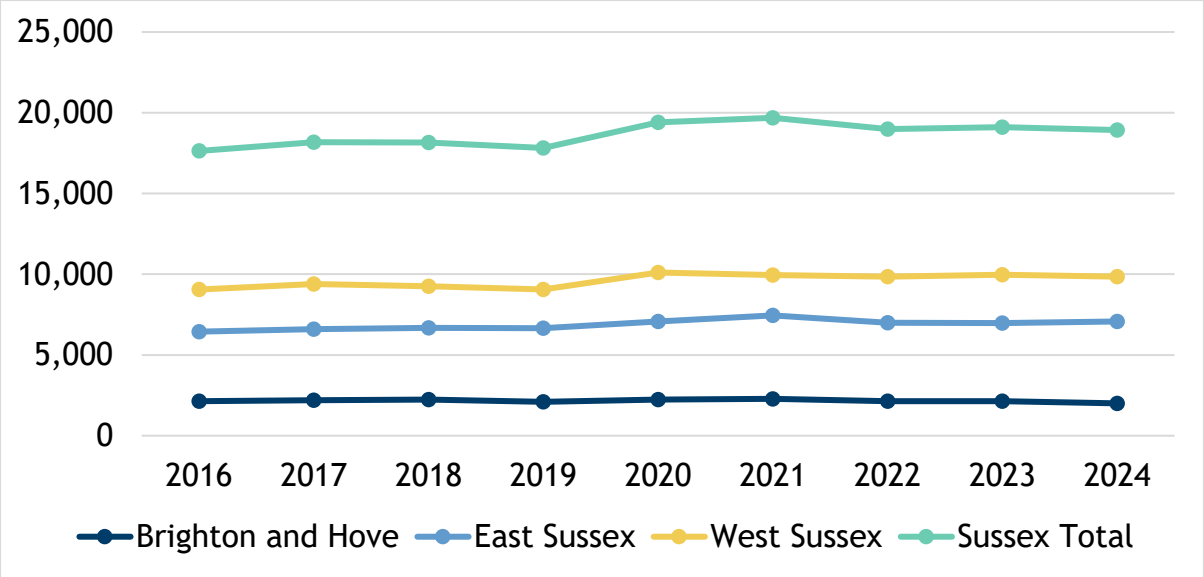
In England, 531,954 deaths were registered in 2024, which was 12,100 (2.2%) fewer deaths than 2023 and 8,379 (1.6%) fewer than 2022.

Within the Southeast region of England, there were 87,449 deaths in 2024 a 2% reduction from 89,229 in 2023. Within Sussex there were 18,927 registered deaths in 2024. (NB there can be variation between recorded deaths between years, as some deaths may occur in one year, but are delayed in being registered.(107)

Table 74 Number of deaths registered in Sussex 2024. Outlines the number of deaths and the percentage deaths annually registered in 2024 at Sussex and each Place.

Locality	Estimated Population	Registered Deaths	% of Population deaths annually
Brighton & Hove	283,870	2,005	0.71%
East Sussex	560,882	7,075	1.26%
West Sussex	915,037	9,847	1.08%
Sussex Total	1,759,789	18,927	1.08%

Figure 27 Number of registered deaths in Brighton & Hove, East Sussex, West Sussex and Sussex overall, 2016-2024.



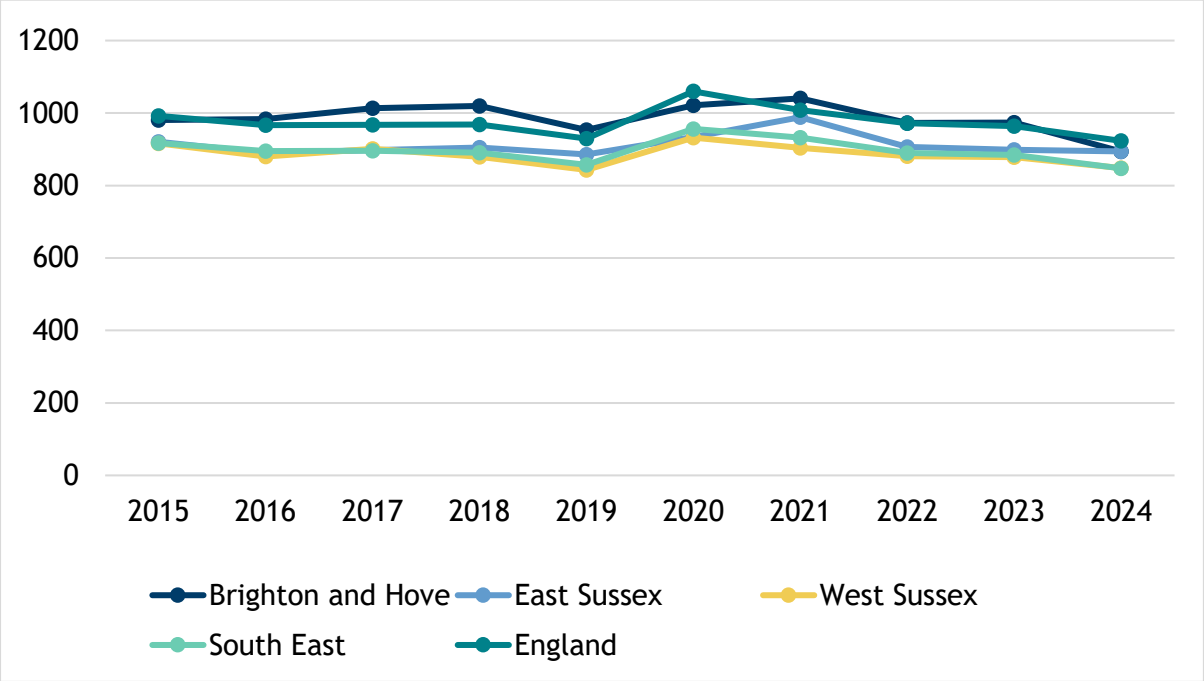
The number of deaths for each locality in Sussex has remained largely unchanged since 2016. West Sussex has the largest population and consistently has between

9,000 and 10,000 deaths per year. East Sussex has the second largest population and consistently had between 6,400 and 7,500 deaths per annum. Whilst Brighton, being the smallest of the localities' populations has approximately 2,000 deaths per year. For all three localities the years 2020 and 2021 saw the highest number of deaths recorded. This pattern coincided with the COVID-19 pandemic.

Mortality rates

Age standardised mortality rates (ASMRs) account for population size and age structure, allowing for more accurate comparison of mortality across time and location. They are expressed per 100,000 population (107).

Figure 28 Age Standardised Mortality Rate (ASMR) per 100,000 people for Sussex Places (Brighton and Hove, East Sussex, West Sussex), the South East region, and England from 2015 to 2024.

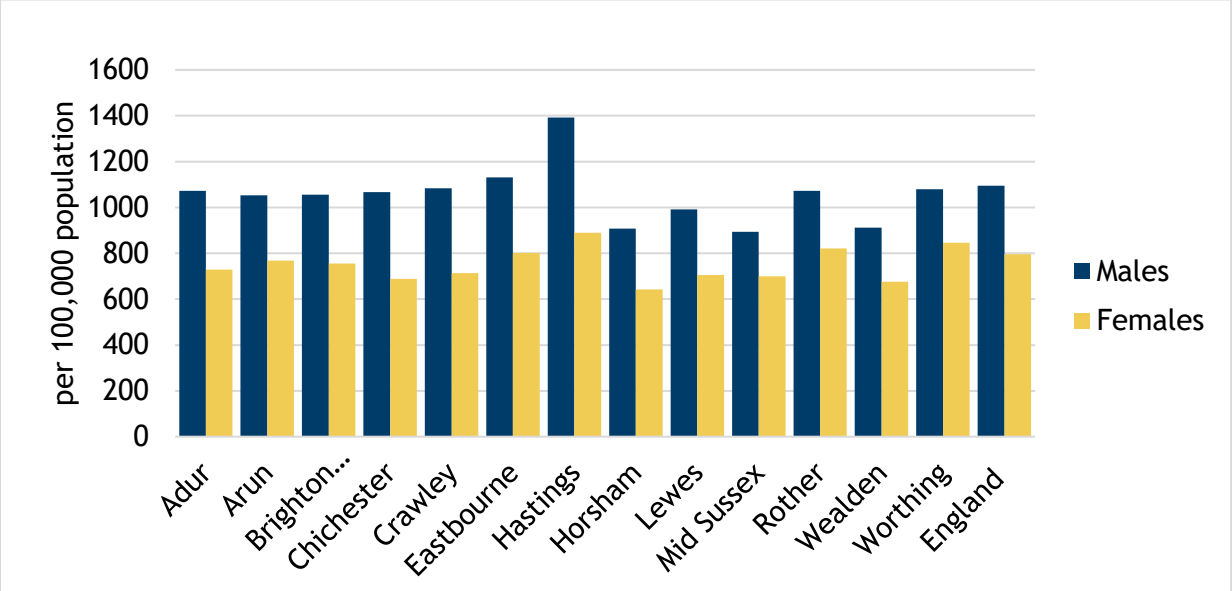


Mortality rates have remained relatively stable across all areas, fluctuating between approximately 850 and 1,050 per 100,000. A noticeable peak occurs around 2020–2021, likely reflecting the impact of the COVID 19 pandemic, after which rates decline back towards pre pandemic levels.

Brighton and Hove consistently shows slightly higher mortality compared to East and West Sussex, while West Sussex tends to have the lowest rates. The South East region and England follow similar patterns, with England generally at the upper end of the range. This suggests that while Sussex aligns broadly with national trends, there are persistent local variations within the county.

However, at upper tier and unitary level, this hides the variation in mortality we observed at district and borough level.

Figure 29 Age standardised mortality rates for 2024 across Sussex districts and boroughs/ICTs, broken down by sex.



In every area, males have higher mortality rates than females. Male rates generally range between 1,000 and 1,200 per 100,000 population and female rates are lower at 700–850 per 100,000. The highest male mortality is seen in Hastings, reaching approximately 1,400 per 100,000, significantly above other areas. Female mortality rates in Hastings are also among the highest, close to 900 per 100,000. Other areas such as Adur, Arun, and Worthing show male rates around 1,100 per 100,000, compared to female rates near 750 per 100,000.

The data highlights a consistent gender gap in mortality across Sussex, with notable geographic variation and Hastings standing out as the area with the highest rates for both sexes.

Life expectancy

Life expectancy (LE) is a statistical measure of the average number of additional years a person would expect to live if they experienced the age specific mortality rates of the given area and time for the rest of their life (108). Improvements in life expectancy slowed after the turn of the century, and life expectancy fell during the COVID-19 pandemic; it has since returned to a level similar to that recorded in 2018.

LE in Sussex varies greatly. Females in St James Street and Queens Park (an MSOA in Brighton) have a LE of 77.9 years compared to females in West Chiltington Common (An MSOA in West Sussex) of 90 years, a gap of 12.2 years. Males in Pier

(an MSOA in Eastbourne) have an LE of 72.1 years compared to men in Crowborough North (an MSOA in East Sussex) of 86.6 years, a gap of 14.5 years.

In every area shown, females have a higher LE than males, with the difference typically around three to four years. Among the Sussex areas, Horsham, Lewes, and Mid Sussex have the highest LE for both males and females, with females in these areas living up to around 86 years. In contrast, Hastings has the lowest LE, with males just above 75 years and females around 81 years. Most other areas fall between these extremes, with male LE generally between 78 and 82 years, and female LE between 83 and 85 years. The England average, shown at the end of the chart, indicates that several Sussex areas are above the national average, while some, such as Hastings and Brighton and Hove, are below or close to it.

Figure 30 LE for local areas of Sussex ICTs/District and Boroughs 2021 to 2023.

NB: Note the scale starts at 72 years old

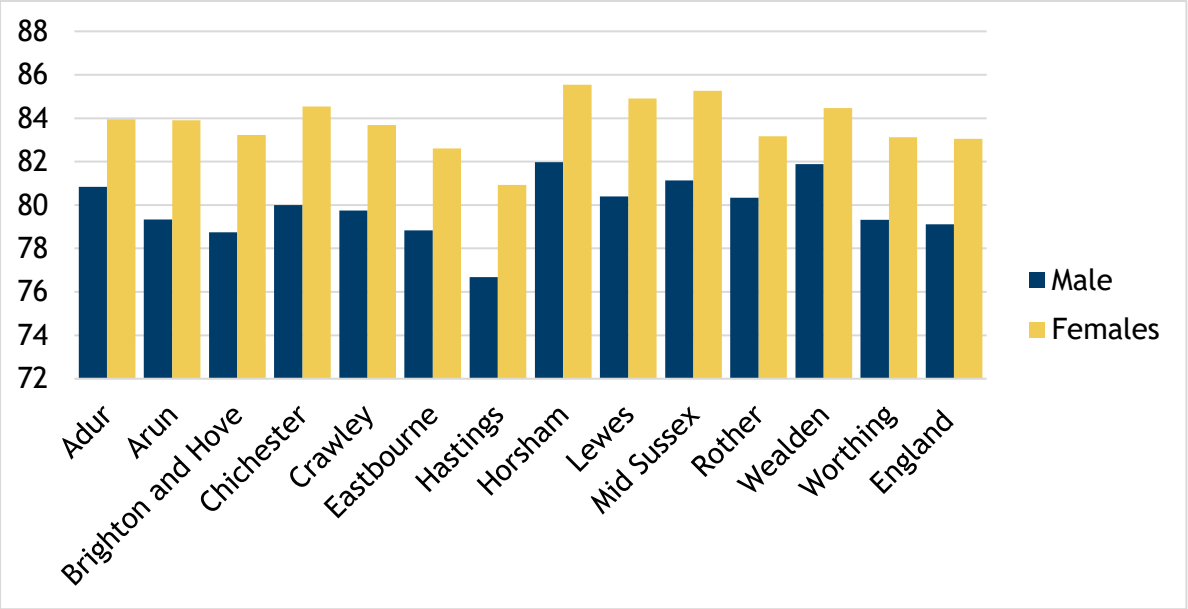


Figure 30 highlights both the consistent gender gap in LE and the variation between different local areas, suggesting underlying differences in health, socioeconomic factors, or access to services. Areas with shorter LE, such as Hastings and Eastbourne (109) may require earlier identification of advanced disease, rapid access to specialist palliative services, and hospital-based teams. While, in contrast, areas in West Sussex such as Horsham and Mid Sussex(3) with longer LE, may require sustained community and social care, with integration with dementia and frailty pathways for longer periods of time.

These variations should be considered currently and the expected increase in the size of the population of those in later life.

Unexpected deaths

Expected and unexpected deaths are important to distinguish. There is a desire to understand the extent to which death is predictable in order to plan care and to estimate costs specifically of PEoLC (52).

An expected death is often defined as a death that occurs when an individual dies due to an illness and conditions they were known to have, though unexpected deaths can still occur in those that have a long-term condition and are receiving PEoLC.

The underlying cause of death is defined by the WHO as the disease or injury that initiated the train of events directly linked to death or the circumstances of the accident or violence that produced the fatal injury and is the cause of death data recorded on a death certificate. To identify unexpected deaths, certain underlying causes of death can be assumed to cause an unexpected death, shown in Table 75 below.

Table 75 Causes of death deemed to be the cause of an unexpected death (52)

	ICD 10 Codes
Acute myocardial infarction	I21*, I22*
Pulmonary embolism	I26*
Pulmonary aneurysm	I281
Sudden cardiac death	I461
Cerebrovascular disease	I60 I69
Aortic aneurysm	I71*
Acute Respiratory disease **includes influenza, pneumonia**	J10 J29, J85 J86, J91 J96
Injury, poisoning, other consequences of external causes	S00 T98
External causes	V01 Y98

Using the ICD 10 Codes[9] in table 75 analysis was completed on pooled mortality data for Sussex 2022-2024, and each of the three Places, shows that approximately

[9] ICD-10 Version:2019

one fifth of deaths in Sussex are from causes that could be considered unexpected, meaning 82% likely required PEoLC.

Table 76 Percentage of causes of death deemed to be the cause of an unexpected death.

East Sussex	West Sussex	B&H	Sussex
17%	19%	19%	18%

It should be noted that although a proportion of unexpected deaths may not require PEoLC, the conditions that are included in the definition are attributed to the deaths of those receiving palliative and EoLC. One paper suggests that up to 5% and 10% of deaths in hospices and PEoLC units were considered unexpected(110). However, this data demonstrates that for 80% of the population of Sussex, they will likely require some form of PEoLC.

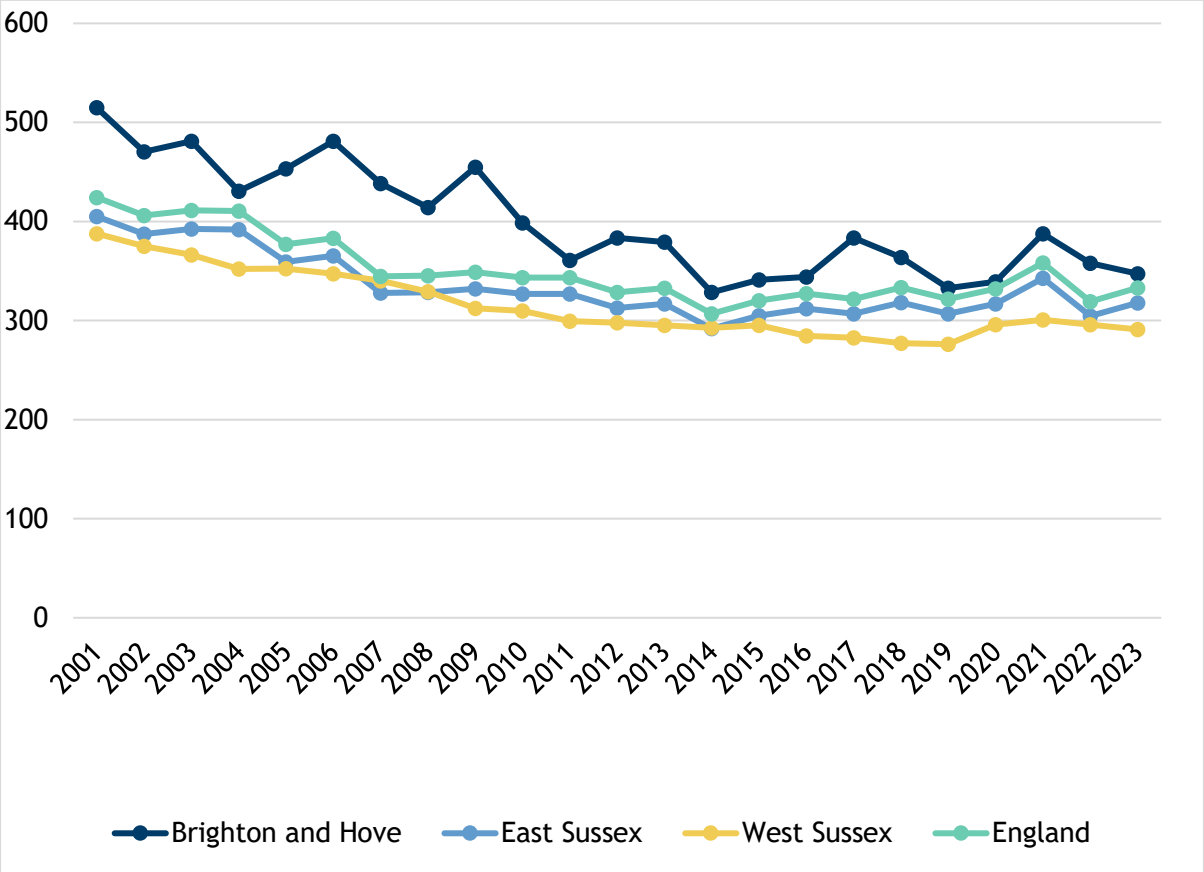
Major conditions and trends in associated mortality

There are differences in the long term trends associated with the major conditions of underlying or contributing causes to mortality in England and Sussex. Overall, rates of mortality associated with cardiovascular disease across all three Places in Sussex have declined.

Although concerns were raised that disruption to cancer screening and treatment pathways during the COVID-19 pandemic may result in increased respiratory and cancer-related mortality, current data suggests mortality rates have remained broadly stable and there is no clear evidence of a corresponding increase at this time.

Long term mortality trends

Figure 31 Long term trends in Under 75 mortality rates from all causes, all persons, Sussex Places/ UTLAs and England

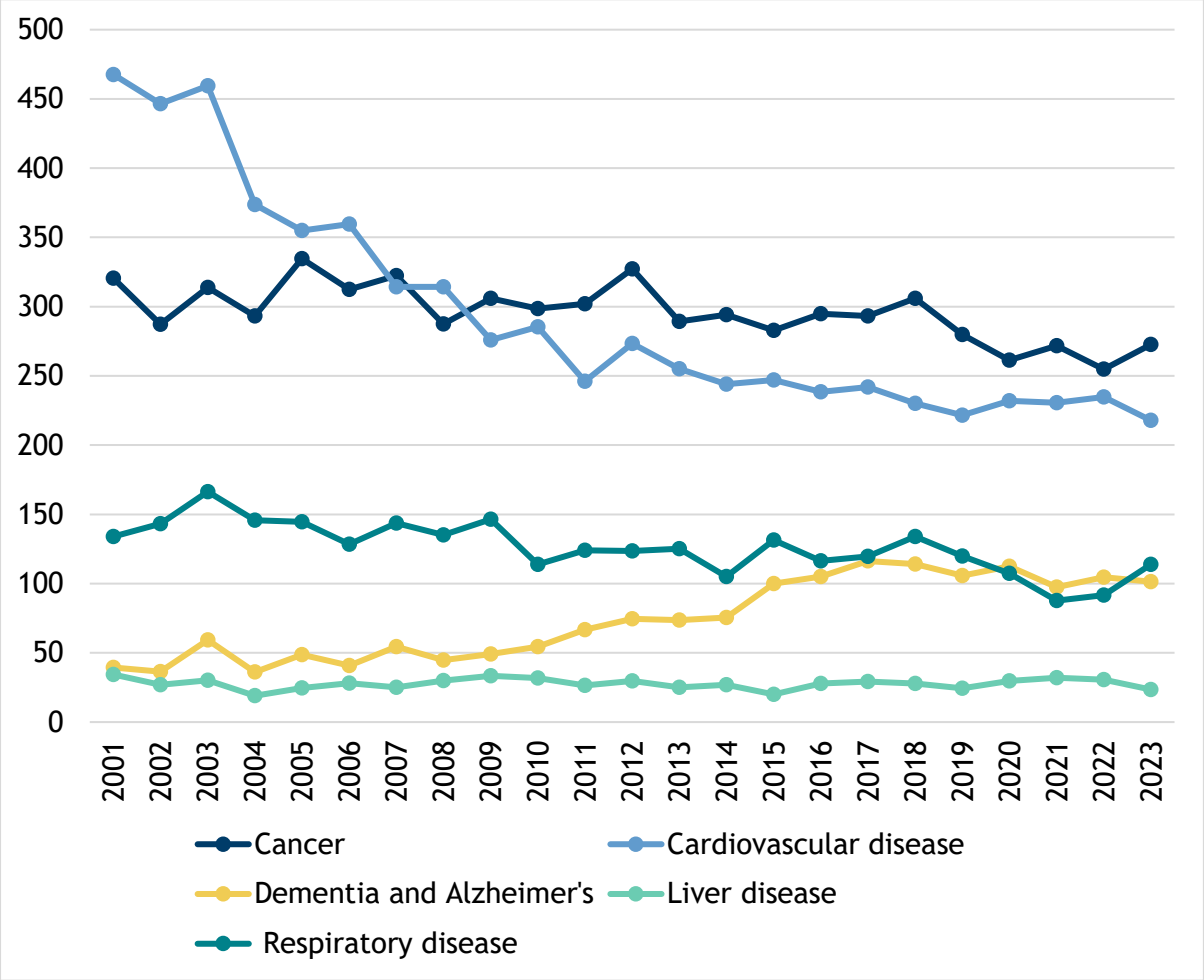


National and Sussex long term under 75 mortality rates have declined. Most deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. (111)

Leading causes of mortality

Mortality rates from dementia and Alzheimer's have increased, mainly because rates from other leading causes of death have decreased (112). When looking at long term trends, despite declines in mortality rates associated with cancer and CVD, these two conditions remain the two leading causes of death in Sussex.

Figure 32 long term trends in mortality rates from major conditions in Brighton and Hove from 2001 to 2023

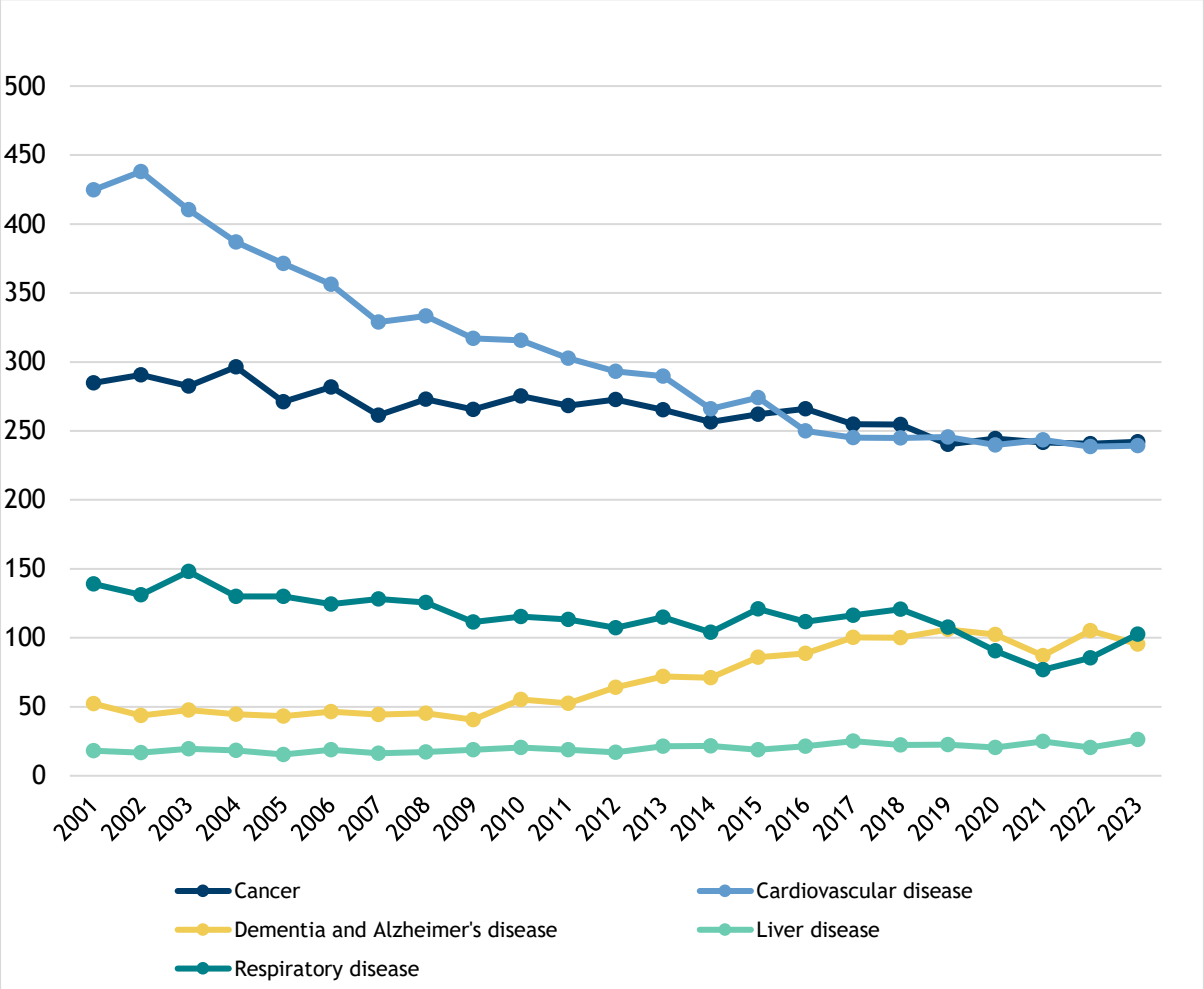


Cardiovascular disease had the highest mortality rate in 2001 at around 467 per 100,000, but it declined sharply over time to about 217 per 100,000 in 2023. Cancer remained relatively stable, fluctuating between 320 and 305 per 100,000. Respiratory disease mortality started at about 130 per 100,000 in 2001 and has gradually decreased to around 113 per 100,000.

In contrast, Dementia mortality increases, rising from roughly 40 per 100,000 in 2001 to about 100 per 100,000 by 2023. Liver disease mortality remained the lowest throughout, staying below 30 per 100,000 with fluctuations.

2023 mortality data show the Brighton and Hove rates from cancer, for all ages and persons, and from cancer for males is worse than England (113).

Figure 33 long term trends in mortality rates per 100,000 population for major conditions in East Sussex from 2001 to 2023



Cardiovascular disease shows the most significant decline and has fallen from a peak of 437 per 100,000 in 2002 to 239 per 100,000 in 2023. This reflects major improvements in prevention and treatment.

In contrast, cancer mortality has remained relatively stable, fluctuating between 270 and 300 per 100,000,

Respiratory disease rates have gradually decreased from 150 per 100,000 to just over 100 per 100,000, while dementia and Alzheimer's disease have steadily increased, rising from roughly 50 per 100,000 in 2001 to nearly 100 per 100,000 in 2023, highlighting the growing impact of ageing populations.

Mortality rates for liver disease remain the lowest throughout the time period, consistently below 26 per 100,000. Overall, the data shows a mix of reducing cardiovascular and respiratory mortality, stable cancer rates, and a notable rise in dementia related deaths.

Figure 34 West Sussex long term trends in mortality rates associated with major conditions

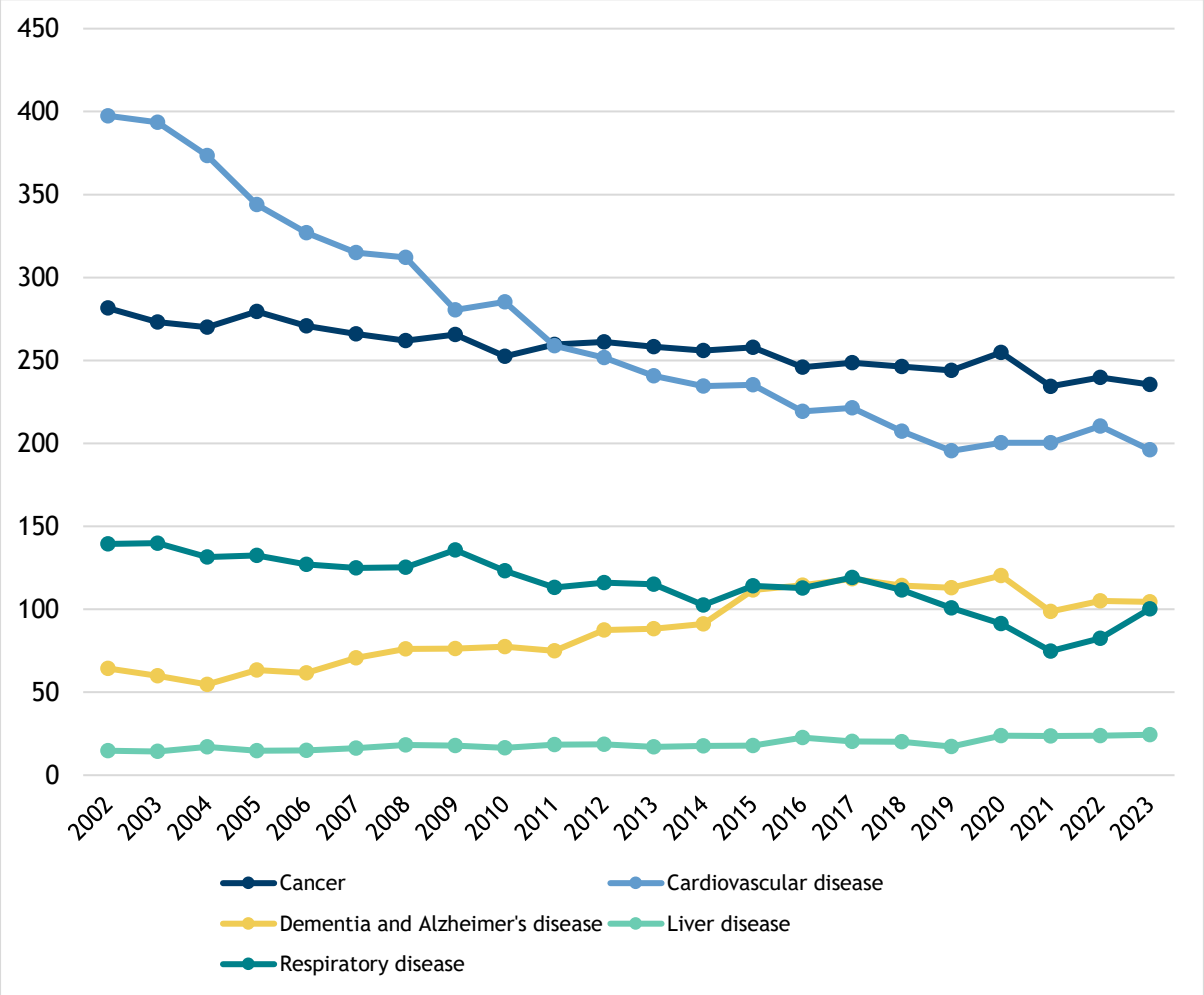


Figure 34 shows long term trends in mortality rates per 100,000 population for major conditions in West Sussex from 2002 to 2023. Cardiovascular disease had the highest mortality rate in 2002 at around 397 per 100,000 but declined sharply over time to about 196 per 100,000 in 2023, showing the most significant improvement.

Cancer remained relatively stable, fluctuating between 281 and 235 per 100,000, with only a slight downward trend. Respiratory disease started at about 139 per 100,000 and gradually decreased to around 100 per 100,000.

In contrast, Dementia and Alzheimer's disease increased steadily from roughly 60 per 100,000 in 2002 to about 100 per 100,000 by 2023, reflecting an ageing population.

Liver disease stayed consistently low, below 20 per 100,000, with minor fluctuations. Overall, the data highlights major reductions in cardiovascular mortality, stable cancer rates, and a growing impact of dementia related deaths over the past two decades.

Leading and contributing causes of deaths in Sussex

This section provides insight into the leading and contributing causes of death in Sussex, with the aim of further understanding PEoLC needs. All data presented is for deaths of Sussex residents aged 18 years or over that occurred during the three-year period 2022 to 2024. A three-year period was used to minimise the impact of annual variation and to reduce the impact of small numbers for those causes that are less common. Excluding 2020 and 2021 also reduces the impact of mortality data attributed to COVID 19.

Data was sourced from Primary Care Mortality Database extracts held by each of the Sussex Public Health teams. A small number of deaths that occurred during the time period awaiting registration due to on-going Coroner's inquest were not included in the analysis. However, these deaths did not have any underlying or contributing causes recorded. These deaths tend to be those due to accidents, violence and suicide and so excluding them from cause analysis has minimal, if any impact in terms of the context of this needs assessment.

The top 10 causes of deaths by broad age group are shown, and these are based on leading causes of death classifications(114) . Further analysis by areas within Sussex, place of death (Classification of place of death GOV.UK) and contributing causes as well as underlying causes of death are also presented. This analysis uses the following conditions:

- Cancer (ICD10 C00 C97).
- CVD (ICD10 I00 I99).
- Dementia and Alzheimer's (ICD10 F00, F01, F03, G30, G310, G318).
- Respiratory conditions (ICD10 J00 J99).
- Liver disease (ICD10 K70 K76).

Certain neurological conditions have also been used (grouped together) and these are those recognised by Hospice UK where PEoLC plays a significant part in their management:

- Parkinson's disease (ICD10 G20).
- Multiple sclerosis (ICD10 G35).
- Huntington's disease (ICD10 G10).
- Motor neurone disease (ICD10 G122).
- Progressive supranuclear palsy (ICD10 G231).
- Multiple system atrophy (ICD10 G903).

All other causes of death are grouped together under 'other'.

Top 10 causes of death in Sussex

There are variations by age group in relation to underlying cause of mortality in Sussex. The burden of the major conditions, cancer, CVD, respiratory and dementia and their role in mortality is visible across all age groups.

For adults aged 18–64 year olds there were less than 650 deaths over the three years due to ischaemic heart diseases, the leading cause of death for this age group. Liver disease, suicides and accidental poisoning appear in the top 10 for 18 64 year olds whereas they appear lower down or outside of the top 10 for the older age groups.

Table 77 Top 10 causes of death for 18-64s, Sussex, 2022 to 2024

	Cause	Number
1	Ischaemic heart diseases	638
2	Cirrhosis and other diseases of liver	492
3	Suicide and injury/poisoning of undetermined intent	417
4	Malignant neoplasm of trachea, bronchus and lung	389
5	Accidental poisoning	320
6	Malignant neoplasm of breast	293
7	Malignant neoplasm of colon, sigmoid, rectum and anus	280
8	Chronic lower respiratory diseases	272
9	Cerebrovascular diseases	210
10	Malignant neoplasm of pancreas	172

In the 65- 74 age group, there is a greater number of major conditions as the underlying cause of death. Ischaemic heart diseases remain the leading cause with cancers making up half of the top 10 causes in this group.

Table 78 Top 10 causes of deaths for 65-74s, Sussex, 2022 to 2024.

	Cause	Number
1	Ischaemic heart diseases	843
2	Malignant neoplasm of trachea, bronchus and lung	683
3	Chronic lower respiratory diseases	576
4	Malignant neoplasm of colon, sigmoid, rectum and anus	349
5	Cerebrovascular diseases	326
6	Malignant neoplasm of pancreas	264
7	Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue	257
8	Dementia	249
9	Malignant neoplasm of breast	241
10	Cirrhosis and other diseases of liver	183

The 75+ age group highlights much higher numbers of deaths compared to younger adults, with dementia now being the number one cause of death. Twice as many people aged over 75 years had dementia recorded as the leading cause of death compared to the next cause of ischaemic heart disease. At this later stage of life there may be multiple conditions that contribute to mortality. This is explored in table 79.

Table 79 Top 10 causes of deaths for 75+, Sussex. 2022 to 2024.

	Cause	Number
1	Dementia	6,761
2	Ischaemic heart diseases	3,279
3	Cerebrovascular diseases	2,538
4	Symptoms, signs and ill-defined conditions	2,362

	Cause	Number
5	Chronic lower respiratory diseases	1,924
6	Influenza and pneumonia	1,893
7	Heart failure and complications and ill-defined heart disease	1,466
8	Malignant neoplasm of trachea, bronchus and lung	1,379
9	Malignant neoplasm of colon, sigmoid, rectum and anus	1,103
10	COVID 19	1,027

Table 80 shows the numbers of deaths by underlying cause of death, but also where conditions were captured as a contributing factor. Cancer is the most common underlying cause of death (approx. 15,000 deaths), but when also considering other conditions that were mentioned, CVD is the most significant condition overall (26,000 deaths with any mention of a CVD condition on the death certificate). Looking across any mention of a condition that contributed to death, whether the underlying cause or not, cancer and respiratory conditions have similar numbers (16,900 for cancer and 16,800 for respiratory). Dementia and Alzheimer's were the underlying cause for approximately 7,200 deaths, but a further 3,200 had them captured as a contributing factor. Liver disease and neurological conditions are far less common, both in terms of the underlying cause of death or a contributing factor.

CVD and cancer dominate as leading causes of death, while dementia and respiratory conditions often act as significant contributory factors in multi-morbidity at EoL.

Table 80 Number of people who died of a grouped major condition as an underlying and or contributory cause of death, Sussex 2022- 2024

Sussex						
Deaths with the condition as	Cancer	CVD	Dementia/Alz	Liver disease	Neuro	Respiratory
Underlying cause of death	14,963	13,999	7,250	896	1,343	6,258

Sussex						
Only a contributory cause of death	1,956	11,936	3190	767	595	10,531
Underlying or contributory cause of death (total)	16,919	25,935	10,440	1,663	1,938	16,789

Figure 35 Place of death and grouped underlying cause of death, Sussex 2022- 24 data, Sussex

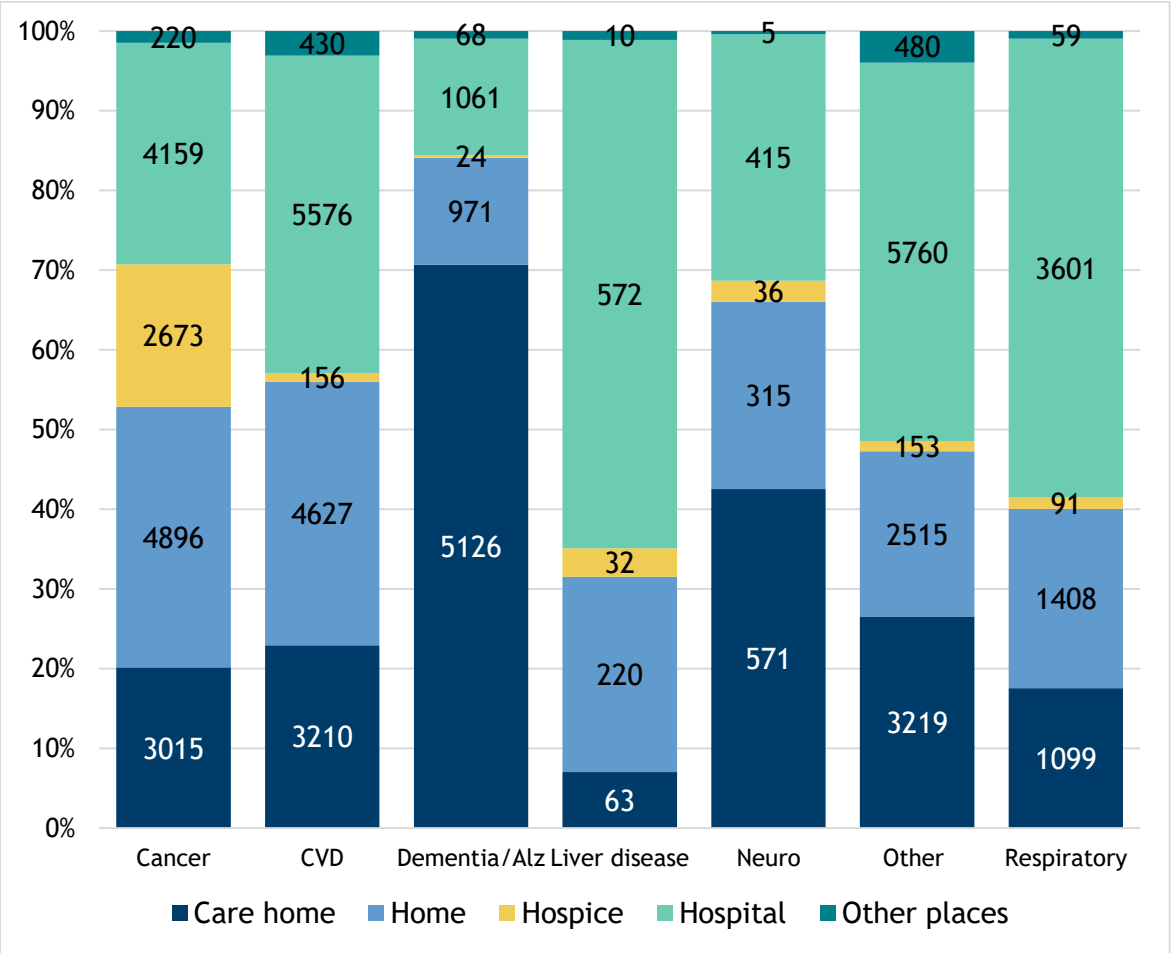


Figure 35 highlights the place of death by underlying cause. There is variation between place of death and condition. For example, a larger proportion of cancer deaths occur in hospices, over 60% of those who died from dementia died in a care home, whilst most people that died from respiratory disease died in hospital.

Figure 36 Place of death and age groups, Sussex, 2022- 2024

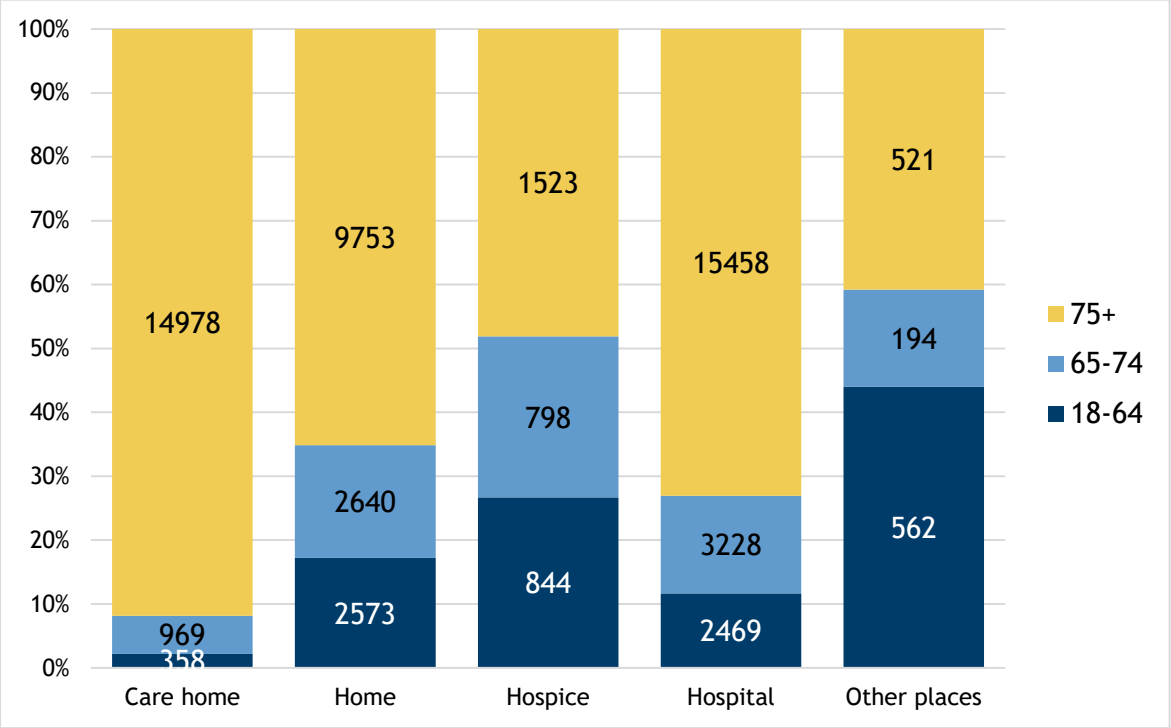


Figure 36 shows the distribution of deaths by place of death and age group in Sussex between 2022 and 2024. The data demonstrate that people aged 75 years and over account for the majority of deaths across all settings, particularly in care homes and hospitals deaths. This reflects the older age profile of those receiving end of life care and the growing importance of frailty, dementia and multiple long-term conditions in later life.

Figure 37 Place of death, Brighton and Hove and its ICT Partnerships, 2022 2024

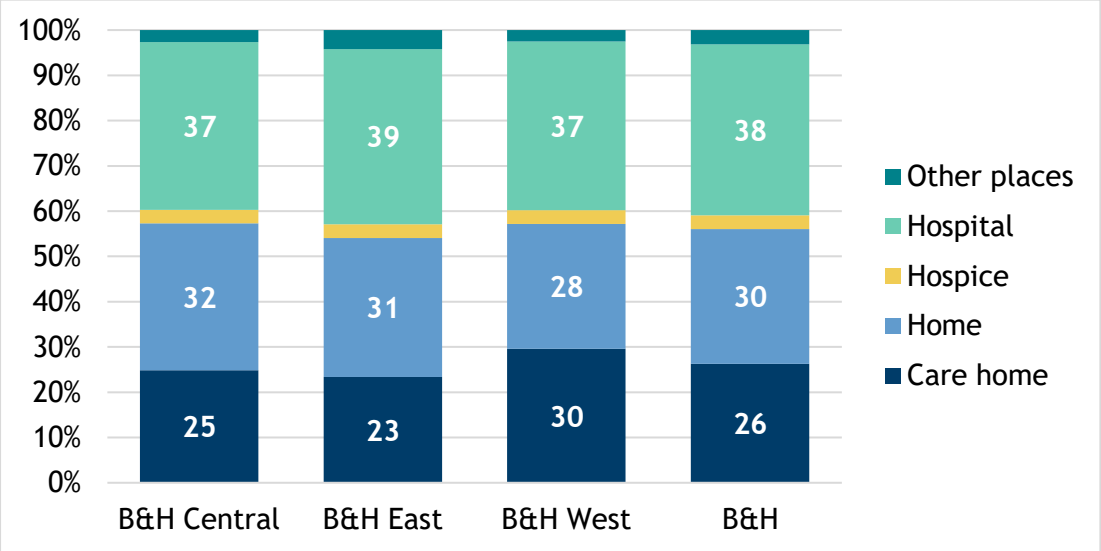


Figure 37 shows the distribution of places of death across Brighton & Hove and its three Integrated Community Team (ICT) localities between 2022 and 2024.

Hospitals were the most common place of death across all areas, accounting for 37% of deaths in Brighton & Hove overall, with a similar proportion seen in Central (37%), East (39%) and West (37%). Home was the second most common place of death, representing approximately 30% of deaths overall, ranging from 28% in Brighton & Hove West to 32% in Brighton & Hove Central.

Figure 38 shows the distribution of places of death across East Sussex and its ICTs. Hospitals account for the largest share in all areas, ranging from about 35% to 38%, followed by care homes at roughly 28–31%.

Home deaths make up around a quarter of cases, while hospices represent a smaller proportion (5–8%), highest in Wealden. Deaths in other places are minimal, under 3% across all areas. Overall, the pattern is consistent across Hastings, Lewes, Rother, Wealden, and East Sussex, with hospitals and care homes being the predominant locations.

Figure 38 Place of death, East Sussex and its ICTs, 2022 2024

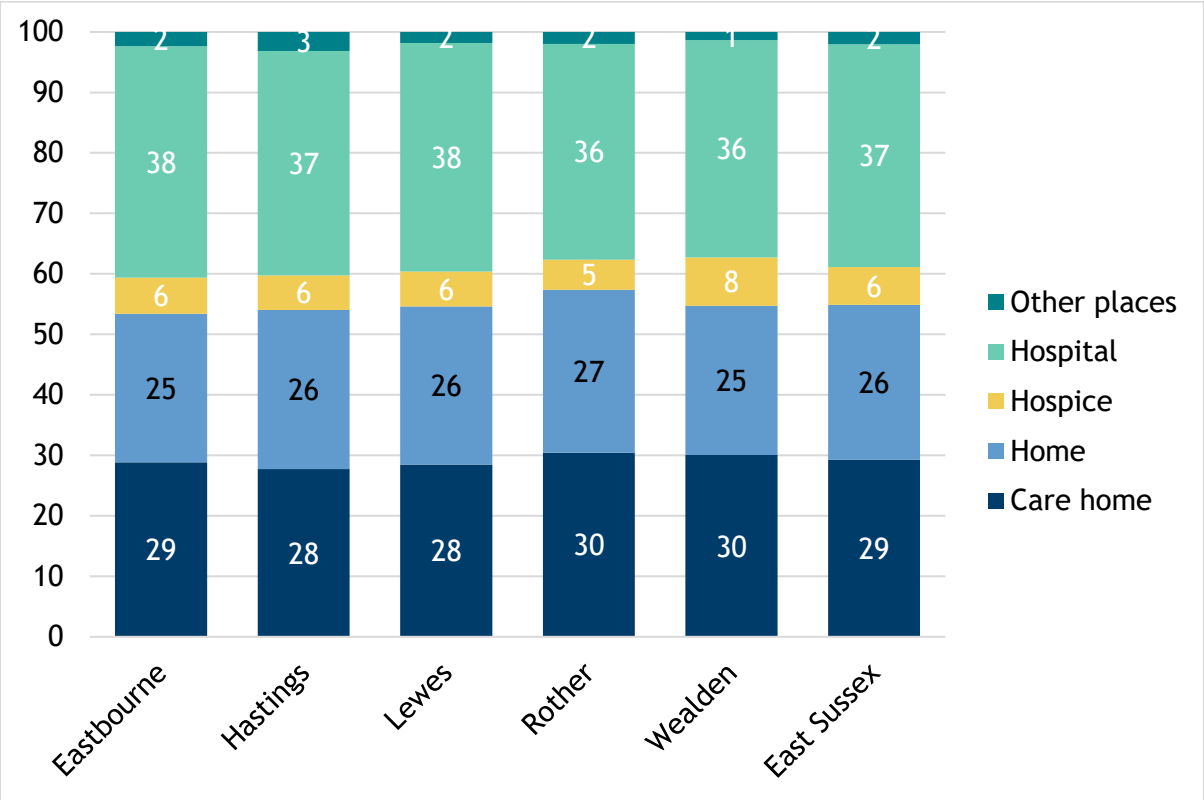


Figure 39 shows the distribution of places of death across West Sussex and its ICT areas. Hospitals account for the largest share in every locality, consistently around or above 40%, making them the most common place of death. Home deaths generally range between 20–30%, while care homes contribute a similar proportion in most areas, with Chichester and Mid Sussex showing higher care home figures. Hospice deaths remain small, typically under 10%, and deaths in other places are minimal.

Figure 39 Place of death, West Sussex and its ICTs, 2022 - 2024

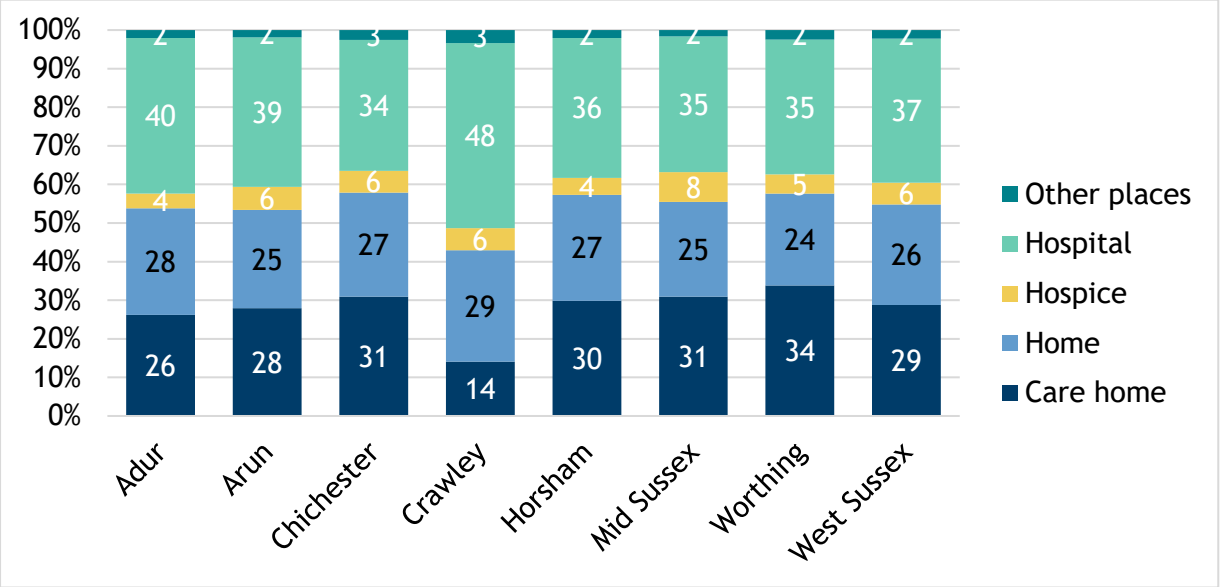
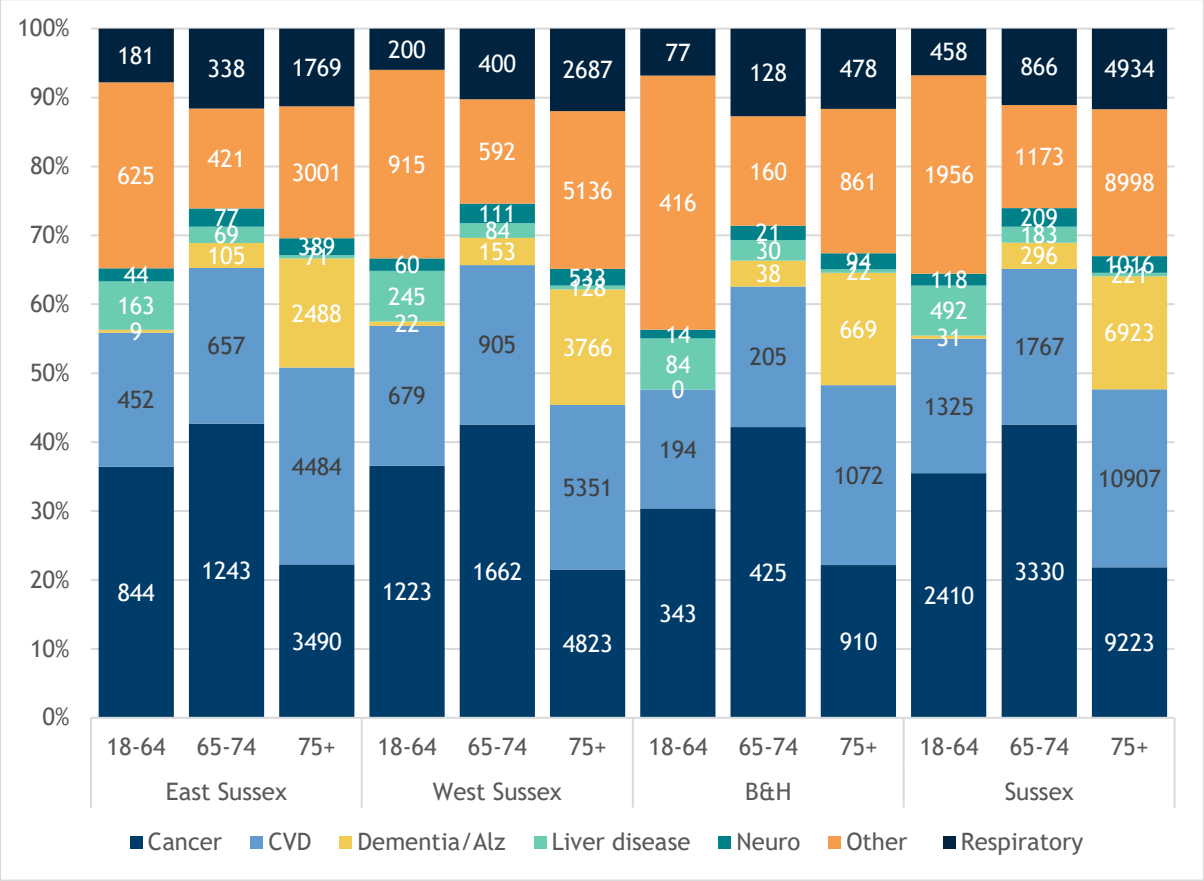


Figure 40 shows the percentage distribution of underlying causes of death by age group (18-64, 65-74, and 75+) across East Sussex, West Sussex, Brighton & Hove (B&H), and Sussex overall.

Cancer is the leading cause among those aged 18-64, accounting for around 50-60% of deaths in all areas, while cardiovascular disease (CVD) becomes more prominent in older age groups, particularly 75+, where it represents roughly 30-35%. Dementia/Alzheimer's rises sharply in the 75+ group, contributing about 20-25% of deaths, whereas it is minimal in younger groups. Respiratory conditions also increase with age, reaching around 10-15% in the oldest group. Liver disease and neurological conditions remain relatively small across all ages, and Other causes make up a minor share. Overall, the data highlights a clear shift from cancer dominance in younger adults to dementia and CVD in older populations, with notable consistency between areas.

Figure 40 Number and percentage of grouped underlying cause of death, Place/ULTA and Sussex, by three age groups, 2022 – 2024.



Chapter 5 Conclusion – What does this mean for Sussex?

Need

Mortality data demonstrates that PEoLC is, and will remain, a core requirement for the Sussex population. In 2024, there were 18,927 registered deaths across Sussex, equivalent to around 1.08% of the population. Analysis of mortality patterns suggests that approximately 80% of deaths are expected and therefore likely to benefit from some form of palliative and EoLC. Broader modelling estimates that up to 90% of people who die may require PEoLC at some stage before death. This highlights the importance of identifying need earlier and ensuring access to appropriate support across all care settings.

Whilst cancer remains a major cause of death, the mortality profile increasingly reflects the impact of ageing, frailty, dementia, cardiovascular disease and multimorbidity. Among people aged 75 years and over, dementia is now the leading cause of death, accounting for more deaths than any other condition. This

indicates that PEoLC in Sussex must increasingly be designed around the needs of people living with prolonged and often unpredictable trajectories of decline.

Unmet need

The mortality data suggests opportunities to strengthen earlier identification and anticipatory care planning. Given that most deaths are foreseeable, there is significant scope to identify people who may benefit from PEoLC earlier and support them over a longer period before death.

The growing contribution of dementia, frailty and multiple long-term conditions to mortality highlights the need for services that move beyond traditional cancer-focused models of palliative care. People living with these conditions may experience prolonged periods of declining health, complex care needs and increasing dependence on carers and services. Failure to identify these needs early risks crisis-driven care, avoidable hospital admissions and missed opportunities for advance care planning.

Variation in place of death and service utilisation also suggests that some people may not always receive care in the most appropriate setting or in a way that reflects their preferences and needs.

Variation

Important variation exists across Sussex in mortality, life expectancy and causes of death. Whilst overall mortality rates are broadly comparable with national trends, significant differences exist between individual Places and Integrated Community Team localities.

Hastings experiences some of the highest mortality rates in Sussex and has among the lowest life expectancy figures, whilst areas such as Horsham, Mid Sussex and Lewes experience lower mortality and longer life expectancy. These differences reflect wider variations in population health, deprivation, lifestyle factors and long-term conditions.

Variation is also evident in place of death. Hospitals remain the most common place of death across all Sussex Places, although the proportion of deaths occurring in hospitals, care homes, hospices and people's own homes differs between localities and population groups. There are also notable differences in mortality patterns by age and underlying cause of death, indicating that service requirements are unlikely to be uniform across Sussex.

Inequalities

The findings reinforce the significant impact of health inequalities on mortality and EoLC need. Life expectancy varies by up to 14.5 years for males and 12.2 years

for females between different Sussex communities, demonstrating substantial inequalities in how long people live and the health they experience throughout their lives.

Areas with lower life expectancy, higher mortality rates and greater levels of deprivation are likely to experience greater need for PEoLC at younger ages, often alongside more complex physical, psychological and social needs. These communities may require earlier identification, greater support from community and specialist services, and targeted approaches to reduce inequalities in outcomes.

Addressing these disparities will be essential if Sussex is to ensure equitable access to high-quality PEoLC for all residents, irrespective of where they live or their socioeconomic circumstances.

Future demand

Demand for PEoLC is expected to increase substantially over the coming decades. Although annual mortality levels have remained relatively stable in recent years, population ageing means that the absolute number of people requiring support is likely to grow. Future demand will increasingly be driven by frailty, dementia, multimorbidity and complex long-term conditions rather than cancer alone.

The age profile of deaths in Sussex demonstrates this shift. Almost half of all deaths occur among people aged 85 years and over, and dementia has become an increasingly important cause of death. Consequently, future services will need to support larger numbers of people living with complex needs for longer periods of time.

This increasing demand will place additional pressure on primary care, community nursing, social care, care homes, hospices, acute services, unpaid carers and bereavement services. Without proactive planning, capacity and workforce pressures are likely to increase significantly across the system.

What this means for Sussex

The mortality profile of Sussex provides a clear indication of where future PEoLC priorities should be focused. The evidence demonstrates that the greatest challenge is no longer simply responding to death, but supporting increasing numbers of people living for longer with frailty, dementia, multimorbidity and complex care needs.

Future service models will need to place greater emphasis on earlier identification, proactive care planning, coordinated care and support delivered closer to home. As dementia, frailty and cardiovascular disease contribute

increasingly to mortality, PEoLC will need to become more integrated with services for older people, community health services, care homes and social care.

Key takeaways for Sussex

Bereavement support should be delivered through a tiered model, with most people supported by family, friends and communities, while timely specialist support is available for those at higher risk of poor outcomes. Around 10–15% of bereaved people experience prolonged or complicated grief and require additional intervention. Tier 4 is an additional crisis and acute mental-health layer added for local mapping purposes and is not part of the core three-tier bereavement model.

Early, proactive and sustained support is needed. Bereaved people and carers often report feeling unprepared for death and unsupported afterwards, with many needing support months after the death rather than immediately following it.

Access to bereavement support is inequitable. Men, LGBTQ+ communities, minority ethnic groups, rural populations, people with disabilities, those facing poverty, and non-English speakers can face additional barriers to accessing appropriate support.

Community, peer and informal support networks are fundamental. Evidence consistently shows that compassionate communities, peer support, faith groups, workplaces and families play a crucial role in reducing isolation, improving wellbeing and supporting adaptation to loss.

The bereavement support system is fragmented and under pressure. Professionals highlighted limited capacity, long waiting times, workforce challenges, inconsistent referral pathways and a lack of coordinated information, creating a need for better integration, clearer pathways and improved awareness of available support.

Chapter 6 Bereavement support needs

Characteristics of effective and equitable bereavement care

Introduction

Bereavement refers to the period of grief and adjustment that follows the loss of something significant. In this report, the term is used specifically to describe the experience of losing an important person (115–117). Grief is the emotional response to that loss and is commonly associated with intense feelings of sadness.

It is a natural reaction to death that can involve emotional, cognitive, physical, spiritual, and behavioural aspects (116–118).

People experience loss and bereavement in different ways. There is no single "right" way to grieve, and reactions can vary widely in intensity, symptoms, duration, and expression (119). For many, grief gradually becomes more manageable over time with the support of family, friends, and community networks (117,120,121).

However, a significant minority, around 10%, experience prolonged or complicated grief, depression, anxiety, trauma responses, social isolation, or declines in physical health (120,122–124). In these cases, personal coping strategies and informal support may not be enough, and additional help can be required (115,125–127). Risk factors for complicated grief include the nature of the relationship with the person who died, previous mental health difficulties, social isolation, the circumstances of the death (such as sudden or violent loss), and pressures associated with caregiving or conflict (123,128,129). Poor end-of-life experiences can negatively affect bereavement outcomes, while compassionate communication from healthcare professionals and opportunities to be present and say goodbye may support healthier adjustment to loss (130).

Because needs vary, bereavement support spans a wide spectrum, from basic information, community empowerment and community-based support to structured peer groups and specialist mental health services (121). The level of support should match the level of need (115,126,127).

National data indicate that each year a substantial number of people in the UK experience the death of a close family member or friend (131,132). In West Sussex alone, there were 9,860 deaths in 2022 (132,133), resulting in thousands of bereaved individuals, some of whom are at risk of developing complicated grief and experiencing long-term adverse health and wellbeing outcomes (131–133) Population ageing is expected to further increase this need; projections suggest that, within the next 20 years, annual deaths in the UK will rise by approximately 100,000. Consequently, demand for end-of-life care, bereavement support, and related services is expected to grow substantially (134).

Across the UK, bereavement support is increasingly recognised as a public health priority (115,135). This growing focus has been driven by several factors, including the impact of the COVID-19 pandemic, increased recognition of prolonged grief disorder, and wider concerns about loneliness, social inequalities, and poor experiences of EoLC (115,127,134,135). Consequently, national policy and palliative care guidance now emphasise bereavement support as an essential

component of holistic care, embedded within primary care, hospice philosophy and palliative care standards (115,135,136).

Effective bereavement support aims not only to assist individuals in adapting to loss and managing acute grief, but also to mitigate longer-term adverse health and social outcomes. Bereavement-related healthcare costs are substantial; for example, hospital admissions following the death of a spouse are estimated to cost between £150 million and £190 million annually in the UK (126). Evidence suggests that high-quality bereavement care may reduce demand on healthcare services, including general practitioner consultations and other forms of healthcare utilisation (127).

This report examines the evidence base for bereavement support, including theoretical models of grief, frameworks for bereavement care, the effectiveness of different interventions, barriers to accessing support, and the features of high-quality bereavement services. It draws on academic research, systematic reviews, policy documents, clinical guidelines, palliative care literature, and public health perspectives to provide an overview of current knowledge and practice.

Understanding bereavement and grief

Grief is a multidimensional response to loss, involving emotional, cognitive, behavioural, physical, social, and spiritual reactions (117,118). Models of grief help individuals and clinicians understand these reactions, normalise intense emotions that may otherwise feel overwhelming or confusing and highlight that grief is not linear and has no single “correct” path (116,118,127,137,138). How a person grieves can be shaped by factors such as:

- Relationship to the deceased.
- Circumstances of death.
- Previous losses and trauma.
- Social support networks.
- Cultural and religious beliefs.
- Age and developmental stage.
- Socioeconomic context.
- Mental and physical health history.

Types of grief

Anticipatory Grief: Occurs before an expected death (e.g., terminal illness). People may feel sadness, fear, or exhaustion while the person is still alive. It may

help some prepare emotionally, whilst for other people it can increase the risk of complicated grief (139).

Disenfranchised grief: Grief that is not socially recognised or supported, such as the loss of an ex-partner, online friend, pet, or someone who died in stigmatised circumstances. This can also affect LGBTQ+ individuals, whose relationships, identities, or losses may not always be fully acknowledged or validated by family, services, or wider society. This can contribute to isolation and emotional invalidation (139,140).

Complicated / prolonged grief: Intense, persistent grief that impairs daily functioning. Individuals may struggle to accept the death or re-engage with life. Professional support is often needed. This is sometimes referred to as complex grief (120,123,124).

Collective grief: Shared grief experienced by communities after events like natural disasters, pandemics, or public tragedies. It can create distress but also foster solidarity and connection (139).

Secondary loss: Additional losses triggered by the death, such as financial changes, shifts in identity, or altered family roles. These can intensify emotional strain and reduce personal coping mechanisms (139).

Delayed or absent grief: Some individuals show minimal immediate reaction due to shock, cultural expectations, or practical responsibilities. Emotions may surface months or years later when the person feels safer to process the loss (139).

Models of grief

Models of grief help individuals and clinicians understand these reactions, normalise intense emotions, and promote understanding of experiences and different models can resonate with different people.

Kübler-Ross's five stages of grief

One of the most widely recognised grief models is Kübler-Ross's five stages of grief (141). Although originally developed in the context of terminal illness, the model has been widely applied to bereavement. These stages are not linear and not experienced by everyone (142). This model can be helpful because it validates a range of emotional responses and reassures individuals that intense and changing emotions are common after loss (141–143).

- **Denial** — difficulty accepting the loss.
- **Anger** — frustration or resentment.

- **Bargaining** — "if only" thoughts.
- **Depression** — deep sadness and withdrawal.
- **Acceptance** — adapting to life with the loss.

Worden's tasks of mourning

This model frames grief as an active process rather than a passive sequence of emotional stages (138,144).

1. Accept the reality of the loss.
2. Process the pain of grief.
3. Adjust to life without the deceased.
4. Maintain an enduring connection while moving forward.

This model highlights the importance of acknowledging pain, adapting to practical and emotional changes, and maintaining an ongoing but transformed connection with the deceased. It can provide practical areas for reflection and intervention while recognising that grieving individuals move through these tasks at their own pace (138,144).

Dual process model

The Dual Process Model developed by Stroebe and Schut conceptualises grief as oscillation between:

- Loss-oriented coping (focusing on grief and emotional pain).
- Restoration-oriented coping (adjusting to changed roles and daily life)(137,145)

This model frames grieving as moving back and forth between these modes, allowing both emotional expression and periods of respite. This can normalise fluctuations in grieving and recognises that people need periods of respite from intense emotional pain (137,145).

Continuing bonds theory

Contemporary grief theory recognises that maintaining an ongoing symbolic relationship with the deceased can be healthy and adaptive (146,147). This may involve memories, rituals, conversations, or commemorative practices. It challenges older ideas that "letting go" is necessary for healing. This perspective can be helpful to reduce guilt or confusion experienced by bereaved individuals who continue to feel emotionally connected to the deceased (148,149).

Meaning making approaches

Meaning-making approaches view grief as a process of reconstructing meaning after a loss. Rather than focusing on stages of grief, they emphasise how bereaved individuals make sense of the death, integrate it into their life story, and rebuild their sense of identity, purpose, and connection to others (150–152).

Impact of bereavement

Bereavement can affect psychological, physical, social, and economic wellbeing. While most people adapt to their loss over time without the need for formal intervention, a significant minority around 10–15%, experience more severe and prolonged difficulties, known as complicated or prolonged grief characterised by (121):

- Persistent, intense emotional pain.
- Difficulty accepting the death.
- Emotional numbness.
- Disrupted sense of identity.
- Impaired daily functioning.

The evidence supports a balanced approach that recognises grief as a normal human experience, avoiding unnecessary medicalisation. While, at the same time, it acknowledges the potential adverse health and wellbeing impacts and that some bereaved people will require additional support. This highlights the importance of proportionate, person-centred bereavement care, with the level of support matched to the individual's needs and circumstances (120,122,128,153).

Psychological effects

For some people, especially those with complicated grief or other risk factors, bereavement can be associated with increased risk of several mental-health difficulties, including (116,118,130,154):

- Depression.
- Anxiety.
- Sleep disturbance.
- Post-traumatic stress symptoms.
- Substance misuse.
- Suicidal ideation.

Physical health effects

Bereavement can have measurable effects on physical health, particularly in the early months after a loss. Research shows increased morbidity and mortality among recently bereaved individuals, especially those at increased risk of complicated grief (116,123,154). Common physical impacts include:

- Cardiovascular problems.
- Immune system dysregulation.
- Fatigue and low energy.
- Reduced self-care (e.g., nutrition, medication adherence).
- Increased healthcare use.

Older adults and those who lose a spouse are at especially high risk of health decline.

Social and economic effects

Bereavement can disrupt multiple areas of daily life (115,116,118,130,155,156):

- Employment and productivity may be affected by distress, fatigue, or caregiving transitions.
- Financial strain can arise from funeral costs, loss of income, or changes in household roles.
- Family relationships may shift as responsibilities change or tensions emerge.
- Social participation can decrease due to isolation, stigma, or emotional withdrawal.

Certain types of loss, such as suicide, traumatic death, child death, or deaths during pandemics or disasters, may also lead to stigma and social exclusion, compounding distress (127,157,158).

Personal, community, and professional support as needed can reduce the adverse impacts of bereavement, especially for those at increased risk (115,153,159).

Bereavement support in the UK

Bereavement support in the UK is primarily provided by informal networks such as friends and family. Where additional support is needed, it is delivered through a combination of voluntary and community organisations, hospices, schools, workplaces, faith groups, communities and specialist mental health services and other NHS services (118,127,134). In England and Wales, bereavement care is often guided by the NICE three-tier model, which provides a stepped framework based on differing levels of need (122,127).

Tier 1: Universal support

The first tier represents universal support available to all bereaved people, primarily from family, friends, workplaces, schools, faith groups, and wider community networks. Support at this level includes:

- Compassionate communication from professionals.
- Information about grief and bereavement.
- Signposting to resources and services.
- Informal social support.
- Community-based support.
- Compassionate workplaces and schools.

NICE guidance and UK commissioning frameworks emphasise that normal grief reactions should not be medicalised, and highlight the essential role of families, communities and social networks (115,127). Informal social support is associated with improved wellbeing and reduced symptoms of depression and trauma, while strong community connections can reduce isolation and support coping (122).

The **Bereavement Is Everyone's Business** report outlines eight principles for change. These emphasise the role of families, friends, schools, workplaces, and wider communities in providing everyday support, alongside the importance of compassionate care at the time of death, supportive professional interactions, and accessible practical processes, including post-death administration, affordable funerals, and financial assistance (115).

However, access to informal and community support is not equitable. Availability of support can vary according to broader social determinants, as well as factors such as disease type and circumstances of death (120,159). Individuals who are socially isolated, marginalised, or bereaved in traumatic circumstances are particularly likely to have limited access to supportive networks and may require additional intervention (115,134,159–161). Awareness and accessibility of services also present key barriers, with limited knowledge of available support commonly reported (120,134).

Furthermore, uncertainty about how to respond to bereavement can lead to avoidance and reduced support from others. Strengthening community capacity through approaches such as Compassionate Communities and death and grief literacy may help address these gaps (115,134). Death literacy refers to the knowledge, skills, and confidence needed to support others, navigate services, and engage with issues of death and bereavement (162,163). These approaches aim to normalise conversations about grief, build confidence, and enable people to respond more effectively and compassionately (115,163). The UK Commission on Bereavement progress report highlights a range of national and local initiatives

designed to strengthen grief literacy and normalise conversations about loss. These include the expansion of the Good Grief Festival, the National Day of Reflection, the Grief Kind campaign, as well as bereavement and death cafés (164). Alongside these, increasing attention to school-based bereavement education and workplace policies reflects growing recognition that everyday environments play a central role in providing early, universal support (164).

Tier 2: Structured or additional bereavement support

The second tier is intended for individuals who require additional structured support, estimated to benefit around 30% of bereaved people (120). Services may include:

- Peer support groups.
- Hospice bereavement services.
- Psychoeducational interventions.
- Charitable sector services.
- Telephone and online support.

NICE guidance and commissioning models identify this level of support as important in reducing isolation, strengthening coping strategies, and preventing progression to more severe grief difficulties. In the UK, this support is commonly delivered through hospices and voluntary sector organisations such as Cruse Bereavement Support (130).

In addition, more tailored pathways exist for those at higher risk or bereaved in specific circumstances. These include suicide bereavement support services and the National Bereavement Care Pathway, which seeks to improve the quality and consistency of bereavement care provided by the NHS following pregnancy loss or the death of a baby (157,158,165).

Tier 3: Specialist bereavement and mental health interventions

A smaller proportion of bereaved individuals (approximately 10%) experience prolonged grief disorder, traumatic grief reactions, or significant mental health difficulties requiring specialist intervention (120,124). Tier 3 services may include:

- Specialist psychotherapy.
- Complicated grief therapy.
- Trauma-focused interventions.
- Psychiatric support.
- Specialist suicide bereavement services.

NICE guidance emphasises that specialist interventions should be targeted toward individuals with the highest level of need, particularly where bereavement is associated with severe psychological distress, trauma, or functional impairment. Clear and timely referral pathways between tiers are therefore essential to ensure that individuals can access appropriate support as their needs change over time (127,156,166,167).

Importantly, requiring Tier 3 support does not indicate failure or absence of informal support. Bereavement responses vary widely and are shaped by multiple factors, including the relationship to the deceased, circumstances of the death, prior mental and physical health, cultural context, and coping resources. The tiered model therefore reflects differing levels of need rather than hierarchies of resilience, and services should be delivered in a way that avoids stigma and promotes accessibility (115,118,127,168).

Commissioning guidance from the National Bereavement Alliance emphasises (127):

- Early compassionate support following bereavement.
- Accessible pathways into support services.
- Partnership working across health, social care, education, and the voluntary sector.
- Community-based approaches to bereavement.
- Culturally sensitive and inclusive provision.
- Prevention of social isolation and poor mental health outcomes.
- Clear referral pathways to specialist services where required.
- Addresses inequalities in access and those at higher risk.

Wider bereavement care models

Other models to consider in bereavement care, include palliative care bereavement models, community-based and Compassionate Communities approaches. Together, these models help describe the different ways bereavement support is delivered across clinical, community, and population levels.

Palliative care bereavement models

Bereavement support is a core component of palliative and end-of-life care, which emphasises continuity before and after death, family-centred approaches, and proactive assessment of bereavement risk (120,135,153,169). In practice, this support is commonly delivered by palliative care teams and hospices. Common elements include:

- Pre-bereavement preparation.
- Family meetings.

- Memory-making activities and memorial events.
- Follow-up contact after death.
- Screening for risk of complicated grief.

Evidence highlights the importance of continuity of care and trusted relationships with professionals involved in end-of-life care, as these can support adjustment and reduce bereavement-related distress. Conversely, negative or distressing EoLC experiences may increase the risk of adverse bereavement outcomes. However, not all deaths are supported by palliative care teams, with an estimated 30% of people who died in the UK in 2023 having unmet palliative care needs (135,169).

Community and compassionate communities' approaches

Community and Compassionate Communities approaches recognise that bereavement is not solely a clinical or mental health issue, but a social experience (122,135,170,171). These approaches focus on:

- Improving grief and death literacy (163)
- Reducing social isolation.
- Encouraging open discussion of death and grief.
- Strengthening informal support network.
- Building compassionate, community-led responses.

They emphasise that supportive communities do not arise by chance, but require intentional investment, local capacity-building, and structures that enable individuals, organisations, and neighbourhoods to participate in bereavement support (121,122,170). Bereavement affects families and communities as well as individuals (122,171). Support therefore extends beyond the individual to include family-focused approaches, support for children and young people, peer networks, community memorial activities, and workplace or school-based responses (153). Compassionate Communities approaches highlight the shared, collective responsibility for supporting people who are bereaved (121,122,170).

What works: Evidence on bereavement interventions

Cross cutting themes and system level considerations

Evidence across bereavement research highlights several principles that underpin effective support.

Person-centred and individualised care

Effective bereavement support must be flexible and tailored. Grief is highly individual, and no single model suits all bereaved people. Good support recognises the uniqueness of grief, avoids assumptions about how people "should" grieve,

respects cultural and personal differences, and adapts to changing needs over time. Individualised care includes flexibility in communication, timing, intensity, and mode of delivery (115,119,121,122,135).

Compassionate relationships and active listening

The quality of the relationship between the bereaved person and the supporter is identified as central. Bereaved individuals value supporters who listen without judgement, validate emotions, tolerate distress, avoid minimising grief, and allow space for silence and emotional expression. Feeling heard and emotionally safe is often more important than receiving advice (115,119,121,168).

Continuity and follow up

Continuity of care before and after death is reported to be beneficial in palliative care research. Good support includes follow-up contact, opportunities to ask questions, access to familiar professionals, and ongoing rather than one-off support. Many bereaved people report feeling abandoned when support ends abruptly or when there is an implicit expectation that grief should resolve within a set timeframe (119,121,168).

Timely and accessible support

UK evidence highlights inequities in access to bereavement support. People from minority ethnic communities, men, LGBTQ+ individuals, socioeconomically disadvantaged groups, and those who are digitally excluded often face greater barriers (160). Carers are also identified as a higher-risk group for complicated grief and frequently report feeling unheard by healthcare professionals, with one report indicating that only around 25% accessed bereavement support services (130).

Good-quality bereavement care addresses these gaps by providing timely information, enabling self-referral, reducing waiting times, and offering flexible delivery formats including in-person, telephone, and online support. Effective provision also requires proactive outreach to under-served groups and attention to broader accessibility factors such as cost, transport, language, and disability inclusion(115,119,134,160).

Risk assessment and appropriate referral

Proactive approaches to identify those most in need including, clear referral pathways and appropriate use of risk-assessment tools to identify and refer those who are at increased risk, are important components of high-quality provision (125,128,130,168,172). Commonly used tools include:

- Prolonged Grief Disorder scale (PG-13 / PG-13-R): a measure aligned with DSM-5-TR criteria (124,125)
- Inventory of Complicated Grief (ICG): widely used in clinical and research settings to assess severity of complicated grief and predict functional impairment (173)
- Brief Grief Questionnaire (BGQ): a short screening tool used in clinical settings to quickly identify individuals who may require more detailed assessment or referral (174)
- Traumatic grief inventory (130)
- Texas Revised Inventory of Grief (TRIG): used to assess grief intensity and monitor changes over time (175)

Cultural competence and inclusivity

Bereavement experiences and mourning practices vary widely across cultures and religions. Effective support respects cultural and religious practices, avoids inappropriate assumptions, uses interpreters where needed, and recognises experiences of discrimination and stigma. Inclusive care also considers LGBTQ+ bereavement, disenfranchised grief, and non-traditional family structures (121,157).

Practical as well as emotional support

Bereaved individuals often need practical assistance alongside emotional support. This may include financial advice, help with funerals, guidance on legal procedures, housing or employment support, and navigation of services (166,168). Practical burdens can significantly worsen psychological distress and should be considered within local needs assessments (121,130,176).

Community partnerships

Dying, death and bereavement touch every individual, family and community. Effective support therefore relies on strong partnerships that bring together health and care services, community organisations, faith groups, cultural communities, and voluntary sector partners to ensure people receive care and support that reflects their needs, values and circumstances (121,166). Local plans should prioritise the development of collaborative partnerships that harness community assets and engage diverse communities and organisations, including those supporting children and young people, people living with life-limiting illnesses, older adults, and individuals and families experiencing bereavement, to create inclusive and responsive support networks (115,122,135,159,171,177). Commissioning bereavement care can bring significant gains in social benefits to the community, including peer support, reduced isolation and the normalising of dying, death and grief (115,126,127,134,135,171).

System challenges and barriers

The literature identifies several recurring barriers that shape the landscape of bereavement support in the UK. The 2022 UK Commission on Bereavement found that, among adult respondents who wanted formal bereavement support, over 40% reported that they did not receive it (127,130).

Geographic inequity ('postcode lottery')

Bereavement support is often felt to be inconsistent and geographically variable, with access depending heavily on local hospice funding, voluntary-sector capacity, and regional commissioning, rather than need (127,160,178).

Service fragmentation

Bereavement services are frequently fragmented across healthcare, voluntary organisations, faith groups, and mental-health systems. This can lead to confusion about referral pathways, inconsistent standards, gaps in care, and poor continuity (130,157,178).

Inequity in access

Minority ethnic communities, rural populations, men, those facing social economic deprivation, older adults, young adults, LGBTQ+ individuals, people with disabilities, and those experiencing poverty face greater barriers to support and may have different needs (179). They are also more likely to report negative experiences around the EoL for their loved one (180). Stigma and cultural expectations may further discourage help-seeking (160,178,181).

Workforce challenges

Healthcare professionals often report inadequate training, limited confidence in discussing grief, lack of supervision, time pressures, burnout, and emotional exhaustion. High-quality bereavement care therefore requires organisational support, training, and staff wellbeing initiatives (126,156,157,168,178,182).

Societal challenges

Wider societal attitudes significantly influence bereavement experiences and access to support. Death and grief are often considered taboo topics in the UK, and many people report discomfort when discussing them (126). National surveys indicate that a substantial proportion of the population feel uneasy talking about death, and avoidance of such conversations can contribute to increased isolation for bereaved individuals (115,135,171,176). Bereaved people may also experience implicit expectations to "move on" or "get on with it," despite evidence that social support is protective against more complex grief reactions (126,161). Strengthening understanding and openness around bereavement in everyday

settings is therefore important. Workplaces and educational settings, in particular, have a key role in this and should be supported to implement compassionate bereavement policies and environments (126,156,171).

Types of interventions:

Bereavement counselling and psychotherapy

Bereavement counselling and psychotherapy provide structured, targeted support for people experiencing significant grief-related distress. Approaches include CBT, complicated grief therapy, narrative and meaning-centred therapies, and trauma-informed interventions (128,183,184).These are typically delivered by trained professionals and evidence suggests outcomes are improved when support is timely, personalised, and grounded in a strong therapeutic relationship (119,128).

Strengths

- Reduces anxiety, depression, and prolonged grief symptoms.
- Supports coping, meaning-making, and adaptation.
- Most effective for high-risk groups.

Challenges

- Variable evidence quality.
- Limited access and long waiting times.
- Not suitable or desired for everyone.
- Difficulty identifying those most in need.
- Inequalities in access

Peer support groups

Peer support groups bring together bereaved individuals with shared experiences of loss. These may be community-based, charity-led, hospice-led, or condition-specific groups such as suicide bereavement groups. Support is typically based on mutual sharing, validation, and emotional connection rather than formal psychotherapy. Evidence suggests peer support groups can reduce social isolation and normalise grief experiences (119,128,177,183). Participants often report benefiting from:

- Feeling understood by others with similar experiences.
- Sharing stories and emotions.
- Mutual emotional support.
- Validation and reassurance.

Research also highlights the importance of matching participants appropriately, as groups may be less effective if individuals feel their experiences differ substantially from others (119,128).

Strengths

- Can reduce social isolation.
- Encourages connection and community.
- Provides emotional validation.
- Can be more accessible and less intimidating than therapy.

Challenges

- Some people may feel uncomfortable sharing grief in groups.
- Group dynamics can affect effectiveness.
- Inequalities in access.

Online and digital bereavement support

Digital bereavement support includes online counselling, peer groups, forums, and telephone services. Use increased during the COVID-19 pandemic, with evidence suggesting it can improve access and provide meaningful support, particularly for rural populations, younger people, and those unable or unwilling to access face-to-face services. Strengths include improving accessibility and flexibility, reduced geographical barriers, and offering timely support. Whilst challenges include digital exclusion, safeguarding concerns, variable quality, and potential difficulties building relationships remotely (178,185,186).

Bereavement support following traumatic or sudden death

This includes support for people bereaved through suicide, homicide, accidents, or sudden and unexpected death. These experiences often involve both grief and trauma and require targeted, trauma-informed support. Interventions typically include early outreach, practical guidance, specialist peer support, and longer-term follow-up. Trauma-informed approaches emphasise emotional safety, clear communication, choice and control, and avoiding re-traumatisation. Individuals bereaved by suicide are at particular risk of adverse mental health outcomes (119,159). Strengths include addressing both grief and trauma with specialist supportive care, while challenges include limited access, stigma, and the need for resource-intensive long-term support (159).

Specialist mental health services

Specialist mental health services in the UK provide assessment, diagnosis, and treatment for individuals experiencing severe or persistent psychological

difficulties following bereavement, including prolonged grief disorder, depression, anxiety, and trauma-related conditions. Care is typically delivered through NHS secondary mental health services such as community mental health teams' NHS Talking Therapies services, with more complex cases referred to specialist psychiatric care. Interventions may include structured psychological therapies alongside pharmacological treatment where indicated, such as antidepressants for comorbid depression or anxiety disorders. These services also provide risk assessment, medication monitoring, and crisis support where symptoms significantly impair functioning or increase risk (167,187,188).

Challenges with the evidence:

Evidence on bereavement support is limited by several challenges. Much of the research uses small samples and observational designs, making it difficult to compare interventions or draw firm conclusions (128,189). There is also inconsistency in how grief and outcomes are measured, and many studies focus on specific groups rather than the wider bereaved population (128,189). In addition, long-term outcomes and community-based approaches are under-researched. As a result, while there is broad agreement on what good support looks like, evidence on the effectiveness of specific interventions remains uneven.

Conclusion: actionable insights

Bereavement support is an essential component of compassionate healthcare and community wellbeing.

- Bereavement support should combine universal, community-based support with targeted support for those at higher risk (115,119,161). Services should be easy to navigate, joined up and accessible (156,166,168).
- To minimise negative health impacts and inequalities, health and care systems should take a proactive approach, identifying individuals at risk and offering support (115,127,134,156,168,178,180).
- Strengthen community capacity and death literacy to improve confidence and effectiveness of informal support networks (120,126,156,166,171)
- Reducing inequalities and improving integration across services should remain central priorities. Local networks should seek to measure and address the shared vulnerabilities that increase a person's likelihood of experiencing inequity in bereavement support and provide services that address their needs (115,127,160).

Insights from bereaved carers

Carers Support West Sussex undertook qualitative engagement with unpaid carers who had experienced bereavement. The purpose of this work was to better

understand carers lived experiences of end-of-life care, bereavement, and the availability and effectiveness of support before and after death.

Unpaid carers are individuals who provide unpaid care or support to someone who could not manage without their assistance. These individuals are highly likely to experience bereavement due to the nature of caring often being associated with chronic, degenerative, or life-limiting conditions. In West Sussex, over 72,000 people in West Sussex provide some unpaid care, and national evidence indicates that carers are more likely to experience socio-economic disadvantage, making it particularly important that their experiences are understood and addressed within service planning.

Three in-depth interviews were conducted with unpaid carers from different backgrounds and caring for individuals with different conditions. Each interview lasted approximately one hour. The findings below summarise the key themes emerging from these discussions, while recognising that bereavement is a deeply personal and individual experience. The accounts highlight that bereavement for carers is rarely a single event, but is instead shaped by prolonged caring responsibilities, anticipatory grief, cumulative loss, and ongoing practical and emotional demands.

Key themes experience of bereavement support:

Limited preparation and reactive support

Carers often reflected that they felt unprepared for both the dying process and bereavement. Whilst many were aware that their loved one was approaching the EoL, they reflected that they received limited guidance on what to expect or how to prepare emotionally or practically. Support was often described as reactive rather than proactive.

> “When we were told my dad was EoL, no one talked to us about what came next – we were left to figure everything out ourselves.”
>
> “We said goodbye multiple times, with no help to prepare us for the emotional impact. We were witnessing decline, responding to false alarms, and grieving long before death, with no support to hold that weight.”

Competing Responsibilities and Constrained Grieving

Carers described experiencing bereavement alongside ongoing responsibilities such as childcare, employment, and other caring roles, which limited their ability to process grief and access support.

> “As a carer, you are in the middle of it [grieving], but you have to continue to support others while receiving little emotional support yourself.”

> “I still had children, a husband to care for, and work to manage, so there was no space to stop or grieve…life had to go on.”

Gaps in access to timely and meaningful support

A key gap identified was the lack of proactive and accessible support before and after death. Information was often limited to written materials or signposting, rather than ongoing human engagement. Carers expressed a need for earlier, more personalised contact that combines practical guidance with emotional support, delivered through accessible formats such as phone or face-to-face conversations.

“I felt emotionally isolated after the bereavement. Despite regular contact with health and social care professionals during my caring role, no one explained what to expect when my wife reached the palliative stage or how I might prepare as her carer. I did receive a booklet, which I have since kept for my children for future use, as it was very helpful in terms of the practical considerations of what to do next (i.e. who to contact, who to update, etc.).” –

Timing, continuity, and unmet ongoing needs

Carers described the immediate post-bereavement period as dominated by administrative tasks and funeral arrangements, delaying emotional processing. The emotional impact of bereavement was often felt more acutely once these practical responsibilities had ended. Carers reported that support ended too soon, with little follow-up, despite grief intensifying later, particularly around key milestones such as anniversaries and holidays.

> “Those first few weeks were a blur of paperwork and organising the funeral. It was only afterward that the weight of grief really hit me.”

> “Support needs to be there for the first anniversaries…the first birthday, the first Christmas…when their absence is felt most”

Variations in Help-Seeking Behaviour

Some differences in help-seeking behaviour were also noted, with participants suggesting that men may be less likely to engage with emotionally focused or group-based bereavement support.

“Men aren’t always good at talking about emotions compared to women, who I feel are able to offload emotionally more easily. So, in the carer group I attended, I was hesitant to share what I was feeling or going through.”

Reliance on informal support networks

In line with national research, many people rely on support from family, friends, and faith groups to cope with bereavement. Carers similarly described depending

heavily on these informal sources, including peer networks. While this support was valued, it was not always sufficient to address the complexity of their emotional and practical needs during bereavement, and carers described an absence of structured services.

Positive experiences of support

Where support was experienced positively, it was characterised by relational, person-centred and empathetic interactions, particularly during interactions with professionals such as funeral directors. Key factors contributing to positive experiences included, being treated with dignity and respect, having time to make decisions without pressure and receiving clear but sensitive communication.

> "They were very sensitive and very understanding… you feel as though they are not treating you as another commodity. They showed respect to the person who has passed away but then also to us as the family." -

Key opportunities for improvement

Carers emphasised that effective bereavement support should be proactive rather than reactive or dependent on self-referral. This was seen as a key issue contributing to inequalities in access, as those who are less able to seek out or navigate support may have greater need and be disproportionately disadvantaged by the current system.

Carers highlighted the importance of consistent, one-to-one relationships with empathetic practitioners, alongside support that is trauma-informed and recognises the cumulative impact of prolonged caregiving and anticipatory grief. Access to clear, practical information was seen as essential to help carers understand, prepare for, and navigate both end-of-life and bereavement processes.

Support was valued when it was flexible and sustained over time, adapting to changing emotional and practical needs rather than ending shortly after death. Carers stressed that bereavement is not a linear experience and that services should reflect different ways of grieving, ensuring inclusivity across communication styles, preferences, and levels of readiness to engage. Stronger coordination between health, social care, and employment systems was identified as critical to delivering a more joined-up and supportive experience.

Carers reported low awareness of available services, the absence of a single trusted source of information, and limited support from employers. Many also felt insufficiently prepared for transitions in care, particularly when individuals were discharged home to die.

To address these gaps, carers recommended the development of a central, regularly updated information hub to improve access and awareness. They also

called for proactive follow-up after bereavement, for example, through primary care contact, and the provision of staged support over time, including at key milestones such as anniversaries. Greater integration with community-based support, including faith groups and peer networks, was seen as important, alongside improved emotional and practical preparation during the caring journey.

Insights from professionals on bereavement support

As part of the NA, a focus group was undertaken with professionals working across bereavement services. The discussion explored system strengths, gaps, and opportunities for improvement. Overall, professionals described a committed and diverse sector, but one that is constrained by capacity pressures, fragmentation, and inequities in access.

Strengths of bereavement support

Professionals highlighted that bereavement services across Sussex provide a wide range of support, including counselling, peer groups, helplines, and community-based provision. Informal and peer support were consistently identified as particularly valuable, with a strong emphasis on the importance of simply being heard and supported through shared experience.

Flexible, tiered models of support were also seen as a key strength, enabling people to access different levels of support depending on need, including step-up and step-down care. Volunteer-led provision and community-based approaches were recognised as important in extending reach and accessibility.

> “People often want to just offload, just speak things through.”
>
> “I do tell them I'm not a counsellor, but I've got an ear for them, that seems to work.”
>
> “It’s become a village… people know that we’re always there.”
>
> “We offer a tiered level of support… help line… group work… one-to-one.”
>
> “There’s some really excellent pieces of work… hospices offer quite a bit of support.”

Capacity and resource constraints

Despite these strengths, professionals consistently described significant capacity challenges. Services were often reported to be operating with limited staffing, heavy reliance on volunteers, and insufficient funding. This results in long waiting times and reduced service availability.

> “There’s only two of us for the whole of the area.”
>
> “I am the only person working on bereavement.”
>
> “Some have a long waiting list as well.”
>
> “People used to be able to offer 12 sessions and it’s gone down to six.”

Fragmentation and coordination

A key issue identified was the fragmented nature of bereavement support across the system. Professionals described a lack of central coordination, limited awareness between services, and inconsistent referral pathways. Information was often seen as outdated or difficult to navigate.

> “There’s so many directories out there… how do we align all of those?”

Timing and nature of need

Professionals emphasised that **bereavement is not time-bound** and that support needs vary widely between individuals. Some require immediate support, while others need help months or even longer after a bereavement. Grief was described as ongoing, unpredictable, and fluctuating over time.

However, services are often structured around time-limited interventions, which can lead to gaps when support ends but need continues.

> “Do they need it immediately? Some do… [some need it] six to nine months later”
>
> “Bereavement has no time limit… it’s something people need to live with.”
> “You could be great one day and then the next day your mood is all over the place.”
>
> “It’s quite difficult for people to wait for three months.”

Inequities in access

Professionals highlighted inequalities in access to bereavement support across different groups. Barriers included cost, language, cultural appropriateness, and lack of tailored provision. Particular gaps were identified for those who are socially or economically disadvantaged, children and young people, men, refugees and asylum seekers, non-English speakers, disabled people, and LGBTQ+ communities.

> “People haven’t got a lot of money to pay for going privately.”
>
> “There’s a gap for children face-to-face.”

> “We’re not quite hitting the mark yet with men.”
>
> “A severe lack of trauma support for refugees, asylum seekers and migrants.”
>
> “Trying to find counselling for parents that don’t speak English… is difficult.”
>
> “People who are severely disabled have very few opportunities.”

Digital and face-to-face support

Digital delivery was recognised as improving accessibility, but professionals also highlighted clear limitations, particularly in relation to emotional depth and digital exclusion.

> “It’s all digital… so it’s quite easy to access.”
>
> “[some people] would rather see someone face-to-face.”
>
> “We don’t just talk verbally… we use body language… that’s what we don’t get online.”
> “Digital poverty is really key for our services.”

Community and peer support

Community-based and peer-led approaches were described as essential in reducing isolation and supporting people through bereavement. Informal spaces and ongoing access to support were seen as particularly valuable. However, professionals also identified gaps in structured psychosocial group support.

> “Bereavement is such a lonely experience.”
>
> “Something that they know is there for them as and when they need it.”
>
> “A free cuppa… that makes a huge difference.”
>
> “That’s a big gap… psychosocial group support.”

Workforce training and skills

The workforce was described as highly committed but inconsistently trained in bereavement support. Many staff and volunteers rely on lived experience rather than formal training, which can create variability in confidence and approach. There was also recognition of challenges in supporting complex grief and trauma.

> “we’re not actually trained counsellors.”
> “I’m purely doing it from my own experience of being bereft.”
> “[training would be beneficial] so that we can feel more confident in giving

> support”
> “It would be nice if there was a central place to do some training.”
> “We do struggle with really high-level trauma.”

Strategic priorities for improvement

Professionals identified several key priorities for strengthening bereavement support across Sussex. These included increasing funding and workforce capacity, improving coordination through centralised information systems, expanding community and peer-led provision, and strengthening workforce training and confidence. Addressing inequities in access and maintaining a balanced approach to digital and face-to-face delivery were also seen as essential.

Summary

The professional perspective highlights a bereavement support system that is characterised by strong commitment, valued relational and community-based practice, and a diverse range of provision. However, this is set against structural challenges including limited capacity, fragmented coordination, inconsistent access, and variability in workforce training.

Table 81 Bereavement Information and Support – Sussex NHS Trust services

Trust	Information Available	Support Offer	Key Links
East Sussex Healthcare NHS Trust (ESHT)	• Practical bereavement guides for Conquest Hospital, Eastbourne DGH, and Irvine Unit • Guidance following bereavement and service changes • Hard copy booklets available on request	• Dedicated Bereavement and Medical Examiner Service • Coordination of Medical Certificate of Cause of Death and cremation documentation • Independent review of all deaths by Medical Examiner • Direct contact with families to explain cause of death and next steps • Liaison with GPs, Coroner, Registrars, Funeral Directors Ongoing communication and practical support	Bereavement & Medical Examiner Service: https://www.esht.nhs.uk/service/bereavement-service/
University Hospitals Sussex NHS Foundation Trust (UHS)	• Bereavement webpages and practical information Specialist leaflets (e.g. baby loss, trauma support) * Resources on mortuary services and care after death * Information for families during bereavement	• Bereavement Officers providing advice and practical support * Organisation of Medical Certificate of Cause of Death * Help with legal processes and funeral arrangements * Site-specific bereavement office access across hospitals	Bereavement services: https://www.uhsussex.nhs.uk/services/bereavement/
Surrey and Sussex Healthcare NHS Trust (SASH)	• Bereavement services leaflet (ward and online access) Information booklet covering	• Bereavement Office offering guidance, information, and signposting Support with arrangements after death	Bereavement services: https://www.sash.nhs.uk/our-services/bereavement-services/

	practical steps and support organisations	Access to external advice and support organisations	
Sussex Community NHS Foundation Trust (SCFT)	• Information about Midhurst Macmillan Service * Community palliative care resources and appointment details	• Specialist community-based palliative care service Holistic support for patients and families with complex life-limiting illness Range of appointment types, including community support	Midhurst Macmillan Service: https://www.sussexcommunity.nhs.uk/patients-and-visitors/services/midhurst-macmillan-service
Sussex Partnership NHS Foundation Trust (SPFT)	• Bereavement and loss resources (CAMHS) * Guidance on coping with grief and emotional wellbeing * Links to external resources (Cruse, NHS, Mind)	• Information and advice for children and young people experiencing bereavement * Signposting to community and voluntary sector support * Access to mental health support pathways where needed	Bereavement and loss (CAMHS): https://www.sussexpartnership.nhs.uk/bereavement-and-loss
NHS (national support referenced locally)	• Guidance on grief, bereavement, and coping strategies * Advice on symptoms, stages of grief, and when to seek help	• Self-help guidance and signposting * Access to NHS talking therapies and GP support if required	NHS bereavement support: https://www.nhs.uk/conditions/stress-anxiety-depression/coping-with-bereavement/

Sussex Hospice Alliance overview of bereavement support in Sussex

Pre-bereavement and post-bereavement support is often delivered by trained volunteers and may include one-to-one support, coffee mornings and informal drop-in sessions, bereavement support groups, counselling, support for anticipatory grief, and ongoing support following a death. Many services also provide annual remembrance events and other opportunities for families and carers to remember loved ones.

These services play an important role in supporting the wider family and carer unit before and after bereavement. Their value extends beyond the individual, contributing to the wider health and care system by helping people access appropriate emotional and practical support during periods of significant loss and adjustment.

it is a priority to ensure that these services are commissioned and provided equitably across Sussex.

Table 82 Sussex Hospice Alliance overview of bereavement support in Sussex

Tier	Description of need and support	Examples of services that may fit this tier	Examples in Sussex
Tier 1 – Universal bereavement support	Support for the general population, recognising that most people experience grief without requiring specialist intervention. Focuses on information, reassurance, social connection and compassionate communities. Support is usually preventative, time-limited and non-clinical.	• Bereavement information and signposting (websites, leaflets, helplines) • GP, primary care and community signposting • Compassionate Communities / community cafés • Faith-based or community-led support • Employer, school or university bereavement policies and support • Libraries, online resources, self-help materials	**Brighton & Hove:** Community cafés in Hove & Peacehaven – Martlets Bereavement information and signposting – Martlets **East Sussex:** Compassionate Communities / community cafés -St Michael's and St Wilfrid's hospices Community café – St Peter St James Bereavement information and signposting - St Michael's, St Wilfrid's Eastbourne, St Peter St James hospices Seahorse project bereavement offer for children and young people - St Wilfrid's Eastbourne **West Sussex:** Community cafés -St Barnabas, St Wilfrid's Chichester, St Catherine's and St Peter St James

			Bereavement information and signposting - St Barnabas, St Wilfrid's Chichester, St Catherine's and St Peter St James
Tier 2 – Targeted or structured bereavement support	For people experiencing moderate or prolonged grief, or at higher risk due to circumstances of the death, social isolation, or existing vulnerabilities. Support is structured but non-specialist, often delivered by trained practitioners or volunteers.	• Bereavement support services commissioned by local authorities or ICBs • Voluntary sector bereavement charities (e.g. structured 1-to-1 support) • Group-based bereavement counselling or peer support groups • Hospice-led bereavement services (non-clinical) • Support for specific groups (children and young people, parents, carers, older adults)	**Brighton & Hove:** Counselling/psychological support: **post bereavement** support -families of patients only -Martlets 1-1 sessions. 6 x 50 minute sessions, Extensions to 8 sessions where clinically indicated. Delivery: face to face, telephone, video, limited home visits. **East Sussex:** Counselling/psychological support: pre-bereavement -Provided by Sara Lee Trust for St Michael's hospice catchment, universally to all residents of Hastings and Rother Bereavement support St Michael's hospice catchment, universally to all residents of Hastings and Rother. The St Michael's bereavement team have a large volunteer base and provide placements for trainee counsellors. Through the use of volunteers St Michael's are able to provide bereavement support to a charity who support homeless and vulnerably housed people. Counselling/psychological support: pre-bereavement and bereavement support - families of patients only – St Wilfrid's Eastbourne and St Peter St James Seahorse project bereavement offer for children and young people - St Wilfrid's Eastbourne

			West Sussex: Counselling/psychological support: pre-bereavement and bereavement support - families of patients only - (both group based, drop-in support and 1 to 1 counselling) St Wilfrid's Chichester, St Catherine's and St Peter St James St Barnabas -families of patients only, **post bereavement** 1-1 sessions. 6 x 50 minute sessions, Extensions to 8 sessions where clinically indicated. Delivery: face to face, telephone, video, limited home visits.
Tier 3 – Specialist bereavement and psychological support	For people experiencing complex, traumatic or prolonged grief, often alongside mental health needs. Support is specialist, skilled and usually one-to-one, requiring clinical oversight or advanced training.	• Specialist bereavement counselling or psychotherapy • Psychological therapies for prolonged grief disorder • NHS Talking Therapies (where bereavement-related) • Specialist hospice bereavement teams • Support following sudden, violent or traumatic deaths	Brighton & Hove: Specialist hospice bereavement teams, counselling sessions – families of patients only - Martlets as Tier 2 (can be extended depending on need) **East Sussex:** Specialist hospice bereavement teams, counselling sessions – for St Michael's hospice catchment, universally to all residents of Hastings and Rother Specialist hospice bereavement teams, counselling sessions – families of patients only – St Wilfrid's Hospice Eastbourne and St Peter St James

			West Sussex: Specialist hospice bereavement teams counselling sessions - families of patients only - (both group based and 1 to 1 counselling) St Wilfrid's Chichester, St Catherine's and St Peter St James St Barbabas -as Tier 2 (can be extended)
Tier 4 – Crisis and acute mental health support	For individuals in acute distress or crisis, where grief is accompanied by serious mental health risk, including self-harm or suicidal ideation. Support is urgent, clinical and crisis-led.	• Crisis mental health teams • Liaison psychiatry • Emergency department crisis support • Crisis helplines (e.g. Samaritans) • Urgent GP or mental health referrals	**Brighton & Hove: East Sussex: West Sussex:** N/A for hospices N/A for hospices

Table 83 Bereavement support in Sussex mapped against project characteristics

Protected Characteristic	Bereavement Support Considerations in Sussex	Examples of services in Sussex (links correct in August 2026)
Age	Children and young people may require specialist bereavement support (e.g. school-based services, youth counselling). Older adults may experience isolation following bereavement;	Bereavement Support Services – Help After Loss (Brighton & Hove) - Trinity Medical Centre; Mental health for children and young people - Amaze Sussex Child Bereavement UK | East Sussex 1Space; The Seahorse Project | East Sussex 1Space;

	access to community-based and home-based support is important, particularly in rural areas.	Supporting Your Child - Seaford Head School Seahorse Project - St Wilfrid's Hospice (Eastbourne); Willow Tree Children's Support, Hastings, East Sussex Willow Tree Children's Support, Hastings, East Sussex; Home - Jigsaw South East; Young Peoples' Support Bereavement and Loss - BHSCP; Bereavement, grief and loss - West Sussex County Council; Bereavement | East Sussex Butterflies Therapy, Wellbeing & Training Centre | East Sussex 1Space; Bereavement - a guide for relatives and friends - Information and support Loneliness and Isolation - Together In Sussex; PowerPoint Presentation - Supporting communities through bereavement and loss Thriving Communities - Adur & Worthing Councils; Coping with loneliness and isolation | Healthwatch Westsussex Loneliness in West Sussex: Solutions with Live-In Care | Promedica24; Age UK West Sussex Brighton & Hove | Home Visiting Service; Home - St Michael's Hospice; Bereavement Support Services in Sussex - Age Space

Disability	Accessible formats (e.g. easy read, BSL interpretation, sensory-friendly environments) are needed. People with learning disabilities may require tailored bereavement support with clear communication and involvement of carers and specialist services.	Bereavement Support Services for Adults, Children, and Families | Sussex Bereavement Services Microsoft Word - Bereavement support .docx Bereavement Support Services | Bereavement Toolkit | CSWS Learning disabilities (adult) ::Sussex Partnership NHS Foundation Trust; Search results | East Sussex 1Space
Sex (Gender)	Men are less likely to engage with traditional bereavement services; targeted outreach and alternative models (e.g. peer support, activity-based groups) can improve access. Women may experience higher caregiving burden prior to bereavement and need ongoing emotional support.	Men's Mental Health - a growing problem :: Sussex Partnership NHS Foundation Trust; Men's Mental Health Local Directory - UOK; Menshare Listening Group (MSLG): Supporting Men's Mental Health in Sussex — AtaLoss.org: UK wide bereavement signposting and information website; UK Mens Bereavement Charity - StrongMen; Men's Counselling for Bereavement, Grief & Loss – Support in Brighton, Hove, Sussex & Online Across the UK - Counselling for Men UK | MEN TALK TOO; piecing-together-the-jigsaw-full-version.pdf; Home - Cruse Bereavement Support Brighton Women's Centre (BWC) - UOK; Search - Women's Services Map;

		Why do we need women only mental health services in Brighton & Hove? | Brighton Women's Centre; Brighton Women's Centre (BWC) - UOK Bereavement Support Services for Adults, Children, and Families | Sussex Bereavement Services: (Wayfinder Woman | East Sussex 1Space); Specialist Women's Services In Sussex | Find Local Support & Centres
Gender reassignment	Trans and non-binary individuals may face discrimination or lack of recognition of relationships. Inclusive, culturally competent bereavement services and staff training are essential to ensure respectful and appropriate support.	Trans and gender-diverse services - MindOut LGBTQ Mental Health; LGBTQ support - West Sussex County Council; The Clare Project | Transgender support and social group; BOLD - Brighton & Hove LGBT Switchboard Mindline Trans + | East Sussex 1Space; East Sussex LGBTQ+ Health Inclusion Award Program - Sussex Training Hub; Code of Conduct | Women in Tech Sussex; Shining a light on our transgender and non-binary workforce - University Hospitals Sussex NHS Foundation Trust; LGBTQ support - West Sussex County Council; EDI Resources - Sussex Training Hub

Chapter 7 Future demand

Sussex has a growing and ageing population, and this varies significantly by place. East Sussex and West Sussex have older age profiles, meaning future health and care needs are likely to be increasingly shaped by age-related conditions, frailty, dementia and wider PEoLC needs. Brighton & Hove has a younger population overall, with a larger working-age population, but it is also expected to see growth among older residents. These demographic differences mean that services need to be tailored locally. Sussex will likely need a stronger emphasis on dementia, complex long-term conditions and support for older people.

A 2023 study suggests that up to 1.7 million people could be living with dementia in England and Wales by 2040 (190). Alzheimer's Research UK estimates that 1 in 11 people over the age of 65 have dementia in the UK, which means there are about 950,000 people with dementia in the UK, and this number could go up to around 1.6 million by 2050. It is estimated that 65% of people with dementia in the UK are women.

Finding accurate future projections for dementia prevalence in Sussex can be challenging. The contrasting demographic projections highlight the importance of tailoring services to the specific needs of each place.

While Brighton & Hove, East and West Sussex would likely all require a greater emphasis on dementia care over the coming decades, recognising these differences allows for a more targeted and effective approach to addressing the health needs of the diverse populations within Sussex.

Providing PEoLC for people living with Dementia is a key need for the health and care system in Sussex to address now, and plan for in the future.

Table 84 outlines the numbers of people aged 65 and over predicted to have dementia, by age, in 2045 within Sussex and it places.

The number of people aged 65 and over with dementia in Sussex is projected to increase from 30,955 in 2025 to 47,763 in 2045, an increase of 16,808 people (+54%).

Growth is expected across all three Sussex areas:

- West Sussex: 16,541 to 25,830 (+9,289; +56%).
- East Sussex: 11,498 to 17,529 (+6,031; +52%).
- Brighton & Hove: 2,916 to 4,404 (+1,488; +51%).

The largest increases occur in the oldest age groups, particularly among people aged 90 years and over:

- East Sussex: +90%.

- West Sussex: +91%.
- Brighton & Hove: +68%.

By 2045, almost half of all people aged 65 and over with dementia in Sussex are projected to live in West Sussex (25,830 people).

The most substantial numerical increases are in the 80–84, 85–89 and 90+ age groups, reflecting the ageing of the Sussex population and rising life expectancy.

A range of existing dementia-related reports, needs assessments, frameworks and strategies have been developed across the three Sussex places. These provide important context for understanding current and future dementia-related PEoLC needs and should be considered alongside the findings of this assessment. Examples are available through the following links:

1. Brighton and Hove Dementia
2. East Sussex in Figures – Data Observatory – JSNA – JSNA: Dementia Needs Assessment 2016
3. Dementia - West Sussex JSNA Website

Dementia is expected to become an increasingly important driver of PEoLC need in Sussex. This will increase demand for coordinated, dementia-informed PEoLC across community, care home, hospice and hospital settings, alongside greater support for carers.

Table 84 People aged 65 and over predicted to have dementia, by age group, projected to 2045 Projecting Older People Population Information System

Place	Age group	2025	2030	2035	2040	2045	Change 2025 to 2045	% change
Brighton and Hove	65 - 69	195	236	254	241	225	+30	+15%
	70 - 74	293	317	384	412	393	+100	+34%
	75 - 79	521	492	539	653	707	+186	+36%
	80 - 84	611	776	732	820	997	+386	+63%
	85 - 89	636	691	888	868	974	+338	+53%
	90 and over	660	684	801	1,049	1,108	+448	+68%
	Total aged 65 and over	2,916	3,196	3,598	4,043	4,404	+1,488	+51%
East Sussex	65 - 69	629	734	756	710	673	+44	+7%
	70 - 74	1,027	1,137	1,332	1,374	1,298	+271	+26%
	75 - 79	2,126	1,880	2,085	2,458	2,544	+418	+20%
	80 - 84	2,570	3,314	2,959	3,331	3,941	+1,371	+53%

Place	Age group	2025	2030	2035	2040	2045	Change 2025 to 2045	% change
	85 - 89	2,517	3,001	3,924	3,581	4,076	+1,559	+62%
	90 and over	2,629	2,994	3,666	4,809	4,997	+2,368	+90%
	Total aged 65 and over	11,498	13,060	14,722	16,263	17,529	+6,031	+52%
West Sussex	65 - 69	905	1,052	1,084	1,039	1,014	+109	+12%
	70 - 74	1,453	1,633	1,910	1,968	1,892	+439	+30%
	75 - 79	2,975	2,685	3,026	3,555	3,681	+706	+24%
	80 - 84	3,679	4,722	4,312	4,897	5,796	+2,117	+58%
	85 - 89	3,698	4,409	5,750	5,332	6,139	+2,441	+66%
	90 and over	3,831	4,373	5,316	7,025	7,308	+3,477	+91%
	Total aged 65 and over	16,541	18,874	21,398	23,816	25,830	+9,289	+56%
Sussex	**Total aged 65 and over**	**30,955**	**35,130**	**39,718**	**44,122**	**47,763**	**+16,808**	**+54%**

Figure 41 Total population aged 65 and over living in a care home with or without nursing, Sussex and Places (POPPI) Projecting Older People Population Information System

Figure 41 Suggests significant growth in demand for care home places for older adults across Sussex, especially in West Sussex. Brighton and Hove will see the smallest growth. Brighton and Hove shows relatively modest growth compared to other areas.

Estimating future demand for palliative care is essential for the effective planning and commissioning of services, as well as for drawing attention to the growing need for palliative and EoLC. Beyond the overall increase in demand, there is likely to be a rise in the complexity of cases, driven by a higher prevalence of multimorbidity, an increasing number of deaths among those aged over 85, and varying requirements depending on the underlying disease (27).

West Sussex County Council have previously published a report that projects growth in older people and comorbidities Forecasting future co morbidity and dependency needs in West Sussex - West Sussex JSNA Website.

About 90% of people who die in the UK are estimated to need palliative care. In 2021, this meant around 600,000 people. This proportion is similar across England, Wales, Scotland, and Northern Ireland. The 90% figure is based on a method that counts deaths with certain diagnoses as either the main or a contributing cause, which better reflects the increasing number of people with multiple health conditions at the EoL. Estimates based only on the main cause of death (not

including contributing conditions) are likely to underestimate the true need for palliative care. If current trends continue, by 2048, over 730,000 people per year in the UK will die with palliative care needs a 25% increase from 2023. (191)

This method estimates how many people may need palliative care but does not show service gaps or which groups are most at risk of missing out.

Local analysis used the Office for National Statistics (ONS) 2022-based sub-national population projections, which includes estimates of deaths each year, alongside evidence that approximately 90% of people who die are likely to PEoLC. This approach was used to estimate future demand for PEoLC across Sussex in 2034 and 2044. Table 85 presents the projected number of deaths alongside percentage change over time, while Table 86 applies the 90% estimate to calculate the expected number of deaths likely to require palliative care.

Table 85 Projected numbers of total deaths (to nearest 100) and percentage change Place, and ICT

	Year			Population	percentage	Change per annum
Area	2024	2034	2044	2024 - 2034	2034 - 2044	2024 - 2044
Brighton & Hove	2,200	2,300	2,500	5%	9%	14%
Eastbourne	1,300	1,500	1,600	15%	7%	23%
Hastings	1,100	1,200	1,300	9%	8%	18%
Lewes	1,200	1,400	1,500	17%	7%	25%
Rother	1,400	1,600	1,800	14%	13%	29%
Wealden	1,900	2,200	2,400	16%	9%	26%
East Sussex County	7,000	7,800	8,600	11%	10%	23%
Adur	700	800	800	14%	0%	14%
Arun	2,300	2,600	2,900	13%	12%	26%
Chichester	1,600	1,800	2,100	13%	17%	31%
Crawley	800	800	900	0%	13%	13%

	Year			Population	percentage	Change per annum
Horsham	1,500	1,700	2,000	13%	18%	33%
Mid Sussex	1,500	1,700	2,000	13%	18%	33%
Worthing	1,400	1,500	1,700	7%	13%	21%
West Sussex County	9,700	11,000	12,400	13%	13%	28%
Sussex Total	18,900	21,100	23,600	12%	12%	25%

Table 86 Estimates of the number of deaths (rounded to the nearest 10) requiring palliative care across Sussex and its constituent areas for three time points: 2024, 2034, and 2044

Area	2024	2034	2044	% Change 2024-2034	% Change 2024-2044
Brighton & Hove	1,980	2,070	2,250	4.5%	13.6%
Eastbourne	1,170	1,350	1,440	15.4%	23.1%
Hastings	990	1,080	1,170	9.1%	18.2%
Lewes	1,080	1,260	1,350	16.7%	25.0%
Rother	1,260	1,440	1,620	14.3%	28.6%
Wealden	1,710	1,980	2,160	15.8%	26.3%
East Sussex County	6,300	7,020	7,740	11.4%	22.9%
Adur	630	720	720	14.3%	14.3%
Arun	2,070	2,340	2,610	13.0%	26.1%
Chichester	1,440	1,620	1,890	12.5%	31.3%
Crawley	720	720	810	0.0%	12.5%
Horsham	1,350	1,530	1,800	13.3%	33.3%
Mid Sussex	1,350	1,530	1,800	13.3%	33.3%
Worthing	1,260	1,350	1,530	7.1%	21.4%

Area	2024	2034	2044	% Change 2024-2034	% Change 2024-2044
West Sussex County	**8,730**	**9,900**	**11,160**	**13.4%**	**27.8%**
Sussex Total	**17,010**	**18,990**	**21,240**	**11.6%**	**24.9%**

Table 86 provides estimates of the number of deaths (rounded to the nearest 10) requiring palliative care across Sussex and its constituent areas for three time points: 2024, 2034, and 2044. The data shows a clear upward trend over time, reflecting projected increases in demand for palliative care.

For example, Brighton & Hove is expected to rise from 1,980 deaths in 2024 to 2,250 by 2044, while East Sussex County as a whole will increase from 6,300 to 7,740. Similarly, West Sussex County shows the largest numbers, growing from 8,730 in 2024 to 11,160 in 2044, indicating it will remain the area with the highest need.

Sussex totals are Projected to increase by 24.9%, equivalent to approximately 4,230 additional deaths requiring palliative care each year by 2044, highlighting significant future pressures on palliative care services across the region.

Chapter conclusion and what this means for Sussex

Demand for PEoLC in Sussex will increase substantially over the coming decades, driven by population growth, ageing, rising dementia prevalence, increasing multimorbidity and greater numbers of people living with frailty. By 2044, an estimated 21,240 people across Sussex will die each year with palliative care needs, representing a 25% increase compared with 2024. This future demand will not be experienced equally across Sussex. West Sussex is projected to see the largest increase in overall need, while areas such as Horsham, Mid Sussex, Chichester, Rother and Wealden are expected to experience the greatest proportional growth. Whilst Brighton & Hove will continue to have a different demographic profile, with a younger population but growing numbers of older residents requiring PEoLC.

These demographic changes are likely to exacerbate existing inequalities in access, experience and outcomes. Areas with higher levels of deprivation, rural communities, coastal communities, people living with dementia, those with multiple long-term conditions, people from minority ethnic communities, inclusion health groups and individuals who are socially isolated may face additional barriers in accessing timely, coordinated and culturally appropriate care. As the population ages, there is also likely to be increasing pressure on unpaid carers, care homes, community services and the health and social care workforce, particularly in areas experiencing the fastest population growth and highest levels of need.

The projected increase in dementia prevalence is particularly significant. The greatest growth is expected amongst people aged 85 years and over, many of whom will have physical, psychological, social and care needs. This highlights the importance of ensuring that future PEoLC services are equipped to support people living with dementia and frailty across all care settings, including care homes, hospitals, hospices and people’s own homes.

These findings underline the need for a proactive, system-wide response that combines capacity planning with a strong focus on equity and multi-disciplinary

working. Future planning should seek not only to meet rising demand but also to reduce unwarranted variation in access and outcomes.

Chapter 8 Key strategic findings, conclusion and recommendations

Need

This NA demonstrates that PEoLC is relevant to every resident in Sussex and that need exists across the life course, from children and young people with life-limiting conditions through to older adults living with frailty, dementia, cancer and multiple long-term conditions.

People consistently report that what matters most is being treated as an individual, maintaining dignity and choice, being comfortable and pain free, being supported by those important to them, and receiving coordinated care in their preferred place of care wherever possible. The evidence also highlights the importance of emotional, social, cultural, spiritual and bereavement support for patients, families and carers.

Sussex has many strengths on which to build. Across the system there are examples of excellent, compassionate and person-centred care delivered by dedicated professionals, hospices, care providers, local authorities, voluntary organisations, carers and communities. Strong partnership working across organisations demonstrates significant commitment to delivering the 6 Ambitions for Palliative and EoLC.

Unmet Need

Despite many examples of excellent care, unmet need remains evident throughout the system. Too many people continue to be identified late, limiting opportunities for advance care planning, symptom management, personalised care and coordinated support. Evidence from children and young people, adults, people living with frailty and dementia, several underserved groups consistently highlights missed opportunities for earlier intervention and support.

The assessment identifies ongoing challenges relating to access to advance care planning, care coordination, out-of-hours support, symptom management, bereavement support and navigation of services. Patients, carers and professionals frequently described fragmented pathways, difficulties accessing support when needed and uncertainty about who to contact during periods of deterioration or

crisis. Earlier identification remains the single greatest opportunity for improvement across Sussex.

Variation

Variation exists across Sussex in palliative care register prevalence, ReSPECT completion and quality, advance care planning, access to 24/7 support, service models, care coordination and outcomes. Whilst some variation reflects genuine differences in population characteristics, geography and local need, some appears unwarranted and cannot easily be explained.

The evidence demonstrates considerable variation between Places, Integrated Community Teams and care settings. People living at home are significantly less likely to have advance care plans or ReSPECT plans recorded than those living in care homes, and notable differences exist between localities in access to services and approaches to care planning. Reducing unwarranted variation represents a major opportunity to improve equity, consistency and quality across Sussex.

Inequalities

Health inequalities remain a significant challenge for Sussex. Evidence throughout this assessment demonstrates that some groups continue to experience barriers to accessing timely, equitable and person-centred care. These include people experiencing poverty and deprivation, people living with learning disabilities, people living with HIV, some ethnic minority groups, LGBTQ+ communities, rural populations and other inclusion health groups.

These inequalities often reflect wider social and health inequalities operating throughout the life course and contribute to differences in access, experiences and outcomes at the EoL. Addressing these challenges will require both improvements to universal services and targeted interventions developed in partnership with patients, carers, communities and VCSE organisations that understand and represent the needs of local populations.

Future demand

Demand for PEoLC and bereavement support will increase substantially over the next 20 years. Demographic projections, increasing deaths, population ageing, rising prevalence of frailty, dementia and multimorbidity, and growing complexity of need all indicate significant future growth in demand across Sussex.

This increase will place additional pressure on primary care, community health services, social care, care homes, hospices, specialist palliative care teams, carers and bereavement support services. Without proactive planning, workforce

development and investment in sustainable models of care, demand is likely to outpace current capacity. Future demand will not simply mean more people requiring support, but more people requiring support over longer periods with increasingly complex physical, psychological, social and practical needs.

Strategic priorities

The evidence consistently identifies five overarching strategic priorities for Sussex:

1. **Earlier identification and proactive care planning** to ensure more people benefit from advance care planning, symptom management and coordinated support.
2. **Reducing unwarranted variation** in access, quality, care planning, coordination and outcomes across Sussex.
3. **Addressing health inequalities** through targeted action alongside improvements to universal services, working closely with VCSE organisations and communities.
4. **Strengthening community-based and coordinated models of care**, supported by effective multidisciplinary working, integrated services and shared digital infrastructure.
5. **Developing sustainable workforce, commissioning and system capacity** to meet increasing future demand whilst maintaining quality, equity and person-centred care.

What Sussex needs to do next

Sussex enters the next phase of improvement with a strong evidence base, a committed workforce and a shared understanding of future challenges. The recommendations within this needs assessment provide a diverse range of activities for action and should be used to inform commissioning, service development, workforce planning, quality improvement and partnership working across Sussex.

Implementation should align closely with the emerging **Modern Service Framework (MSF) for Palliative and EoLC**, the **NHS England Strategic Commissioning Framework**, and the ambitions set out within the **NHS 10 Year Health Plan**, particularly the ambition to shift care from hospitals into communities and support more care closer to home. This "left shift" of resources, workforce and service delivery provides an important opportunity to strengthen community-based palliative care, hospice at home services, primary care, care homes, social care, carers' support and bereavement services.

Future delivery should focus on:

- Implementing earlier identification and proactive care planning at scale.
- Expanding coordinated neighbourhood and community-based models of care.
- Improving digital interoperability, shared care records and information sharing.
- Reducing health inequalities and unwarranted variation.
- Strengthening support for carers, communities and bereaved people.
- Developing sustainable workforce, commissioning and funding arrangements.
- Embedding co-production with people with lived experience, carers, VCSE organisations and local communities.
- Establishing robust outcomes, quality and equity monitoring arrangements including through system-wide Learning from Deaths processes.

A stronger public discourse around death, dying and bereavement will also be required. Improving death literacy, normalising conversations about future planning and supporting the development of compassionate communities will be essential if Sussex is to meet future demand sustainably. Health and care services alone cannot meet this challenge.

Achieving the ambitions set out in this assessment will require shared leadership and collective responsibility across families, communities, VCSE organisations, health and care providers, commissioners and wider society.

By building on existing strengths and taking forward the recommendations within this needs assessment, Sussex has an opportunity to create a more equitable, coordinated, sustainable and person-centred PEoLC system that enables every resident, and those important to them, to experience dignity, compassion, choice and high-quality support at the EoL.

Recommendations development

The recommendations were developed through a structured three-stage process designed to ensure they were evidence-based, informed by stakeholder experience, and tested with the wider Sussex system before finalisation.

Step 1: Evidence gathering and needs assessment analysis

The first stage involved bringing together evidence from a wide range of sources to identify unmet need, inequalities, service gaps and opportunities for improvement across PEoLC. This included analysis of routine data, service activity and performance information, literature reviews, stakeholder interviews, focus groups,

surveys, strategic documents, national guidance, and patient, carer and public feedback. Evidence was organised thematically against the six Ambitions for PEoLC and key cross-cutting themes such as workforce, coordination, equity, bereavement support, community services and advance care planning. This stage generated an initial long list of issues and potential areas for action.

Step 2: Recommendation development and co-production with steering group

Findings from the needs assessment were used to draft an initial set of recommendations and supporting rationales. These were reviewed and refined by the project steering group.

Step 3: System development and co-production with the Sussex Palliative and EoLC Oversight Group

The draft recommendations were then tested through a series of multi-agency stakeholder workshops involving representatives from NHS Surrey and Sussex, acute trusts, community services, hospices, primary care, local authorities, adult social care, VCSE organisations, public health teams, equality and inclusion leads, bereavement services and patient representatives.

Within the first workshop on the 30 June 2026. Participants reviewed recommendations in facilitated breakout groups, considering whether the recommendations were sufficiently ambitious, achievable, evidence-based and equitable.

Approximately 50 stakeholders were broadly supportive of the recommendations and agreed they reflected the needs assessment findings and strategic direction for Sussex.

Key responses included:

- Strong support for a greater shift towards community-based and coordinated care, alongside improved discharge planning and out-of-hours support.
- The need for improved digital integration, shared records, interoperability and data sharing across organisations.
- Concerns that workforce capacity, funding and sustainability may limit implementation without additional investment and planning.
- Support for improving Advance Care Planning (ACP) and ReSPECT, with emphasis on the quality of conversations rather than completion of forms alone.
- Calls for stronger action to tackle health inequalities, improve inclusion, and increase engagement with underserved communities.

- Recognition that children and young people's palliative care needs require distinct pathways and consideration throughout implementation.
- Strong support for developing death literacy, compassionate communities, co-production and bereavement support, with greater involvement of communities and voluntary sector organisations.

The recommendations were reviewed and updated following the first workshop. They have been developed as all-age recommendations to support improvement across PEoLC, and bereavement support in Sussex.
However, a separate set of recommendations has also been developed and published at the end of chapter 2. These have been developed to inform future programmes of work specifically focused on specialist paediatric palliative care, and EoL and bereavement support for babies, children and young people, and their families.

The recommendation development day was held in person on Monday 27 July 2026.

A wide range of system partners were invited, with attendance and representation from the following agencies:

Local Authorities

- East Sussex County Council (Public Health, Adult Social Care and Health, Joint Commissioning, Equality and Inclusion)
- Brighton & Hove City Council (Public Health and Adult Social Care)
- West Sussex County Council (Public Health)

NHS Surrey and Sussex and NHS Provider Organisations

- NHS Surrey & Sussex PEoLC Commissioning
- Sussex Community NHS Foundation Trust (SCFT)
- University Hospitals Sussex NHS Foundation Trust (UHSx)
- South East Coast Ambulance Service NHS Foundation Trust (SECAmb)

Hospices and Specialist Palliative Care Providers

1. St Wilfrid's Hospice Chichester
2. St Wilfrid's Hospice Eastbourne
3. St Peter & St James Hospice
4. Southern Hospice Group (including hospice representation across Sussex)
5. Demelza Children's Hospice

Voluntary, Community and Charitable Sector

- Care for the Carers
- Sussex Beacon

Primary Care and Pharmacy

- Community Pharmacy Sussex.
- Worthing ICT.
- NHS Surrey & Sussex ICB primary care colleagues.

Lived experience and public representation

- East Sussex Citizens' Panel representative
- East Sussex Disability Rights Reference Group.

Participants were tasked to consider the recommendations from a variety of viewpoints, this was to explore:

Participants were asked to consider the recommendations from a range of perspectives through a series of structured exercises.

1. The first exercise involved reviewing the recommendations in groups aligned to the Six Ambitions for PEoLC. This activity was designed to identify which recommendations were considered most acceptable, achievable, and relevant within each of the six ambition areas and to promote familiarity with the recommendations.
2. The second exercise asked participants to categorise recommendations as "must do" or "should do" priorities across the Six Ambitions. The intention was to identify a set of priority actions that could inform future commissioning decisions and system development activity, enabling organisations to select and implement recommendations that best addressed identified local needs and ‘selected’ by local stakeholder.
3. The third exercise focused on prioritisation. Participants were asked to identify the recommendations they considered the highest priorities for the Sussex system overall, as well as those most relevant to their own organisations. They were also invited to highlight any actions that could be implemented immediately within existing resources and organisational arrangements.

The first exercise was designed to generate discussion about the recommendations using the APEASE framework. This is a six-part checklist used in behavioural science and public policy to design and evaluate intervention options. It stands for Acceptability, Practicability, Effectiveness, Affordability, Spill-over effects (or side-effects), and Equity. This generated considerable discussion among participants about the recommendations and how to implement them.

Many of the most highly scored recommendations using the APEASE criteria were for recommendations where there are established ways of working that could be adapted for improvement, previously existed in a similar format or could be implemented with existing resources, these included:

Recommendation (4) Develop neighbourhood, ICT and MDT approaches that improve proactive PEoLC support, involving general practice, community teams, care coordinators, hospices, care homes, social care and acute specialists.

Recommendation (5): Establish a Sussex-wide PEoLC learning and improvement framework to systematically review, collate, share, implement and monitor learning from mortality reviews, including LeDeR, CDOP, Prevention of Future Deaths reports, complaints, audits, provider reviews, ambulance incidents and other quality assurance processes, with clear governance, named leads and measurable actions.

Recommendation (15): Require consistent recording, reporting and use of protected characteristic and inclusion health group data across PEoLC and bereavement services.

Recommendation (27): Use targeted, meaningful and actionable digital prompts within clinical systems to support identification, ACP/ReSPECT review, carer support and signposting. (e.g., EMIS, SystmOne and hospital systems) to trigger timely identification, ACP/ReSPECT review, carer assessment, and referral/signposting to Single Points of Coordination (SPoC)/Out Of Hours (OOH) and community support, aligned to agreed criteria such as frailty, dementia, repeated admissions, or palliative and supportive care code entry.

The second exercise asked attendees to select ‘Must Do’ or ‘Should Do’ recommendations across the six ambitions. This provides system partners with a clear indication of the actions considered most important for implementation. This offers a structured basis for prioritising recommendations that can address specific elements of the Six Ambitions across Sussex.

It should be acknowledged that, although some ambitions clearly identified one "must do" recommendation alongside one or two "should dos", participants reached a strong consensus that several recommendations were equally essential in certain areas, particularly within Ambition 4. Consequently, multiple recommendations were designated as "must dos" following review and agreement by consensus.

Ambition 1: Each person is seen as an individual

Must Do

Recommendation: Implement a quality focused digital universal care plan (inclusive of ACP & ReSPECT) improvement programme that increases appropriate use, review and visibility of these plans, while avoiding a tick-box approach. Across all care settings for children and adults. Implement activities that meet the ICB commissioning intentions of 95% of EoL patients to have plans in place, which are regularly reviewed and enacted. This should especially focus on people living at home and in underperforming ICT areas. Introduce prompts or reminders in clinical

systems (EMIS and SystmOne) to support completion in services at specific points including

- When a person is identified as at risk of clinical deterioration or dying in the foreseeable future.
- At key trigger points, such as:
- Diagnosis of a serious or life-limiting condition.
- Significant change in health status or functional decline.
- Hospital admission or discharge planning.
- Entry into care homes or receipt of intensive community support.

Explore if measures and metrics relating to ReSPECT, ACP etc can be added to the ICT dashboards to monitor and promote improved completion.

Should Do

Recommendation: Develop and evaluate a proactive ‘What matters to me approach’ and ‘later life planning offer’ for older adults (for example from age 65 or for people with frailty indicators), integrating ReSPECT/ACP prompts, information and community signposting within primary care, community services and care homes, with clear safeguards to ensure it is person led.

Recommendation: Strengthen dementia inclusive PEoLC, align PEoLC and Dementia workstreams, and carer support by ensuring timely identification, tailored communication, and proactive respite and bereavement support for carers. Use anchor institutions and workplace health initiatives to improve awareness of PEoLC, carers’ rights, and bereavement support across the workforce and wider community.

Ambition 2: Each person gets fair access to care

Must do

Recommendation: Require consistent recording, reporting and use of protected characteristic and inclusion health group data across PEoLC and bereavement services.

Recommendation: Assess and embed rural proofing across Sussex PEoLC, and bereavement support planning, commissioning and service delivery to ensure equitable access for rural populations. Assessing how services work in rural areas and adapting delivery models to reflect transport barriers, workforce constraints, digital exclusion and dispersed populations.

Should do

Recommendation: Develop and deliver an extensive rolling programme of Sussex wide learning and knowledge exchange events to strengthen understanding of the EoL and bereavement needs of specific communities (those with sensory loss, Gypsy, Roma and Traveller Communities, those experiencing homelessness, Autistic people etc.) led jointly by statutory services, voluntary and community organisations, and people with lived experience.

Recommendation: Embed community engagement and co-production capacity within PEoLC and bereavement planning, commissioning and service improvement. This should include exploring systematic approaches for sharing information, insight and knowledge with Sussex's diverse communities, and enabling this intelligence to be actively mobilised through a wide range of well-established and well networked Voluntary, Community and Social Enterprise (VCSE) organisations.

Ambition 3. Maximising comfort and wellbeing

Must do

Recommendation: Develop neighbourhood, ICT and MDT approaches that improve proactive PEoLC and support to reduce avoidable hospital admissions and enable timely discharge through proactive care planning, involving general practice, community teams, care coordinators, hospices, care homes, social care and acute

Should do

Recommendation: Review and improve EoL medicines access, prescribing and community pharmacy provision across Sussex, including rural and non-rural access, out-of-hours prescribing and timely prescribing.

Ambition 4. Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

Must do

Recommendation: Develop a shared Sussex PEoLC and bereavement support demand, capacity and investment plan, aligned with the 'left-shift' of resources and care from hospitals towards community-based services, as set out in 'Fit for the Future'. This should account for different populations and needs at local levels, use population modelling, service activity, workforce data, hospice

capacity, social care pressures, digital infrastructure and future demand projections.

Recommendation: Implement a consistent Sussex wide, place based or other locality, Single Point of Coordination (SPoC) and Out of Hours PEoLC support model for all patients in Sussex in their last year of life, with clear triage, access routes, response times and links to ambulance, urgent care, prescribing, pharmacy, hospice and social care.

Recommendation: Prioritise real time interoperable shared records for PEoLC, therefore ACP, ReSPECT, preferred place of care, key clinical information and carer details are visible across primary care, acute, community, hospice, ambulance and social care services.

Ambition 5. All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

Must do

Recommendation: Large local anchor institutions (NHS and Local Government) should develop and embed workforce wide communications and approaches that normalise conversations about EoL, death and bereavement, supporting dialogue, planning and access to information at scale.

Should do

Recommendation: Produce and actively promote accessible, practical PEoLC and bereavement information in digital and non-digital formats for the population.

Ambition 6. Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Must do

Recommendation: Develop a Sussex death literacy and compassionate communities strategy that normalises open conversations about death, dying, caring and bereavement. This should build on a range of existing local initiatives.

The recommendation development day also asked System stakeholders to identify their top priorities outside of the Ambitions Framework.

The sample included 27 respondents from across the Sussex PEoLC system, comprising seven from adult hospices, five from the ICB, three from public health, two from CYP hospice services, two from social care, two from other sectors, and one respondent each from an acute hospital trust, the ambulance service, community NHS services, community pharmacy, general practice and the VCSE/voluntary sector.

The results provide broad system coverage but should not be interpreted as representative sampling of the entire Sussex workforce. The survey shows a clear system-wide preference for a small group of enabling and delivery-focused recommendations.

The strongest overall priority is:

Top Priorities

1. Recommendation 3: a consistent Sussex-wide or place-based Single Point of Coordination (SPoC) and out-of-hours PEoLC support model. It was selected in the top ten by 22 of 27 respondents (81%), ranked first by seven respondents, and appeared in 12 sector-specific top-three selections.
2. Recommendation 1, covering a shared demand, capacity and investment plan, ranked second overall and attracted the broadest strategic support across hospices, public health, the ICB, ambulance and pharmacy respondents.
3. Recommendation 7, on real-time interoperable shared records, ranked third and was particularly prominent among clinical and operational respondents.

Stakeholders most commonly identified Recommendation 16 as something that could be progressed within existing resources. This recommendation focuses on improving the recording, reporting and use of protected characteristic and inclusion health group data across PEoLC and bereavement services.

Most respondents considered the recommendations comprehensive and felt that no major recommendations were missing.

Suggestions for strengthening the final set focused on greater emphasis on care homes and social care providers, the needs of people living with HIV, recognition of chosen family and non-traditional support networks, stronger community engagement and co-production, improved patient information, and closer alignment with existing frailty, dementia, mental health, homelessness and equalities work programmes.

Stakeholders overwhelmingly called for the recommendations to move into implementation. The most common requests were for a clear delivery and accountability plan with named leads, milestones and measures of success; strong commitment from system leaders; ongoing governance and co-production arrangements; regular progress updates; integration with wider health and care

programmes; and a focus on achieving measurable improvements in outcomes and experiences for patients, carers and bereaved families.

Notably there was a request for the reestablishment of the Sussex palliative and EoLC oversight group, or a similar group noting the new NHS Surrey and Sussex ICB.

Following the workshops, recommendations were revised to incorporate stakeholder feedback, remove duplication, strengthen wording and improve clarity, resulting in the final set of recommendations presented within the needs assessment.

Recommendations

10 strategic recommendations have been developed which are aligned to more detailed all age recommendations and BCYP subset. The rationale for the more detailed recommendations is outlined later in this chapter.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
SG 1. Implement a consistent Sussex-wide Single Point of Coordination and 24/7 PEoLC support model, ensuring equitable access to care navigation, clinical advice, urgent response, prescribing support, pharmacy advice and hospice expertise regardless of postcode.	R3: Implement a consistent Sussex wide, place based or other locality, Single Point of Coordination (SPoC) and Out of Hours PEoLC support model for all patients in Sussex in their last year of life, with clear triage, access routes, response times and links to ambulance, urgent care, prescribing, pharmacy, hospice and social care. R32: Review and improve EoL medicines access, prescribing and community pharmacy provision across Sussex, including rural and non-rural access, out-of-hours prescribing and timely prescribing.	BCYP 5: Establish equitable access to 24/7 paediatric palliative care advice and urgent response across Sussex. This should include access to specialist consultant advice, community children's nursing, hospice at home and clear escalation routes for children approaching end of life. BCYP 6: Ensure every BCYP with a life-limiting or life-threatening condition has access to a named medical lead and identified key worker. This role should coordinate care across health, social care, education, SEND, short breaks, hospice and voluntary sector services
SG 2. Develop and implement a Sussex interoperable PEoLC digital record that enables access to Advance Care Plans, ReSPECT plans, preferred place of care and death, key contacts, medication information and carer details across all settings.	R7: Prioritise real time interoperable shared digital records for PEoLC, therefore ACP, ReSPECT, preferred place of care, key clinical information and carer details are accessible and visible by patients and across primary care, acute, community, hospice, ambulance, social care services.	BCYP 8: Implement consistent use and sharing of CYP-specific advance care plans, emergency healthcare plans and ReSPECT plans where appropriate. These should be routinely shared across maternity, neonatal, paediatric, community, hospice, ambulance, primary care, social care and education settings.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	R27: Use targeted, meaningful and actionable digital prompts within clinical systems to support identification, ACP/ReSPECT review, carer support and signposting. (e.g., EMIS, SystmOne and hospital systems) to trigger timely identification, ACP/ReSPECT review, carer assessment, and referral/signposting to Single Points of Coordination (SPoC)/Out Of Hours (OOH) and community support, aligned to agreed criteria such as frailty, dementia, repeated admissions, or palliative and supportive care code entry.	
SG 3. Develop a Sussex demand, capacity and investment plan for PEoLC and bereavement support that aligns future commissioning, workforce development and resource allocation to projected increases in deaths, dementia, frailty and multimorbidity.	R1: Develop a shared Sussex PEoLC and bereavement support demand, capacity and investment plan, aligned with the 'left-shift' of resources and care from hospitals towards community-based services, as set out in 'Fit for the Future'. This should account for different populations and needs at local levels, use population modelling, service activity, workforce data, provider and social care pressures, digital infrastructure and future demand projections. R13: Review existing evidence and undertake separate but linked population health and care needs assessments for carers, people living in	BCYP 1: Recognise babies, children and young people with life-limiting and life-threatening conditions as a distinct population within Sussex PEoLC strategic planning and commissioning. BCYP 2: Develop a Sussex-wide BCYP palliative care population health approach. BCYP 16: Contribute to the development of a national CYP hospice dataset while building a local Sussex dataset for children's palliative care.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	poverty, and priority condition groups including MND, neurological conditions, dementia and HIV. R31: Develop local systems, partnerships and projects, working with Public Health and academic partners, to robustly evaluate the health and economic impacts of new and emerging models of EoLC in Sussex. Consider developing and supporting local PhDs, externally funded, to support this. R38: Contribute to the development of a national Children and Young People (CYP) hospice dataset, building on the existing national activity and demographic data currently submitted by adult hospices to Hospice UK. This should be nationally led, with Sussex system partners contributing learning and development work undertaken to date. R43: Develop a Sussex-wide programme of engagement, research and data collection with residential care homes, nursing homes, domiciliary care providers, supported living services, personal assistants, and wider social care partners to improve understanding of PEoLC needs, experiences, outcomes and inequalities. R44: Ensure equitable access to PEoLC services for people regardless of their usual place of	

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	residence or existing care arrangements, including those living in nursing and residential care homes and people receiving home care, so that the presence of existing care or nursing provision does not itself create a barrier to accessing appropriate community or specialist PEoLC support.	
SG 4. Embed PEoLC within Sussex Neighbourhood Health, MDT and Integrated Community Team models, strengthening multidisciplinary working between general practice, community nursing, social care, hospices, care homes, ambulance services and VCSE partner	R2: Implement co-produced community based PEoLC models that enable people to remain at home, in care homes or community settings where appropriate and in line with their preferences. R4: Develop neighbourhood, ICT and MDT approaches that improve proactive PEoLC support to reduce avoidable hospital admissions and enable timely discharge through proactive care planning, involving general practice, community teams, care coordinators, hospices, care homes, social care and acute specialists. R12: Implement a specific ambulance PEoLC development programme, covering recognition of dying, ACP/ReSPECT interpretation, non-conveyance, specialist advice and avoidance of inappropriate resuscitation or conveyance. R22: Develop a system-wide approach to workforce and community roles that strengthen	BCYP 4: Develop an integrated Sussex model of community-based paediatric palliative care. BCYP 6: Ensure every BCYP has access to a named medical lead and identified key worker. BCYP 11: Ensure timely access to medicines and specialist pharmacy advice for BCYP receiving palliative and end of life care.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	social prescribing and wider practical, emotional and social support for people approaching the EoL and those important to them, including testing and evaluating 'EoL Doula' 'No-one dies alone' (volunteers) or similar companion/support roles in community settings. R28: Strengthen dementia inclusive PEoLC, align PEoLC and Dementia workstreams, and carer support by ensuring timely identification, tailored communication, and proactive respite and bereavement support for carers. Use anchor institutions and workplace health initiatives to improve awareness of PEoLC, carers' rights, and bereavement support across the workforce and wider community. R37: Explore how quality assurance schemes, or specific elements of them, could be implemented locally at scale. Schemes aimed at care homes, domiciliary care, retirement villages, supported living, and primary care services are available to support great care at the EoL with people needs met.	
SG 5. Implement a Sussex-wide ReSPECT and Advance Care Planning improvement programme that increases the quality,	R8: Implement a quality focused digital universal care plan (inclusive of ACP & ReSPECT) improvement programme that increases appropriate use, review and visibility of these	BCYP 7: Strengthen early identification, proactive advance care planning and parallel planning for BCYP.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
consistency, visibility and use of personalised care planning.	plans, while avoiding a tick-box approach. Across all care settings for children and adults. Implement activities that meet the ICB commissioning intentions of 95% of EoL patients to have plans in place, which are regularly reviewed and enacted. This should especially focus on people living at home and in underperforming ICT areas. Introduce prompts or reminders in clinical systems (EMIS and SystmOne) to support completion in services at specific points including: When a person is identified as at risk of clinical deterioration or dying in the foreseeable future At key trigger points, such as: Diagnosis of a serious or life-limiting condition Significant change in health status or functional decline Hospital admission or discharge planning Entry into care homes or receipt of intensive community support Explore if measures and metrics relating to ReSPECT, ACP etc can be added to the ICT dashboards to monitor and promote improved completion.	BCYP 8: Implement consistent use and sharing of CYP-specific advance care plans, emergency healthcare plans and ReSPECT plans where appropriate.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	R11: Implement a set of evidenced and coproduced pilot models of care within specific settings and patient groups, that increase timely and person-centred Advance Care Planning (ACP), ensuring that ACP and other EoL interventions are initiated proactively by clinicians, particularly for people with frailty, dementia or non-cancer diagnoses, and reviewed when appropriate' R25: Develop and evaluate a proactive 'What matters to me approach' and 'later life planning offer' for older adults (for example from age 65 or for people with frailty indicators), integrating ReSPECT/ACP prompts, information and community signposting within primary care, community services and care homes, with clear safeguards to ensure it is person led.	
SG 6. Develop a Sussex PEoLC workforce strategy that addresses recruitment, retention and workforce development challenges, with specific focus on communication skills, frailty, dementia, neurodiversity, learning disability, HIV, bereavement support, inclusion and culturally competent care.	R9: Implement a consistent, multi-disciplinary training and quality assurance programme on ReSPECT and potentially Advance Care Planning (ACP), tailored to different professional roles, life stage/course and care settings, to ensure staff have the confidence, competence and clinical judgement to initiate, complete and review ACP and ReSPECT plans to a high standard and in a timely manner. Training should	BCYP 9: Develop a children's palliative care workforce model for Sussex. BCYP 10: Provide targeted training and specialist support for professionals caring for BCYP with palliative care needs.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	prioritise practical skills in sensitive conversations, clinical decision making, legal and ethical responsibilities, and high-quality documentation, with ongoing supervision and access to specialist advice. R14: Develop condition specific PEoLC workforce learning modules for dementia, neurological conditions, HIV, sensory loss, learning disability and autism, with specialist input and lived experience. R19: Train and build confidence and skills around sensitive PEoLC conversations, especially with diverse and marginalised groups, at every level within the workforce, including medical, specialist and non-specialist workforce, including volunteers R35: Develop and sustain a long-term PEoLC and bereavement workforce strategy for Sussex that addresses current and future health, care and medical workforce challenges, with a specific focus on coastal communities, and expands early intervention initiatives such as the Aspirations project in East Sussex.	

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
SG 7. Establish a Sussex PEoLC equity programme that combines improved recording of protected characteristics, communication needs, targeted engagement, co-production and service improvement to reduce inequalities in access, experience and outcomes	R10: Develop, implement and evaluate a Sussex inclusive PEoLC practice framework that embeds resources on Carers, LGBTQ+ inclusion, neurodiversity, faith, culture, sensory loss and other inclusion needs into commissioning, service training and quality assurance. Examples include: Care Home Guide for Creating Inclusive Residential Care for LGBTQ+ Elders EoL Care Planning Toolkit| Victoria and Stuart Autism Good practice guide Trans and Gender Diverse Inclusion handbook | Hospice UK Respecting Faith and Culture in EoL Care Handbook April 2025.docx Faith at EoL: public health approach resource for professionals - GOV.UK R15: Require consistent recording, reporting and use of protected characteristic, sensory loss, communication needs and inclusion health group data across PEoLC and bereavement services. R16: Commission and undertake targeted equity focused engagement and action planning with underserved communities, including LGBTQ+	BCYP 3: Assess and reduce inequalities in access to children's palliative care services across Sussex.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	communities, faith groups, people in poverty, migrants, refugees, people ageing without children and people with lower trust in services. R33: Develop and deliver an extensive rolling programme of Sussex wide learning and knowledge exchange events to strengthen understanding of the EoL and bereavement needs of specific communities (those with sensory loss, Gypsie, Roma and Traveller Communities, those experiencing homelessness, Autistic people etc.) led jointly by statutory services, voluntary and community organisations, and people with lived experience. R34: Embed community engagement and co-production capacity within PEoLC and bereavement planning, commissioning and service improvement. This should include exploring systematic approaches for sharing information, insight and knowledge with Sussex's diverse communities, and enabling this intelligence to be actively mobilised through a wide range of well-established and well networked Voluntary, Community and Social Enterprise (VCSE) organisations. R36: Assess and embed rural proofing across Sussex PEoLC, and bereavement support	

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	planning, commissioning and service delivery to ensure equitable access for rural populations. Assessing how services work in rural areas and adapting delivery models to reflect transport barriers, workforce constraints, digital exclusion and dispersed populations. R40: Establish a Sussex PEoLC co-production framework involving patients, carers, bereaved families, CYP, communities and VCSE organisations in commissioning, service design, evaluation and quality improvement.	
SG 8. Develop a Sussex Compassionate Communities and Death Literacy Strategy that normalises conversations about death, dying and bereavement, increases public understanding of available support and strengthens community-based networks.	R17: Develop a Sussex death literacy and compassionate communities strategy that normalises open conversations about death, dying, caring and bereavement. This should build on a range of existing local initiatives. R18: Produce and actively promote accessible, practical PEoLC and bereavement information in digital and non-digital formats for the population. R21: Ensure the availability of strong, coordinated and sustainable community-based bereavement support working in partnership with VCSE organisations, faith and community groups, and peer support/ lived experience networks, to ensure timely, culturally	BCYP 12: Strengthen coordinated emotional, psychological, practical and bereavement support for families of BCYP. BCYP 13: Develop accessible, culturally sensitive and age-appropriate information for children, young people and families. BCYP 14: Develop age-appropriate death literacy and community engagement approaches for children, young people and families.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	appropriate, and accessible support for bereaved children, young people, and adults across Sussex. R24: Consider and test a local 'Making Every Contact Count' (MECC) approach for PEoLC and bereavement. Equipping a wide and varied workforce (health, social care, VCSE, care homes and community services) to have confidence to offer brief, sensitive prompts about planning, support and signposting when appropriate. R26: Support community led death literacy activity, including death cafés, bereavement forums, community conversations, workplace initiatives and locally tailored resources, with specific approaches for children, young people and families. Ensure consistent signposting across NHS, local authority and VCSE networks, and include tailored approaches that help children and young people talk about death and bereavement within families. R29: Large local anchor institutions (NHS and Local Government) should develop and embed workforce wide communications and approaches that normalise conversations about EOL, death and bereavement, supporting dialogue, planning and access to information at scale.	

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	R30: Explore how the Death Reflection Scale (DRS) could be embedded within local health, care and organisational practice to support reflective conversations, compassionate cultures and improved preparedness around death, dying and bereavement. R39: Explore how the professional Bereavement Forum, led and coordinated by Public Health officers in Brighton and Hove and West Sussex, could be expanded to include East Sussex. This would develop a Sussex wide opportunity for the sector to explore and develop bereavement support across the system.	
SG 9. Re-establish a Sussex PEoLC Oversight Group and develop a Sussex-wide Implementation Plan with named leads, delivery partners, milestones, measurable outcomes, governance arrangements and regular public reporting.	R5: Establish a Sussex-wide PEoLC learning and improvement framework to systematically review, collate, share, implement and monitor learning from mortality reviews, including LeDeR, CDOP, Prevention of Future Deaths reports, complaints, audits, provider reviews, ambulance incidents and other quality assurance processes, with clear governance, named leads and measurable actions R20: Establish regular, population-based surveys and audits, and or embed indicators relating to the EoL within future surveys, to monitor the quality, equity, and outcomes of PEoLC. This	BCYP 15: Embed BCYP indicators within Sussex PEoLC quality improvement, audit and system learning processes.

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
	could include developing the Brighton and Hove Health counts survey, the East Sussex Community Survey or be based on the Vital Signs work undertaken in the Southwest. Use findings to inform service delivery, improvement, commissioning, service redesign, and strategic and operational planning. R23: Develop a Sussex-wide PEoLC outcomes, equity and improvement framework that embeds outcome, equity and experience measures within commissioning, performance monitoring and service improvement. This could include a routine system-level 'Vital Signs' approach that tracks quality, outcomes, inequalities and patient, carer and bereaved family experience, alongside regular reporting of learning, improvement actions and variation across Places and Integrated Community Teams (ICTs). R42: Develop a Sussex implementation and accountability plan for the final recommendations, identifying leads, delivery partners, milestones, resources, risks, measures of success and reporting routes.	
SG 10. Further develop existing service and implement a Sussex Babies, Children and Young People (BCYP) PEoLC programme	R6: Develop a dedicated Children and Young People (CYP) Palliative and End of Life Care (PEoLC) Multidisciplinary Team (MDT) pathway	All BCYP Recommendations (1-15). This strategic recommendation provides the umbrella programme under which all BCYP

Strategic recommendation (SG)	All age more detailed PEoLC Recommendations	Aligned BCYP recommendations
that establishes coordinated all-age pathways, equitable access to specialist support, 24/7 paediatric advice and response, named care coordinators, integrated transition arrangements and coordinated bereavement support for children, young people and families.	that promotes early identification, diagnostic vigilance, appropriate escalation, Advance Care Planning (ACP), Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) processes, and parallel planning. The pathway should be delivered collaboratively by specialist paediatric, tertiary, hospice and community services, with active involvement from General Practitioners (GPs) as members of the MDT, to ensure seamless coordination, shared decision-making and high-quality care R41: Develop a distinct CYP PEoLC implementation plan covering early identification, parallel planning, hospice involvement, tertiary-specialist-community-primary care coordination, community nursing capacity, data, family support and bereavement.	recommendations relating to strategic planning, population health, inequalities, community care, 24/7 access, care coordination, advance care planning, workforce development, medicines optimisation, bereavement support, information, community engagement, quality improvement and data development would be delivered.

All age more detailed recommendations and rationale.

1. **Recommendation: Develop a shared Sussex PEoLC and bereavement support demand, capacity and investment plan, aligned with the 'left-shift' of resources and care from hospitals towards community-based services, as set out in 'Fit for the Future'. This should account for different populations and needs at local levels, use population modelling, service activity, workforce data, provider and social care pressures, digital infrastructure and future demand projections.**

   Why: The report identifies substantial and growing demand (including projected increases in the size of the older population, Dementia and PEoLC need), high system pressure, high hospice occupancy and workforce capacity constraints. A shared evidence-based narrative supports strategic planning and strengthens the case for the left shift of investment from acute to community, to meet needs, ideally in the community, reduce inequalities and maintain quality and sustainability.

2. **Recommendation: Implement co-produced community based PEoLC models that enable people to remain at home, in care homes or community settings where appropriate and in line with their preferences.**

   Why: Evidence from an audit conducted by local hospital Consultants, shows that over half of patients under hospital PEoLC could be better supported elsewhere. Shifting care, where appropriate, to the community, home or care home, may improve patient quality of life, reduce hospital care demand, and allow resources to be used more effectively. The workforce survey and the public engagement highlighted the preference for 'Hospice' at home models.

3. **Recommendation: Implement a consistent Sussex wide, place based or other locality, Single Point of Coordination (SPoC) and Out of Hours PEoLC support model for all patients in Sussex in their last year of life, with clear triage, access routes, response times and links to ambulance, urgent care, prescribing, pharmacy, hospice and social care.**

   Why: This needs assessment consistently identifies gaps in out of hours support and coordination as drivers of avoidable 999 calls, ambulance attendance, A&E use and distress for families. SECAmb data also shows inappropriate resuscitation is more likely at home and is lower in areas with a dedicated SPoC. A consistent Sussex wide or place based SPoC and OOH offer may reduce inequity between places, support people to remain in their preferred setting, support families providing significant volumes of unpaid care, and improve system navigation and clinical decision making.

4. **Recommendation 4: Develop neighbourhood, ICT and MDT approaches that improve proactive PEoLC support to reduce avoidable hospital admissions and enable timely discharge through proactive care planning, involving general practice, community teams, care coordinators, hospices, care homes, social care and acute specialists.**

   Why: Evidence received highlights that patients and families experience both *actual* and *perceived* barriers in accessing general practice, including difficulty navigating appointment systems, limited continuity of care, uncertainty about who to contact, and a lack of proactive engagement at times of changing need for some patient. General practitioners also report barriers related to workload pressures, fragmented multidisciplinary working, and limited capacity to provide reactive and proactive care for people with complex EoL needs. A specific phoneline for palliative care patients was suggested via the public engagement.

5. **Recommendation: Establish a Sussex-wide PEoLC learning and improvement framework to systematically review, collate, share, implement and monitor learning from mortality reviews, including LeDeR, CDOP, Prevention of Future Deaths reports, complaints, audits, provider reviews, ambulance incidents and other quality assurance processes, with clear governance, named leads and measurable actions**

   Why: The needs assessment highlights that a robust and established process for both children and young people, and people with learning disabilities is in place in Sussex. However, a significant proportion of deaths, particularly among children and people with learning disabilities, contain modifiable factors and missed opportunities for intervention, including delays in recognition of deterioration, poor information sharing between professionals, and gaps in advance care planning and service coordination.

6. **Develop a dedicated Children and Young People (CYP) Palliative and End of Life Care (PEoLC) Multidisciplinary Team (MDT) pathway that promotes early identification, diagnostic vigilance, appropriate escalation, Advance Care Planning (ACP), Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) processes, and parallel planning. The pathway should be delivered collaboratively by specialist paediatric, tertiary, hospice and community services, with active involvement from General Practitioners (GPs) as members of the MDT, to ensure seamless coordination, shared decision-making and high-quality care.**

   Why: CDOP thematic findings identify that while many children and young people received timely diagnoses, a significant proportion experienced delays in diagnosis, particularly for rare conditions such as brain tumours, where symptoms were misattributed to more common or benign causes (e.g. reflux,

anxiety, musculoskeletal pain). These findings underline the importance of supporting GPs and other primary care clinicians to recognise evolving or persistent symptoms, challenge cognitive bias, and escalate concerns appropriately, even when initial examinations are normal. Early recognition in general practice is critical to improving outcomes and reducing distress for both children and families.

Learning from CDOP reviews highlights that the needs of children with life-limiting conditions are dynamic and change over time, requiring ACP and ReSPECT documentation to be reviewed regularly rather than treated as one off conversations. While many children who died from malignancy had an ACP in place, reviews also found challenges in initiating timely conversations and ensuring families understood disease progression and what to expect, particularly where deterioration occurred suddenly or families were not emotionally ready to engage.

7. **Recommendation: Prioritise real time interoperable shared digital records for PEoLC, therefore ACP, ReSPECT, preferred place of care, key clinical information and carer details are accessible and visible by patients and across primary care, acute, community, hospice, ambulance, social care services.**

   Why: Fragmented data systems hinder continuity and the ability to respect patient wishes, particularly when these wishes have been discussed, collected and recorded. Enhanced integration supports better coordination, reduces duplication, improves patient and family experience, and better use of healthcare resources.

8. **Recommendation: Implement a quality focused digital universal care plan (inclusive of ACP & ReSPECT) improvement programme that increases appropriate use, review and visibility of these plans, while avoiding a tick-box approach. Across all care settings for children and adults. Implement activities that meet the ICB commissioning intentions of 95% of EoL patients to have plans in place, which are regularly reviewed and enacted. This should especially focus on people living at home and in underperforming ICT areas. Introduce prompts or reminders in clinical systems (EMIS and SystmOne) to support completion in services at specific points including:**
   - When a person is identified as at risk of clinical deterioration or dying in the foreseeable future.
   - At key trigger points, such as:
   - Diagnosis of a serious or life-limiting condition.
   - Significant change in health status or functional decline.
   - Hospital admission or discharge planning.

- Entry into care homes or receipt of intensive community support.

Explore if measures and metrics relating to ReSPECT, ACP etc can be added to the ICT dashboards to monitor and promote improved completion.

Why: While 53% of people on the palliative care/supportive care register have a ReSPECT plan/form documented, uptake varies significantly, 79% in care/nursing homes compared to 40% at home. Consistent use of ReSPECT plans/forms ensures emergency care accounts for patient wishes and prevents inappropriate interventions. Inappropriate CPR and avoidable admissions are associated with plans not being present or not followed. Setting a shared ambition, paired with quality standards and support and would reduce unwarranted variation.

9. **Recommendation: Implement a consistent, multi-disciplinary training and quality assurance programme on ReSPECT and potentially Advance Care Planning (ACP), tailored to different professional roles, life stage/course and care settings, to ensure staff have the confidence, competence and clinical judgement to initiate, complete and review ACP and ReSPECT plans to a high standard and in a timely manner. Training should prioritise practical skills in sensitive conversations, clinical decision making, legal and ethical responsibilities, and high-quality documentation, with ongoing supervision and access to specialist advice.**

   Why: The data highlights wide variation in ACP and ReSPECT uptake across Sussex and settings, with lower completion rates for people living at home and significant inconsistency between localities and services. Inappropriate CPR, avoidable hospital admissions and care that does not align with people's wishes are associated with ACP and ReSPECT plans not being completed, completed late, not being shared, not being followed, or being of poor quality.

10. **Recommendation: Develop, implement and evaluate a Sussex inclusive PEoLC practice framework that embeds resources on Carers, LGBTQ+ inclusion, neurodiversity, faith, culture, sensory loss and other inclusion needs into commissioning, service training and quality assurance. Examples include:**
    - Care Home Guide for Creating Inclusive Residential Care for LGBTQ+ Elders
    - EoL Care Planning Toolkit| Victoria and Stuart
    - Autism Good practice guide
    - Trans and Gender Diverse Inclusion handbook | Hospice UK
    - Respecting Faith and Culture in EoL Care Handbook April 2025.docx

- Faith at EoL: public health approach resource for professionals - GOV.UK

Why: Maximising the use of established frameworks and resources will promote consistent, inclusive and evidence-based practice across Sussex, ensuring services are better equipped to meet diverse PEoLC needs while reducing duplication and improving quality and equity of provision.

11. **Recommendation: Implement a set of evidenced and coproduced pilot models of care within specific settings and patient groups, that increase timely and person-centred Advance Care Planning (ACP), ensuring that ACP and other EoL interventions are initiated proactively by clinicians, particularly for people with frailty, dementia or non-cancer diagnoses, and reviewed when appropriate'**

    Why: Only 13% of people on the palliative care register in Sussex have an ACP recorded, with notable variation across areas and settings. Early and individualised ACP ensures awareness of and alignment with patient wishes where possible, reduces unnecessary hospital admissions, and upholds dignity at the EoL. Recording ACPs in all care settings supports continuity and respect for patient preferences.

12. **Recommendation: Implement a specific ambulance PEoLC development programme, covering recognition of dying, ACP/ReSPECT interpretation, non-conveyance, specialist advice and avoidance of inappropriate resuscitation or conveyance.**

    Why: Evidence from the ParaAid Study demonstrates that fear, uncertainty, and limited education significantly undermine paramedic confidence when responding to people at the EoL. A substantial proportion of paramedics' report fears about doing the wrong thing and difficulty distinguishing active dying from reversible deterioration, alongside low confidence in supporting patients and families in the last year of life. Limited pre-registration education, staff capacity and inconsistent access to continuing professional development further exacerbate these challenges.

13. **Recommendation: Review existing evidence and undertake separate but linked population health and care needs assessments for carers, people living in poverty, and priority condition groups including MND, neurological conditions, dementia and HIV.**

    Why: The needs assessment demonstrates that people with care responsibilities have specific needs, whilst people living with HIV, particularly those that have lived with HIV for many decades, those with neurological conditions, such as MND and dementia follow prolonged, complex and less predictable EoL trajectories compared with cancer, yet they are consistently identified later and are less likely to access timely palliative care. Condition specific work

would enable deeper understanding of unmet need, service gaps, workforce capability, equity of access, and carer burden, informing earlier identification, tailored pathways and more appropriate models of support.

14. **Recommendation: Develop condition specific PEoLC workforce learning modules for dementia, neurological conditions, HIV, sensory loss, learning disability and autism, with specialist input and lived experience.**

    Why: The assessment identifies gaps in knowledge, confidence, skills and experience among professionals in recognising and responding to the specific needs and deterioration of individuals with cognitive, communication and learning disabilities, as well as in communicating effectively with them. Targeted, condition specific education delivered with specialist services and people with lived experience would improve quality, consistency and equity of care. There are many forums, patients groups and agencies ready to work with services to address workforce capability.

15. **Recommendation: Require consistent recording, reporting and use of protected characteristic, sensory loss, communication needs and inclusion health group data across PEoLC and bereavement services.**

    Why: More data and local evidence could be collected on LGBTQ+ groups and their PEoLC needs, and while ethnicity data is more consistently recorded, minority group numbers remain small. National and local evidence reveals these groups face barriers and inequalities in access and outcomes. Addressing data gaps is essential for equitable service planning and delivery.

16. **Recommendation: Commission and undertake targeted equity focused engagement and action planning with underserved communities, including LGBTQ+ communities, faith groups, people in poverty, migrants, refugees, people ageing without children and people with lower trust in services.**

    Why: National and local evidence reveals these groups face barriers and inequalities in access and outcomes. Understanding and addressing data gaps is essential for equitable service planning and delivery.

17. **Recommendation: Develop a Sussex death literacy and compassionate communities strategy that normalises open conversations about death, dying, caring and bereavement. This should build on a range of existing local initiatives.**

    Why: The public and professionals are often reluctant or unprepared to discuss EoLC, resulting in late recognition of needs and missed opportunities for effective care. Public engagement is key to normalising these conversations and improving care outcomes.

18. **Recommendation: Produce and actively promote accessible, practical PEoLC and bereavement information in digital and non-digital formats for the population.**

    Why: Providing accessible and visible information about EoL planning is essential because many individuals and families lack awareness or understanding of the processes involved, such as expressing wishes, registering a death, organising funeral arrangements, accessing bereavement advice. This knowledge gap can lead to uncertainty, stress, and missed opportunities for ensuring that care and post death arrangements reflect personal values and preferences. By making this information widely available, we can empower people to make informed decisions, promote open dialogue, and support a smoother experience during what is often a challenging time.

19. **Recommendation: Train and build confidence and skills around sensitive PEoLC conversations, especially with diverse and marginalised groups, at every level within the workforce, including medical, specialist and non-specialist workforce, including volunteers.**

    Why: Wider health, care and wider professionals are often reluctant or unprepared to discuss EoLC, resulting in late recognition of needs and missed opportunities for effective care. Professional engagement is key to normalising these conversations and improving care outcomes.

20. **Recommendation: Establish regular, population-based surveys and audits, and or embed indicators relating to the EoL within future surveys, to monitor the quality, equity, and outcomes of PEoLC. This could include developing the Brighton and Hove Health counts survey, the East Sussex Community Survey or be based on the Vital Signs work undertaken in the Southwest. Use findings to inform service delivery, improvement, commissioning, service redesign, and strategic and operational planning.**

    Why: Ongoing monitoring ensures improvements are sustained and responsive to changing needs (particularly if legislation changes relating to assisted dying bill), and that inequalities are addressed. Regular evaluation enables evidence-based decision making and accountability. Embedding in existing surveys and engagement routes could support efforts to normalise this topic.

21. **Recommendation: Ensure the availability of strong, coordinated and sustainable community-based bereavement support working in partnership with VCSE organisations, faith and community groups, and peer support/ lived experience networks, to ensure timely, culturally appropriate, and accessible support for bereaved children, young people, and adults across Sussex.**

Why: Across multiple sources of evidence from various sources. It's clear that bereavement support is highly valued but currently inconsistent, fragmented, and difficult to navigate, particularly for people who experience barriers to accessing traditional services. There are opportunities to maximise the wealth of the VCSE agencies that are well placed to support the development of community bereavement support.

22. **Recommendation: Develop a system-wide approach to workforce and community roles that strengthen social prescribing and wider practical, emotional and social support for people approaching the EoL and those important to them, including testing and evaluating 'EoL Doula' 'No-one dies alone' (volunteers) or similar companion/support roles in community settings.**

    Why: Evidence in this assessment highlights that people value dignity, emotional safety, chosen family and not being alone, yet families often feel unsupported and care can be fragmented. A trained companion/support role could provide continuity, help people and carers navigate services, encourage earlier conversations, and link people to community and bereavement resources, potentially reducing crisis escalation and improving experience, especially for those living alone or in inclusion health groups. However, the risks, quality, vetting, and assurance of such roles will need to be considered and managed.

23. **Recommendation: Develop a Sussex-wide PEoLC outcomes, equity and improvement framework that embeds outcome, equity and experience measures within commissioning, performance monitoring and service improvement. This could include a routine system-level 'Vital Signs' approach that tracks quality, outcomes, inequalities and patient, carer and bereaved family experience, alongside regular reporting of learning, improvement actions and variation across Places and Integrated Community Teams (ICTs).**

    Why: This needs assessment identifies rising demand for PEoLC, increasing system pressures, unwarranted variation in access and outcomes, and persistent inequalities experienced by some population groups. At the same time, evidence suggests that well-coordinated community-based models of care can improve patient and carer experience, reduce avoidable hospital admissions, support care in people's preferred place, and make more effective use of health and care resources. Historically, commissioning and performance management have often focused on activity, service contacts or contractual thresholds rather than whether services are improving outcomes, experience and equity. A complementary PEoLC 'Vital Signs' approach would provide regular, population-level insight into quality, equity and experience, including

feedback from patients, carers and bereaved families. It would support transparency, accountability and continuous improvement by identifying variation, monitoring progress against agreed outcomes, and informing commissioning decisions. Combined with existing arrangements for complaints, learning from deaths, audits and Prevention of Future Deaths actions, this approach would strengthen system-wide learning, support value for money, align with national ambitions for PEoLC, and incentivise improvements in quality, continuity and fairness rather than simply increasing activity.

24. **Recommendation: Consider and test a local 'Making Every Contact Count' (MECC) approach for PEoLC and bereavement. Equipping a wide and varied workforce (health, social care, VCSE, care homes and community services) to have confidence to offer brief, sensitive prompts about planning, support and signposting when appropriate.**

    Why: Public and professional engagement in this needs assessment suggests planning is often introduced too late and people are unsure where to find information. A MECC style approach would help normalise conversations, widen access beyond specialist teams, improve signposting, and support earlier and wider identification, particularly for frailty, dementia and non-cancer trajectories.

25. **Recommendation: Develop and evaluate a proactive 'What matters to me approach' and 'later life planning offer' for older adults (for example from age 65 or for people with frailty indicators), integrating ReSPECT/ACP prompts, information and community signposting within primary care, community services and care homes, with clear safeguards to ensure it is person led.**

    Why: Sussex has an ageing population with increasing multimorbidity, and frailty/dementia account for a large, and growing, proportion of deaths. Earlier, routine opportunities to discuss preferences could reduce late crisis planning, support autonomy, and help align care with what matters most, while ensuring communication is clear to avoid misunderstanding about motives.

26. **Recommendation: Support community led death literacy activity, including death cafés, bereavement forums, community conversations, workplace initiatives and locally tailored resources, with specific approaches for children, young people and families. Ensure consistent signposting across NHS, local authority and VCSE networks, and include tailored approaches that help children and young people talk about death and bereavement within families.**

    Why: Public engagement and Healthwatch evidence cited in this report indicates that people struggle to find clear information and that planning is not

normalised. Community led approaches, can reduce pressure on the NHS, can reduce stigma, build confidence to have conversations, and provide low threshold routes into support. Accessible materials (including non-digital options) support inclusion for people with low health literacy, limited digital access, and diverse cultural needs.

27. **Recommendation: Use targeted, meaningful and actionable digital prompts within clinical systems to support identification, ACP/ReSPECT review, carer support and signposting. (e.g., EMIS, SystmOne and hospital systems) to trigger timely identification, ACP/ReSPECT review, carer assessment, and referral/signposting to Single Points of Coordination (SPoC)/Out Of Hours (OOH) and community support, aligned to agreed criteria such as frailty, dementia, repeated admissions, or palliative and supportive care code entry.**

    Why: The report identifies late identification and missed opportunities for planning, with variation between areas and settings. Clinical system prompts can support busy clinicians to take timely action, improve recording quality, and reduce unwarranted variation, particularly for people living at home who currently have lower rates of recorded planning.

28. **Recommendation: Strengthen dementia inclusive PEoLC, align PEoLC and Dementia workstreams, and carer support by ensuring timely identification, tailored communication, and proactive respite and bereavement support for carers. Use anchor institutions and workplace health initiatives to improve awareness of PEoLC, carers' rights, and bereavement support across the workforce and wider community.**

    Why: Dementia and frailty are major drivers of PEoLC need and will increase with population ageing. Evidence in this report highlights the importance of being seen as a person, and the burden on families and carers. Embedding dementia inclusive practice and strengthening carer support can improve experiences, reduce avoidable admissions and support bereavement outcomes. Workplace/anchor approaches extend reach and normalise support beyond clinical settings.

29. **Recommendation: Large local anchor institutions (NHS and Local Government) should develop and embed workforce wide communications and approaches that normalise conversations about EoL, death and bereavement, supporting dialogue, planning and access to information at scale.**

    Why: The needs assessment highlights that conversations about EoL and bereavement are often avoided, delayed or crisis driven, limiting opportunities for early planning, informed choice and emotional preparedness. Large anchor

institutions, particularly the NHS and local authorities, have substantial reach across Sussex as major employers, service commissioners and community leaders. By using their internal and external communications, learning offers and wellbeing programmes, these organisations can contribute to the normalisation of EoL and bereavement conversations within the workforce and across health and care, shaping culture, increasing confidence, and supporting earlier engagement. This approach has the potential to improve staff wellbeing, enhance death literacy, reduce stigma, and indirectly support better outcomes for individuals, families and communities through a more informed, compassionate and prepared health and care system.

30. **Recommendation: Explore how the Death Reflection Scale (DRS) could be embedded within local health, care and organisational practice to support reflective conversations, compassionate cultures and improved preparedness around death, dying and bereavement.**

    Why: The needs assessment highlights persistent challenges for both the public and the workforce in engaging with conversations about death, dying and bereavement, often driven by discomfort, fear and limited opportunities for structured reflection. The Death Reflection Scale (DRS) offers a validated, reflective approach that supports individuals and groups to explore attitudes, emotions and beliefs about death in a structured and psychologically safe way. Exploring the use of the DRS within local practice, such as workforce development, supervision, team reflection, education and organisational wellbeing initiatives, could help normalise conversations about mortality, increase confidence in EoL discussions, and support staff to process the emotional labour associated with caring for people at the EoL. Embedding this approach has potential to strengthen compassionate organisational cultures, improve readiness for advance care planning conversations, and indirectly enhance the quality of care and support provided to individuals, families and communities across Sussex.

31. **Recommendation: Develop local systems, partnerships and projects, working with Public Health and academic partners, to robustly evaluate the health and economic impacts of new and emerging models of EoLC in Sussex. Consider developing and supporting local PhDs, externally funded, to support this.**

    Why: The needs assessment identifies increasing demand for palliative and EoLC alongside growing pressures on health and care services. While innovative models of care particularly those focused on digital support, remote monitoring, and home-based care have the potential to improve people's experiences and support more care in community settings, their health, wellbeing and economic impacts are not yet consistently or systematically

evaluated at a local level. Developing coordinated programmes of economic evaluation, including through Public Health led approaches, would strengthen the local evidence base and support more informed commissioning, investment and scaling decisions. This work could include the evaluation of specific interventions such as digital tools to support advance care planning, remote clinical support and symptom management, and enhanced home-based care models that aim to reduce avoidable hospital use while improving quality of life, choice and person-centred outcomes. Embedding economic evaluation within local service development will help Sussex transition towards more sustainable, value-based models of EoLC that deliver better outcomes for individuals, families and the wider health and care system.

32. **Recommendation: Review and improve EoL medicines access, prescribing and community pharmacy provision across Sussex, including rural and non-rural access, out-of-hours prescribing and timely prescribing.**

    Why: Timely access to EoL medicines is essential to support good symptom control, reduce distress and enable people to remain in their preferred place of care where possible. However, delays in accessing anticipatory medicines can occur at multiple points in the pathway and are not solely within the control of community pharmacy. Effective provision relies on timely anticipatory prescribing by GP practices, out-of-hours services and other authorised prescribers, as well as prompt prescription issue, dispensing, stock availability and clear communication between professionals. Strengthening this whole pathway is needed to reduce avoidable delays, improve comfort and wellbeing, and prevent unnecessary crisis contacts, hospital admissions and additional pressure on families, carers and community services.

33. **Recommendation: Develop and deliver an extensive rolling programme of Sussex wide learning and knowledge exchange events to strengthen understanding of the EoL and bereavement needs of specific communities (those with sensory loss, Gypsie, Roma and Traveller Communities, those experiencing homelessness, Autistic people etc.) led jointly by statutory services, voluntary and community organisations, and people with lived experience.**

    Why: Evidence and insight highlight that people from some communities experience unequal access, poorer experiences, and unmet needs at the EoL, often linked to cultural, social, spiritual, communication, and trust-based barriers. Learning from system maturity assessments and stakeholder engagement also indicates that while Sussex has a rich and diverse Voluntary, Community and Social Enterprise (VCSE) sector, opportunities for structured, reciprocal knowledge sharing across health, care and voluntary services remain underdeveloped.

34. **Recommendation: Embed community engagement and co-production capacity within PEoLC and bereavement planning, commissioning and service improvement. This should include exploring systematic approaches for sharing information, insight and knowledge with Sussex's diverse communities, and enabling this intelligence to be actively mobilised through a wide range of well-established and well networked Voluntary, Community and Social Enterprise (VCSE) organisations.**

    Why: This report highlights the essential contribution of the VCSE sector in delivering practical, emotional, spiritual and bereavement support, particularly within community and home-based settings. Sussex has a rich and diverse VCSE landscape with deep connections to local communities, including groups who may be underserved by statutory services. Strengthening community engagement capacity would support two-way dialogue with communities, improve awareness and understanding of EoL and bereavement support, and enable locally held knowledge and lived experience to inform service design and delivery.

35. **Recommendation Develop and sustain a long-term PEoLC and bereavement workforce strategy for Sussex that addresses current and future health, care and medical workforce challenges, with a specific focus on coastal communities, and expands early intervention initiatives such as the Aspirations project in East Sussex.**

    Why: Coastal communities in Sussex experience persistent and deep-rooted health inequalities, alongside long-standing challenges in recruiting and retaining health, care and medical professionals. Evidence from Sussex coastal health and inequalities work consistently highlights that these workforce challenges are closely linked to wider social and economic factors, including lower educational attainment, limited local employment opportunities, and reduced exposure to professional role models in health and care careers.

36. **Recommendation: Assess and embed rural proofing across Sussex PEoLC, and bereavement support planning, commissioning and service delivery to ensure equitable access for rural populations. Assessing how services work in rural areas and adapting delivery models to reflect transport barriers, workforce constraints, digital exclusion and dispersed populations.**

    Why: A significant proportion of Sussex residents live in rural areas with older age profiles and higher levels of isolation, increasing demand for PEoLC care.

    Without a rural lens, services risk being designed around urban assumptions, resulting in poorer access, unmet need and inequitable outcomes. Rural proofing will support earlier planning, improve access to community-based

care, and ensure services are responsive to hidden deprivation and social isolation, aligning with system ambitions for equitable, person-centred PEoLC.

37. **Recommendation: Explore how quality assurance schemes, or specific elements of them, could be implemented locally at scale. Schemes aimed at care homes, domiciliary care, retirement villages, supported living, and primary care services are available to support great care at the EoL with people needs met.**

    Why: Frameworks such as the Gold Standards Framework (GSF) and The Daffodil Standards for pharmacies, provide a clear, evidence-based model for high-quality care, supporting early identification, advance care planning, coordinated multidisciplinary working, effective symptom control, and ongoing review.

38. **Recommendation: Contribute to the development of a national Children and Young People (CYP) hospice dataset, building on the existing national activity and demographic data currently submitted by adult hospices to Hospice UK. This should be nationally led, with Sussex system partners contributing learning and development work undertaken to date.**

    Why: There is currently no consistent, standardised dataset for CYP hospice services, limiting the ability to understand need, monitor equity of access, and inform service planning at both local and national level. Developing a national dataset, would enable improved benchmarking, strengthen evidence on unmet need, and support commissioning decisions. Building on the established Hospice UK adult dataset would ensure alignment, efficiency, and comparability across the life course. Local work across Sussex provides a strong foundation that could inform and accelerate national development.

39. **Recommendation: Explore how the professional Bereavement Forum, led and coordinated by Public Health officers in Brighton and Hove and West Sussex, could be expanded to include East Sussex. This would develop a Sussex wide opportunity for the sector to explore and develop bereavement support across the system.**

    Why: A professional forum would improve coordination and shared learning but should be clearly described as a coordination forum rather than a direct support service.

40. **Recommendation: Establish a Sussex PEoLC co-production framework involving patients, carers, bereaved families, CYP, communities and VCSE organisations in commissioning, service design, evaluation and quality improvement.**

Why: lived experience should be embedded into implementation and evaluation, not limited to consultation. Professionals within the NA workshops believe this should be developed locally.

41. **Recommendation: Develop a distinct CYP PEoLC implementation plan covering early identification, parallel planning, hospice involvement, tertiary-specialist-community-primary care coordination, community nursing capacity, data, family support and bereavement.**

    Why: Stakeholders highlighted a risk that CYP needs may be overlooked within all-age recommendations. Children's palliative care differs from adult services in that care may begin before birth, continue for many years, and require specialist multidisciplinary and family-centred support. Specific consideration of CYP needs may therefore help ensure these requirements are appropriately recognised within service planning and delivery.

42. **Recommendation: Develop a Sussex implementation and accountability plan for the final recommendations, identifying leads, delivery partners, milestones, resources, risks, measures of success and reporting routes.**

    Why: The recommendations within this NA require clear ownership, deliverability, resourcing, workforce capacity, accountability and prioritisation to move from aspiration into system change.

43. **Recommendation: Develop a Sussex-wide programme of engagement, research and data collection with residential care homes, nursing homes, domiciliary care providers, supported living services, personal assistants, and wider social care partners to improve understanding of PEoLC needs, experiences, outcomes and inequalities.**

    Why: Social care providers are central to the delivery of PEoLC in Sussex, supporting large numbers of people living and dying in care homes, supported living settings and their own homes. However, this needs assessment identified significant gaps in available data and intelligence relating to PEoLC within social care. Limited information was available on service activity, workforce pressures, outcomes, advance care planning, inequalities, place of death, quality of experience, and unmet need within the care home and domiciliary care sectors. The report also notes that there is comparatively little social care data available when compared to NHS datasets, which limits system understanding of current and future need and makes it more difficult to commission, plan and evaluate services effectively.

44. **Ensure equitable access to PEoLC services for people regardless of their usual place of residence or existing care arrangements, including those living in nursing and residential care homes and people receiving home**

care, so that the presence of existing care or nursing provision does not itself create a barrier to accessing appropriate community or specialist PEoLC support.

Why: People receiving care and support through residential, nursing or home care services can experience barriers to accessing additional community or specialist PEoLC support where this is perceived as duplicating provision already in place. However, these services can offer complementary or unique expertise and support for many individuals, helping to optimise symptom management and comfort at the end of life and avoid unnecessary hospital admission. A further consideration is that, although some care providers have access to registered nursing staff, particular end of life skills and interventions may be required relatively infrequently, which can make it more difficult for staff to maintain confidence and competence, particularly in settings experiencing workforce turnover. Access to community and specialist PEoLC support should therefore be based on individual need, rather than being limited by a person's place of residence, existing care arrangements, the presence of nursing provision or how their care is funded.

Table 87 Recommendations mapped against the Six Ambitions for PEoLC and the Modern Service Framework for Palliative and End of Life Care. **Several recommendations could legitimately sit under more than one MSF area, but I have allocated them according to their primary intent.**

Modern Service Framework Area for Action	Relevant Six Ambition(s)	Recommendation numbers
1. Support our staff and our population to better understand palliative care, death and dying	Ambition 5: All staff are prepared to care Ambition 6: Each community is prepared to help Ambition 1: Each person is seen as an individual	9, 10, 17, 18, 19, 24, 26, 29, 30, 33, 35, 37
2. Provide a person-centred approach and ensure equitable access to earlier and more effective identification of needs, in all settings of care	Ambition 1: Each person is seen as an individual Ambition 2: Fair access to care Ambition 4: Care is coordinated	6, 8, 10, 11, 12, 14, 15, 16, 25, 27, 28, 34, 38, 40, 41, 43,44
3. Prevent distress through proactive and equitable assessment and management of need closer to home	Ambition 2: Fair access to care Ambition 3: Maximising comfort and wellbeing Ambition 4: Care is coordinated	1, 2, 3, 4, 7, 8, 12, 22, 23, 27, 31, 32, 35, 36, 39, 42, 43,44
4. Ensure equitable access to personalised palliative care	Ambition 1: Each person is seen as an individual Ambition 2: Fair access to care Ambition 3: Maximising comfort and wellbeing	10, 14, 15, 16, 18, 21, 23, 28, 33, 34, 36, 38, 40, 43,44

APPENDIX PEoLC services and provider descriptors.

Service information was correct at August 2026. Readers should check the linked provider website for current access arrangements.

Services Supporting Palliative and End of Life Care in Sussex

Palliative and end of life care (PEoLC) in Sussex is delivered through a complex, integrated system of health, social care, hospice, voluntary sector and community services. Effective PEoLC relies on coordinated support across multiple organisations and care settings to meet the physical, psychological, social, practical and spiritual needs of individuals approaching the end of life, as well as the needs of their families and carers. Care is provided in people's homes, care homes, hospitals, hospices and community settings, with services working together to ensure care is person-centred, coordinated and aligned to individual preferences wherever possible.

Primary care services, including General Practice, play a central role in identifying people who may be approaching the end of life, coordinating care, supporting advance care planning and working with multidisciplinary partners to manage complex and progressive conditions. Community pharmacies provide essential access to palliative medicines and advice, while residential and nursing homes support many people during the final months, weeks and days of life. Specialist hospice services across Sussex provide expert palliative care, symptom management, psychosocial support, bereavement services, education and professional advice, alongside inpatient, outpatient and community-based care. Specialist services are also available for specific populations, including children and young people and people living with HIV.

Hospital services across Sussex provide both generalist and specialist palliative care, supporting patients with complex symptoms, facilitating advance care planning, and enabling discharge to preferred places of care where appropriate. Community health services, including district nursing, urgent community response teams, virtual wards, specialist palliative care teams and care coordination services, increasingly support people to remain at home and avoid unnecessary hospital admissions. These services work closely with General Practice, hospices, care homes and social care providers to deliver integrated care across neighbourhoods and localities.

The voluntary, community and social enterprise (VCSE) sector also makes a significant contribution, providing practical assistance, peer support, counselling, advocacy, condition-specific services, bereavement support and community-based initiatives that complement statutory services. Families and carers remain fundamental partners in care, providing practical, emotional and advocacy support throughout a person's illness and following bereavement.

This chapter describes the key services involved in delivering PEoLC across Sussex, outlining how they operate, work together and support people with PEoLC needs. Understanding the current service landscape is essential to identifying strengths, gaps and future opportunities to ensure the Sussex system can meet increasing demand and deliver high-quality, equitable and person-centred care for all residents.

General Practice

General Practitioners (GPs) and primary care health teams working within General Practice surgeries provide PEoLC. Approximately 0.5% of the registered GP practice population (all ages) in England will be nearing the end of their life with a palliative/supportive care code within their record (90). As the national population ages, this older population often has increased healthcare needs, with multiple morbidity and complex care required. GPs help identify patients potentially at the EoL and then work with colleagues and partners to review care needs. GPs are involved in PEoLC in several ways such as advance care planning, helping those at the end of their life to explore what’s important to them in relation to their care and treatment. They are also involved in structured reviews of medications, other treatments and prescription of anticipatory medications. Where possible, they may support patients to die in their preferred place of care. Some GPs have extended roles, where they have both the general practitioner and PEoLC skills (192).

In Sussex, there are currently 156 GP practices.

NHS England GP Contract:

The 2025 Standard GMS contract does not stipulate specific requirements relating to palliative or EoL care, but does require GP services to support patients living with frailty through:

- Identifying patients aged 65+ with moderate to severe frailty using specified tools.
- Undertaking clinical reviews, including medication reviews, discussion of falls, and other clinically appropriate interventions.
- Advising patients on Summary Care Record (SCR) benefits and activating if requested.
- Recording relevant codes and clinical interventions on the SCR.

NHS England Primary Care Network (PCN) Network Contract Directed Enhanced Service (DES).

The PCN DES is a national NHS programme that helps local GP practices work together to provide joined up care. It is optional for practices to join.

The DES does not explicitly reference PEoLC but its focus on proactive care for complex patients benefits those with such needs. PCNs are required to achieve this through participation in Integrated Neighbourhood Teams (INTs) (ICTs in Sussex), aiming to reduce avoidable health deterioration and hospital admissions and improve patient care and experience.

NHS Sussex ICB Frailty and EoL Locally Commissioned Service (LCS) and Proactive Care Implementation Scheme:

Since December 2020, NHS Sussex ICB has commissioned a Frailty and EoL LCS to support GP practices in providing more comprehensive care for frail and EoL patients. As of October 2025, 148 of 156 practices are signed up.

Key interventions include:

- Personalised care and support planning, including ReSPECT where appropriate.
- Structured Medication Reviews.
- Maintenance of an EoL register.
- Named Practice Lead for EoL Care.
- Enhanced MDT working with community services.

The LCS encourages early discussion of ReSPECT to ensure patients' care wishes are known in emergencies, respecting both patient preferences and clinical judgement.

A refresh of this LCS occurred April 2026. In lieu of this, an optional Proactive Care Scheme (Oct 2025–Mar 2026) is supporting GP practices to develop integrated proactive care for high need patients, including those with frailty and approaching EoL. Key additional interventions include:

- Named Clinical Proactive Care lead.
- Collaborative work to establish Integrated Care Teams.
- Enhanced data sharing and risk stratification using specified tools such as the EARLY toolkit.
- Validation of proactive care and EoL registers to improve accuracy.
- Support to clinical pharmacist networks.
- And engagement with The Daffodil Standards to provide a framework for quality improvement in EoL care

Community Pharmacy

Pharmacists can play a vital role in community palliative care to enhance the quality of life of patients (193). Community Pharmacy and its supporting workforce have a role in PEoLC in Sussex.

Patients and their family, friends and carers will likely access pharmacy services more frequently. Access to medications to alleviate symptoms and for pain management are key for those at the end of lives. Community Pharmacies can be commissioned to provide a service to support anticipatory prescribing and allow rapid access to medicines commonly prescribed in palliative care, to enable a greater percentage of patients to have a home death, rather than to be moved to an institution such as hospital or hospice (194).

The three Pharmaceutical Needs Assessments (PNAs) for Sussex (195–197) have all been updated in 2025. Alongside data shared by NHS Sussex, across Sussex, there are now 72 pharmacies commissioned to provide the Community pharmacy 'Emergency Palliative/EoL Care (EoLC) medicines' LCS service from 1 November 2025 – 31 March 2028 (43). This was set up in 2020 to improve access to EoLC medicines when they are required in an emergency, by ensuring prompt access and continuity of supply during the hours participating pharmacies are open. The PNAs collectively note that out of hours and weekend, rural for East and West Sussex, a commissioned service from existing pharmacies could enhance general and PEoLC pharmacy provision in Sussex. Public and stakeholder feedback highlights a desire for more extended hours, especially for urgent needs like EoL care. It should be noted that the impact of limited out of hours, and rural pharmacy provision can have significant negative impacts on those at the end of their life, and their families and carers.

NHS Sussex ICB Community Pharmacy LCS for Emergency Palliative Care Medicines:

Through this LCS, NHS Sussex ICB commissioned local pharmacies to stock agreed levels of specified emergency EoL medicines and provide advice or referral. A number of pharmacies are chosen by NHS Sussex ICB and are listed on website.

Currently pharmacies across Sussex Community pharmacies signed up to EoLC LCS - NHS Surrey and Sussex clinical extranet

PEoLC prescribing resources which cover symptom control, drug administration charts at Palliative and end of life care | Prescribing resources - NHS Surrey and Sussex clinical extranet

The LCS will be reviewed as part of future work to integrate provision across Surrey and Sussex

Residential care homes and Nursing homes

A care home is a communal setting where personal care is provided. There are two main types of care homes, care homes with nursing care, known as nursing homes, and residential care homes that only offer personal care. Personal care can include a variety of support with oral care, dressing, washing, eating and drinking and accessing toilet facilities. These homes are supported by local primary care providers such as GPs.

There are approximately 700 care homes in Sussex.

There are about 26,000 staff employed in social care in Sussex of whom 14,000 are care and support workers.

EoL care is provided predominantly (but not exclusively) in care homes with or without nursing care, and the majority of them provide care to their residents in their final years, months or days of their life.

Most care/nursing homes want to provide care at the end of their resident's life as in many cases they have become part of their family, although some homes admit people purely to provide EoL care, rather than dying in hospital.

EoL care is achieved by providing person-centred holistic care by understanding the person as a unique individual and acknowledging their wants and wishes at the end of their life, whilst supporting them to have as much control as possible and allowing them to die with dignity at a place of their choice surrounded by the people and things that they choose.

Good EoL care includes providing all aspects of physical care (including appropriate pain relief, and accessing anticipatory drugs), spiritual care, practical support and emotional care for both them and their loved ones. It is noticing someone’s deterioration and alerting healthcare professionals (including hospices where appropriate), families and important others, that things are changing and acting accordingly.

Good EoL care includes having all the right paperwork in place to prevent avoidable admissions to hospital and ensuring that everyone involved knows of the resident's wishes which is reflected in the documentation.

After someone dies it is important to provide support to the family, staff and other residents as they will be mourning someone that they have known for some time, as well as reflecting as a staff team if there were any lessons learnt.

Hospices

Hospice care aims to improve the quality of life and wellbeing for adults, children and young people who have a terminal illness or a long term condition that cannot be cured, also known as life-limiting. It is free for patients, their carers and family members. Hospice care can be provided at any stage of a person's condition, not just at the end of their lives. It can include symptom management, and social, practical, emotional and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be. This type of care is also known as palliative care, and can also be provided in other places, such as in a hospital, at home, or in a community setting by a Hospice. (47) All Sussex based Hospices are charities.

Chestnut Tree House & COAST (Part of Southern Hospice Group)

Service Summary

Southern Hospice Group is a group of hospices providing specialist palliative care and post bereavement services to babies, children and adults across Sussex and Southeast Hampshire. SHG consists of 2 adult hospices and 1 children's hospice. Together they support all who have life-limiting conditions which will significantly shorten their lives. The hospices help those they care for, and their loved ones, to make the most of the precious time they have left.

Chestnut Tree House is the children's hospice for Sussex and Southeast Hampshire. Our goal is to provide the best quality of life for babies, children, young people and their families, and to offer practical, psychosocial and spiritual support throughout each child's life, as well as bereavement care ensuring dignity and support at the end of life and in the months and years to come.

In April 2026, Southern Hospice Group was awarded the contract for the provision of 24/7 specialist paediatric PEoLC(non-oncology), for babies, children and young people, across Sussex. This service had been running as a proof of concept for the prior 18 months, as COAST, the Children's Outreach & Symptom Team. COAST is situated at Chestnut Tree House, comprising a multidisciplinary team of medical consultants and specialist nurses. The service works closely with the Chestnut Tree House teams, including the End-of-Life Community Nursing Team, to ensure we are there for all those who need us, at the end of life.

Who they are

The Chestnut Tree House team is nurse led and made up of clinical nurse specialists, specialist nurses, health care assistants, social workers, counsellors, a

spiritual care lead, activities and engagement co-ordinators and family support workers. The teamwork within the hospice, in the community and in-reach to hospitals to meet the holistic needs of those in our care.

What they do

Chestnut Tree House provides specialist paediatric palliative care for babies, children and young people with life-limiting and life-threatening conditions across Sussex and Southeast Hampshire. We work alongside families from diagnosis through to end of life and into bereavement, delivering holistic, family-centred care wherever it is needed.

Services include:

Specialist PEoLC

- Specialist symptom management.
- Planned and emergency end of life care.
- Medical and nursing care delivered by a multidisciplinary team.
- Advance care planning.
- Clinical review and care coordination.
- 24-hour specialist advice and support through the COAST (Children's Outreach and Symptom Team) service.
- Rapid response and end of life care in the community where appropriate.

Hospice-Based Care.

- Planned short breaks for children and young people.
- Symptom management admissions.
- End of life care within the hospice.
- Emergency and crisis admissions where appropriate.
- Day care services.
- Therapeutic play and meaningful activities.
- Inclusive family events and seasonal celebrations.
- Accessible facilities for children and young people with complex needs.
- ‘Stars’ Bereavement Suite.

Community Children's Nursing and Outreach

- Specialist nursing visits at home.
- Clinical assessment and monitoring.
- Symptom management in the community.

- Support for children with complex health needs.
- Education and support for parents and carers.
- Joint visits with local health professionals.
- Partnership working with hospitals, community nursing teams and primary care.
- Care coordination across multiple agencies.

Child and Family Support Team (CFST)

- Family support and care coordination.
- Emotional support for parents and carers.
- Counselling for children, young people and family members.
- Social work support.
- Practical advice and advocacy.
- Chaplaincy and spiritual care for families of all faiths and none.
- Support with advance care planning conversations.
- Signposting to financial, educational and community resources.

Psychological and Emotional Wellbeing

- Individual counselling.
- Family counselling.
- Therapeutic interventions.
- Emotional support during periods of uncertainty.
- Support following deterioration in a child's condition.
- Bereavement preparation.

Bereavement Services

- Pre-bereavement support
- Bereavement counselling.
- Support groups.
- Memory-making activities.
- Sibling bereavement support.
- Family remembrance events.
- Ongoing support following the death of a child or young person.
- ‘Stars’ Bereavement Suite.

Play, Activities and Family Engagement

- Specialist play opportunities.
- Creative arts and music activities.
- Sensory experiences.
- Family fun days.
- Sibling groups.
- Young carers support.
- Friendship groups.
- After-school activities.
- Holiday activities.
- Parent and family cafés.

Parent and Carer Engagement

- Parent and Carer Forum.
- Quarterly family newsletter.
- Regular family feedback opportunities.
- Patient and Family Engagement and Involvement projects.
- "You Said, We Did" programme.
- Co-production of service developments with families.

Transition to Adult Services

- Individual transition planning.
- Joint working with adult hospice services.
- Support for young people approaching adulthood.
- Information and guidance for families.
- Partnership working with adult health and social care providers.
- Continuity of care throughout transition.

Education, Training and Professional Support

- Education for hospice staff.
- Clinical supervision.
- Student placements.
- Training for health and social care professionals.
- Advice to external professionals caring for children with life-limiting conditions.
- Promotion of best practice in paediatric palliative care.

Partnership Working

We work closely with:

- Acute children's hospitals.
- Community children's nursing teams.
- GPs and primary care.
- Local authorities.
- Special schools and education providers.
- Adult hospice services.
- Therapy services.
- Children's continuing care teams.
- Voluntary sector organisations.
- Integrated Care Boards and commissioners.

Their Commitment

Everything we do is centred on helping children and young people with life-limiting conditions live as well as possible for as long as possible. We support the whole family through every stage of their journey, delivering compassionate, specialist care that is responsive, equitable and tailored to individual needs.

Our aim is simple: to ensure every family receives the right care, at the right time, in the right place.

How we work:

At Chestnut Tree House, we work in partnership with babies, children, young people and their families to provide compassionate, specialist palliative care that is tailored to individual needs. We deliver holistic support that addresses physical, emotional, psychological, social and spiritual wellbeing, recognising that every family's journey is unique. Working as one multidisciplinary team, we provide care in the hospice, at home, in hospital and within the community, collaborating closely with NHS partners, education, social care and the voluntary sector to ensure children and families receive coordinated, seamless care.

Our approach is centred on providing the right care, at the right time, in the right place. We aim to build trusting relationships with families from an early stage, adapting our support as needs change and ensuring care remains flexible and responsive throughout a child's life, including transition into adult services where appropriate. We are committed to continually improving our services through quality improvement, education, innovation and meaningful co-production with children, young people and families, ensuring that their experiences and feedback shape the way we deliver care now and in the future.

Access:

Referrals to our service can be made by any health care professional via the form on our website.

If further information is required prior to referral, then the care team can be contacted at any time by phone.

Emergency referrals for end of life and crisis care are actioned within 24 hours of receipt.

Hours of operation

The hospice is open 24/7, 52 weeks of the year, although we offer a limited service on Christmas Day and Boxing Day. Members of the care team are available for advice and support 24 hours a day, 7 days per week.

Demelza Hospice Care for Children

www.demelza.org.uk

Demelza's Involvement in COAST

COAST (Children's Outreach and Symptom Team) is a new service based within Chestnut Tree House, providing specialist paediatric palliative care for children with complex symptoms and their families across East and West Sussex.

Demelza has seconded a very experienced Children's Palliative Care Nurse into the COAST team as a Clinical Nurse Specialist for 30 hours per week. This role supports the team to develop into a 24/7 service, increase referrals and ensure more families receive the care and support they need.

How we help

Demelza Hospice Care for Children provides specialist palliative, end-of-life and bereavement care for babies, children and young people across East Sussex, Kent and South East London. We support families from birth or diagnosis through to end of life and into bereavement, delivering care that is tailored to each child's and family's individual needs.

Our services are organised into three **Circles of Care**, ensuring all families receive holistic support, with additional specialist services available according to clinical need.

Family Services (Yellow Circle of Care)

All families referred to Demelza have access to our Family Services, providing wraparound emotional, practical and therapeutic support.

Services include:

- Family liaison support – advice, information, signposting and personalised one-to-one support.
- Groups and events – regular opportunities for families to connect, share experiences and make lasting memories.
- Sibling support programme – one to one sessions, group activities and events, and virtual support, plus a residential trip for a targeted age range.
- Transition support – helping young people move into adult services.
- Creative arts therapies – including art, music and dance movement therapy.
- Volunteer transport service – trained volunteers providing transport to hospital appointments, and Demelza activities and events, using our wheelchair-accessible vehicles where needed.
- Bookable facilities – access to sensory rooms, play facilities and other specialist facilities at Demelza sites.

Specialist Short Breaks (Blue Circle of Care)

Families of children with the most complex care needs may be offered specialist short breaks delivered by experienced nurses and healthcare assistants.

Support includes:

- Daytime short breaks at home, in the community or at a Demelza hospice.
- Planned overnight respite stays in one of our hospices.
- Emergency short-break provision, where appropriate.

Families in the Blue Circle of Care also have access to all Family Services.

Specialist Nursing Care (Pink Circle of Care)

Demelza's nurse-led specialist nursing team provides expert care for children with complex symptoms and those approaching end of life.

Support includes:

- Symptom management.
- End-of-life care at home or in one of our hospices.
- Support with advance care planning and coordination with local and tertiary healthcare teams.
- Assisted ventilation withdrawal in partnership with hospital teams.
- Post-death care, including in the family home or the use of dedicated bereavement suites in our hospices.
- Step-down support following hospital discharge, helping families develop confidence in managing complex care needs at home.

Families receiving Specialist Nursing Care can access the full range of services across all three Circles of Care.

Other Demelza services:

Commissioned care packages

Demelza provides individually tailored packages of healthcare and support to meet the assessed needs of children and young people with complex health conditions. These are delivered in the community by our nursing and care teams.

Hospital In-Reach by Demelza

Our specialist nurses work closely with hospital teams to support children and families. Demelza has dedicated in-reach Nurses who have honorary contracts with the local NHS Trusts and undertake weekly visits to the acute hospitals. In East Sussex we attend the Conquest hospital in Hastings for a full day every week. Staff respond flexibly to both planned in-reach days and urgent, unplanned requests.

Key activities of hospital in-reach:

MDT engagement and clinical integration

- Regular attendance at MDTs, ward rounds, staff handovers and grand rounds.
- Ongoing liaison with consultants, CNSs, ward managers, outreach and POSCU teams.
- Contribution to discharge planning and anticipatory care planning.

Direct support to children and families

- Face-to-face emotional and practical support to families during admission.
- Sitting with children to enable parents to rest or leave the ward.
- Support during deterioration, uncertainty and end-of-life situations.
- Practical actions including medication coordination and multi-agency liaison.

Referrals and early identification

- New referrals are consistently made directly by the in-reach team and NHS professionals across neonatal, paediatric and oncology pathways.
- Multiple potential referrals identified early and tracked until appropriate to progress.
- Sensitive, timely engagement with families.

Support to NHS staff

- Staff debriefs and delivery of training sessions and study days (e.g. gastrostomy care, end-of-life education).
- Contribution to policy development, audit and benchmarking, including NICE EoL guidance.
- Direct support during complex events such as rapid discharge home and bereavement.

Impact and strategic value

- Strengthens hospital–community pathways.
- Enables earlier identification and engagement of eligible families.
- Improves experience for children, families and NHS staff.
- Adds capacity, continuity and specialist palliative expertise within acute settings.

Bereavement Support

We continue to support families after the death of a child through:

- Bereavement events and groups.
- Peer support opportunities, including online communities.
- Individual bereavement support where required.

Support During Pregnancy

Demelza can provide support to families during pregnancy when a baby is diagnosed with a life-limiting or life-threatening condition.

Safeguarding

Demelza works closely with partner agencies to safeguard children and young people and may support Place of Safety arrangements where appropriate.

How We Work

We take a coordinated, family-centred approach, working in partnership with hospitals, community teams, GPs, hospices, social care, education services and other professionals to ensure seamless support for children, young people and their families.

We are committed to empowering families, involving them in decision-making and ensuring care is delivered in line with their wishes, values and goals. We have a dedicated engagement team, involving families in shaping our services.

Referrals

Referrals can be made by healthcare professionals, social care professionals, education professionals, family liaison workers, or directly by parents and carers.

Children and young people may be referred if they:

- Are aged 0–25 years (service eligibility criteria apply).
- Have a serious, life-limiting or life-threatening condition.
- Live in East Sussex, Kent or South East London.
- Have consent from a parent or person with parental responsibility.

Referrals can also be accepted during pregnancy.

Bereavement Referrals

Bereavement support referrals can be accepted for families whose child has died from a life-limiting or life-threatening condition and would have met Demelza's eligibility criteria. Referrals may be made up to six months following a child's death.

Hours of Operation

Demelza provides support 24 hours a day, 7 days a week, 52 weeks per year. Demelza has a hospice in Kent and South East London, and a community team in East Sussex, with an accessible base in St Leonards on Sea. Children from East Sussex can access the in-house services, alongside the community offer.

Adult hospices serving the Sussex population

Who we are:

The Sussex Hospice Alliance members are charitable hospices that provide community and inpatient based specialist palliative and EoL care services across seven hospice sites provided by: St Michael's Hospice, St Leonards on Sea, St Wilfrid's Hospice, Eastbourne, St Wilfrid's Hospice, Chichester, St Catherine's Hospice, Crawley, St Peter and St James Hospice, North Chailey, Martlets, Brighton and Hove and St Barnabas House, Worthing, (which are both now part of Sussex Hospice Group along with Chestnut Tree House children's hospice).

The hospices' specialist multi disciplinary teams include Consultants in palliative medicine, specialty doctors, resident doctors, clinical nurse specialists, registered nurses, independent prescribers, physiotherapy and occupational therapy teams, healthcare assistants, wellbeing assistants, social workers, counsellors, spiritual care leads, clinical admin and volunteers.

What we do:

Hospices within the Sussex Hospice Alliance provide a wide range of specialist palliative and EoL care (PEoLC) services, to people who have advanced, progressive and life-limiting illness.

The hospices offer specialist assessment, advice and support to patients and those closest to them, for complex palliative and EoL care needs across all diagnoses whether due to cancer or non-cancer diagnosis.

Specialist multi-disciplinary teams conduct face to face holistic, patient centred assessments and interventions. This includes supporting personalised advance care planning discussions and facilitating rapid actions to avoid unwanted admissions to

the acute hospital setting, working with the primary care and community teams, including the patient's registered GP.

Services are delivered through a range of methods in different settings:

- People's homes, including care settings (a member of hospice community staff visiting people where they live. (sometimes referred to as Hospice @ Home, however it is recognised that the term means different things to different people and SHA are undertaking a review to establish consistent service descriptors)
- outpatient support (where the person lives at home but travels to the hospice for assessment, review and support).
- inpatient care (where the person stays in the hospice for a period of time, to address needs that are too complex that they cannot be met at home or in a care home, or for end of life care.
- remote services such as advice lines and digitally enabled virtual support.
- the community (including activities in community spaces, or hospice spaces open to community and outreach work) .

Holistic, Inclusive Support for the Patients, Families and Carers

The mission for the hospices within the SHA is to empower people with multiple complex needs to manage their physical, social and psychological symptoms so they can live as well as they are able as they approach the end of their lives, to achieve what matters to them, and to die in their preferred place with dignity and with optimal symptom control.

Alongside support for physical symptoms, the hospices offer complex psychosocial assessment and support to patients and their families and or carers, specialist help with rehabilitation or adjustment to deteriorating function and/or specialist EoL care and support.

Hospices provide compassionate well being and supportive services and networking opportunities, (sometimes called Living Well Services) to enable patients and their families to find strategies to manage the social, emotional and practical impacts of their illness, focussing on optimising quality of life managing anxiety and preventing the development of crisis situations.

The specific well being offers vary across places according to resources available and the needs of the local population. Hospices offer pre and post bereavement support to families and carers of all patients who are or have been under their care.

In addition to supporting families of hospice patients, St Michael's Hospice offers open access to all bereaved people in Hastings and St Leonards.

St Catherine's Hospice offers bereavement support for all families that have had care provided by the hospital palliative care team at SASH, even if not known to the hospice service.

St Wilfrid's Hospice, Eastbourne is unique in Sussex for its charitably funded Seahorse Project, a bereavement service specifically for children and young people, delivered through short term bereavement focused counselling support to any bereaved child aged 6 18 across Seaford, Hailsham, Uckfield, Heathfield, Pevensey and Eastbourne.

Workforce and support to other professionals

All hospices within the Alliance provide 24/7 specialist clinical telephone advice and guidance for health and social care professionals, with access to a Consultant in Palliative Medicine.

Hospices within the Alliance coordinate and deliver a programme of commissioned education to health and care staff in Sussex. Hospices also individually offer additional training on request.

How we work:

All hospice services strive to be inclusive and welcoming to patients and those closest to them irrespective of faith, culture, beliefs, background or protected characteristics.

Hospices work collaboratively together across the Alliance, with colleagues in primary and community care, across hospital and other care settings, social care and other VCSE partners to deliver person-centred integrated care. Hospices are partners in implementing Neighbourhood health and Integrated Neighbourhood Teams across Sussex to create compassionate multi-disciplinary teams that achieve reduced admissions to hospital.

Digital enablement and integration is a priority for hospices to enable them to be active partners in the neighbourhood multidisciplinary teams supporting patients more effectively. Some hospices are already able to share electronic patient records with local GPs and community nursing teams and SHA will be looking to ensure this is consistently the case to improve communications and care. Two hospices are piloting Plexus integration to SystmOne prior to roll out across SHA, electronic prescribing is being implemented as part of the community offer. There has also been a recent proof of concept of shared records within SystmOne across hospices in East Sussex for managing calls out of hours.

The SHA works closely with Hospice UK and is currently undertaking work to align service descriptors and currencies for a more consistent understanding of hospice service offerings.

Access

Patients can be referred to their adult hospice by their health professional or clinician, if they are

- registered with a GP in Sussex.
- 18 years and over
- have advanced, progressive and life-limiting illness (across all diagnoses whether due to a cancer or non-cancer diagnosis)
- require support for complex needs (symptom control and psychosocial)

Whilst referrals largely come from hospital, GPs, Primary Care Networks, and community teams, the hospices also work closely and effectively with other providers such as SECAmb, IC24, care home teams and social care. Some patients and families self refer.

Hours of Operation

All the hospices within the Alliance operate inpatient services 24 hours, 7 days a week and professionals are able to access urgent telephone advice and guidance 24/7.

Some hospices are currently only able to offer telephone advice to patients and their families and carers, during office hours, as this is dependent on resources.

St Barnabas House, Worthing and St Wilfrid's, Chichester, covering Coastal West Sussex are part of the team delivering the ECHO hub co ordination service to any patients that have registered (in addition to the hospices' own community caseload). This service hosted by SCFT has not been expanded across Sussex, but NHS Surrey and Sussex and providers are currently exploring options to achieve an equitable service level across the rest of Sussex in future so that all patients can access 24/7 coordination of their PEoLC needs.

Funding

As charitable organisations, the non NHS hospices within SHA receive a grant towards their running costs from NHS Surrey and Sussex, but most of their income comes from community fund raising, retail, lotteries and major donors. Particular projects and services are funded by national lottery or other short term grants which limits the ability for services to be established on a long term sustainable footing.

There is an ongoing national campaign run by Hospice UK regarding the funding crisis facing all charitable hospices.

In Sussex, there is wide historical variation in the funding of hospices which remains to be addressed in order to provide equitable access and reduce health

inequalities. Costs of service delivery also vary due to a number of factors. Current services are fragile and the SHA was created to enable greater resilience and sustainability, working in partnership with NHS Surrey and Sussex. This needs assessment will assist the future planning of system resources to meet local population needs.

Links to published information:

SHA quality and impact reports:

Southern Hospice Group.

St Barnabas Martlets.

Impact reports 2024 Southern Hospice Group

St Catherine's.

Our Impact On Our Patients St Catherine's

St Michael's.

QualityAccounts24 25Web.pdf

St Wilfrid's Eastbourne.

Quality and Impact annual reports.

Publications St Wilfrid's Hospice (Eastbourne)

St Wilfrid's Chichester.

Annual Review St Wilfrid's Hospice

St Peter and St James.

Annual Reports St Peter and St James Hospice

Hospice in the Weald

Service Summary

Who we are:

Our hospice care and support is available completely free of charge for adults and children across Kent and East Sussex. We are here day and night to help patients with an illness where a cure is no longer possible, and for patients who will at some stage die from their illness (you may hear this referred to as "palliative care").

The Adult Inpatient Ward team is made up of Clinical Nurse Specialists, Staff Nurses, Specialty Doctors, Consultants, Hospice Paramedics and Nursing Assistants.

What we do:

We offer a full range of hospice care and support – from inpatient care and hospice outreach at home for adults, to counselling, chaplaincy, bereavement support, cancer care and practical advice for carers. Our compassionate, multidisciplinary team of doctors, nurses, counsellors, therapists and volunteers works together to provide personalised care focused on what matters most to you.

If you have an illness that cannot be cured, our palliative care helps manage pain and symptoms, while also supporting emotional, social and spiritual wellbeing — for you and those close to you. Hospice in the Weald is here throughout terminal and life-limiting illness, not only at the very EoL, so that patients, families and friends feel supported every step of the way.

How we work:

Hospice in the Weald strives to provide care, advice, and support for everyone in our community living with terminal or life-limiting illness, together with their loved ones. We empower people to celebrate life and make the most of the precious time they have for living.

Hospice in the Weald provides care completely free of charge to patients with a terminal illness, and those important to them, in West Kent and northern East Sussex. This means we are there 24 hours a day to help, support and care for patients with an illness where a cure is no longer possible, and for patients who will at some stage die from their illness, whenever that may be (you may hear this referred to as “palliative care”).

People are often confused by what a Hospice actually does. We’re there 24/7 for anyone who needs us, caring for our patients, as well as those important to them, providing physical, medical and emotional support through our services. Anyone can also access our Help Hub, full of information, advice and guidance, including direct contact with our team.

It’s not just at the EoL that Hospice in the Weald can help. We want to ensure that anyone affected by a terminal illness, not just patients, but also those important to them, can access the support they need when they need it. Whether this means a family member or friend, our Services will provide support to anyone important to a patient. We provide care which is completely tailored to each person as an individual, to help our patients make decisions that are right for them and their loved ones.

Inpatient services:

Notice: Currently we are currently consolidating our adult inpatient services at our site in Pembury. Outpatient appointments, counselling sessions, and living well services all continue to operate from Cottage Hospice as usual.

The In-Patient Ward at Pembury has 15 individual rooms for symptom control and EoL care. We offer personalised care to suit each patient's physical, emotional and spiritual needs, as well as caring for and supporting those important to the patient. This might be family members, or friends.

Without seeing it for yourself, it can be difficult to imagine what our Inpatient Ward is like. It's often described by patients and their loved ones as a calm, tranquil and peaceful place to be – almost a haven. Some rooms face out onto beautiful apple orchards, whilst others open into our stunning Hospice gardens, and all have their own en suite bathroom. We will always be flexible and accommodating for each family, whatever their needs.

There are no fixed/limited visiting hours on the Ward, family and friends can visit at any time of the day or night. Pets can also visit with prior arrangement.

Hospice Outreach Service

Support and advice in your own home when you need it most.

Living with a life-limiting or terminal illness can feel overwhelming — not just for the person diagnosed, but for their loved ones and carers too. That's where our Hospice Outreach Service comes in. We bring our expertise out into the community. Whether someone is living at home, in a care home, or staying with family, our Outreach team is there to offer support, guidance, and reassurance when it's needed most.

Your GP remains your healthcare professional lead, we work alongside them to help you manage symptoms, make informed choices, and plan ahead with confidence based on your needs. Although we are available for support and advice we don't operate emergency services.

Cottage Hospice

Notice: At this time, we are currently consolidating our in patient services at our site in Pembury. Outpatient appointments, counselling sessions, and living well services all continue to operate from Cottage Hospice as usual.

Cottage Hospice is a beautiful in-patient care setting designed to provide the best care possible to patients and their loved ones. Nestled in Five Ashes, with a backdrop of the rolling East Sussex landscape, Cottage Hospice offers 24/7 EoL

care to patients with noncomplex needs as well as providing support for family and loved ones.

Often described as either a hotel or home from home, we aim to make stays as comfortable as possible, encouraging patients and their families to bring whatever they want and need to make their rooms feel the way they want. Whether that means bringing, photos, plants, or pets there aren't many restrictions (as long as it's safe and fits through the doors).

Some patients and their families may want to be more involved in the care, and many will have been caring for their loved ones for some time already. We can help empower people to deliver care, but it isn't a requirement to become a family caregiver. Nurses will always be on hand to help provide care and support to those staying with us, day, and night.

Access

You don't have to wait for a referral from a health or social care professional to access our care. If you, or someone you love needs our support, fill out one of our short forms to get in touch.

An admission to the Ward can be arranged by your Hospice Outreach Service Nurse, or by contacting us

Hours of Operation

Contact a member of our Hospice team for support at any time of the day or night. Telephone service will be answered by a Hospice Nurse or Hospice Paramedic to support and advise you, 24/7.

Links to published information:

Hospice Care Services & Support | Hospice in the Weald

Impact Report 2025 Final Draft.pdf

The Sussex Beacon

Who we are

The Sussex Beacon

The Sussex Beacon is a Brighton-based charity specialising in supporting people living with HIV in Sussex and beyond to become the first dedicated LGBTQ+ hospice with a specialism in HIV in the UK. With over 32 years of experience, we deliver community-based support and clinical services, championing inclusive, accessible healthcare for a diverse cohort including LGBTQ+ people, migrants, refugees, and

women. Our staff and volunteers reflect the communities we serve, ensuring culturally competent, trauma informed care.

What we do

We provide a range of services, including:

- Specialist inpatient care for complex, chronic, and palliative needs
- Community outreach and psycho social support
- Peer mentoring and support groups
- Day services for health, wellbeing, and social connection
- Women and families' support, including formula milk provision
- Advocacy and navigation for welfare, housing, mental health, and immigration issues.

How we work

Our integrated model combines clinical expertise, multidisciplinary teamwork, and strong partnerships with NHS, local authorities, and third sector organisations. We operate a hub and spoke approach, with central coordination and flexible community based support. Our trauma informed, user led ethos empowers patients to self manage, build resilience, and access timely interventions, reducing crisis admissions and improving quality of life.

In Patient Ward

The In-Patient Unit (IPU) provided specialist care for people living with HIV, focusing on complex medical, mental health, and palliative needs. In 2024–2025, the IPU admitted 112 patients over 1,842 bed nights, with most patients aged 50+ and presenting with multiple comorbidities. The unit closed in January 2025 and due to reopen 6 beds in March 2027. Following an NHS review recognising its essential role, and some services were reinstated 2026. The IPU excelled in holistic care, managing acute episodes, long term conditions, and facilitating step-down care from hospitals.

Hospice Outreach Service

Our outreach service extends hospice care into the community, supporting patients who cannot access inpatient care. Outreach workers, including specialist aging and frailty staff, provide home visits, casework, and group support. The service addresses barriers such as stigma, complex referral pathways, and social isolation, especially for women, migrants, and those in rural areas. Peer led groups and mentoring are central to our outreach, fostering connection and resilience.

While the Sussex Beacon's main hub is in Brighton, our outreach and partnership work extends to areas like Five Ashes and the wider Weald. We collaborate with local clinics and community organisations to ensure patients in these regions have access to specialist support, peer groups, and tailored interventions, addressing the unique challenges faced by rural and minoritised communities.

Access to Care

Access is central to our mission. We operate multiple referral pathways, including self referral, professional referral, and direct engagement through clinics and community hubs. Our services are designed to overcome barriers related to stigma, language, cultural differences, and complex social needs. We prioritise equity, ensuring marginalised groups women, LGBTQ+, migrants, refugees can access timely, appropriate care. Our data shows a significant increase in self-referrals and engagement from diverse communities.

Hours of Operation

Our core services operate Monday to Friday, with flexible hours to accommodate patient needs. Outreach and day services are scheduled to maximise accessibility, including evening and weekend sessions for peer groups and community events. Emergency and crisis support is coordinated with NHS partners to ensure continuity of care outside standard hours.

The Sussex Beacon: Supporting People Living With HIV

Hospitals

Hospitals provide PEoLC with specialist teams supporting other hospital doctors, nurses and other staff.

University Hospitals Sussex NHS Foundation Trust

Service Summary

EoL care is one of the core services provided by University Hospital Sussex NHS Foundation Trust (UHSx). When a patient is recognised to be in the last days of life, and further treatment will not change the outcome or is not in line with their wishes, our ward teams provide personalised EoL care using our Comfort Care measures.

Who we are:

- The hospital palliative care team is a specialist, multi professional service made up of doctors, nurses, therapists, and support staff working across our four acute hospital sites.

- We provide a liaison service to support ward teams in meeting the holistic needs of patients with life-limiting, progressive illnesses.

What we do:

- Support ward teams in managing pain and other distressing symptoms for adults with life-limiting, progressive illnesses.
- Promote compassionate palliative care at all stages, including the final hours and days of life.
- Support the physical, psychological, social, and spiritual needs of patients, and provide emotional support to families and carers, including facilitating conversations about future care planning.
- Work with patients and those important to them to develop personalised care plans that prioritise comfort, dignity, and, where possible, respects their EoL preferences, including the option of discharge home for EoL care.
- Support ward teams to deliver compassionate, individualised EoL care using our **Comfort Care** measures.
- Review patients who may need consideration of transfer to a specialist hospice bed.
- Provide education and training to staff to support high quality palliative and EoL care.
- Represent our Trust externally to guide and enhance palliative and EoL care across our communities.

The UHSx Specialist Palliative Care Team provides support for:

- multiple, complex or refractory physical symptoms
- complex EoL care
- difficult social, psychological and spiritual issues
- complex family and carer needs requiring specialist support
- discharge planning when the situation is complex or to facilitate transfer to hospice for appropriate patients
- support and advice to ward teams in all aspects of caring for patients at the EoL
- support with the rapid discharge of patients who have been identified as being in the last days to short weeks of life whose preferred place of care is not hospital.

The SPCT supports discharge from hospital:

- The SPCT works closely with the hospital discharge co ordinators and ward teams to support patients to achieve their preferred place of care and death
- On discharge patients will be referred to appropriate community teams including community nursing services
- Referral to hospices for patients with specialist palliative care needs

How we work:

We collaborate closely with hospital teams and community services—including local hospices and community nursing teams— supporting with referrals and sharing clinical information where appropriate.

The SPCT has daily MS Teams meetings with the hospices to discuss and triage referrals for specialist palliative care on hospice in patient unit.

UHSx are proud to be working in partnership with the Anne Robson Trust charity and funded by Friends of Brighton & Hove Hospitals to create a volunteer service focused on supporting people nearing the end of their life.

A Friend in Need' is volunteer based programme aimed at providing compassionate companionship and support to patients approaching the end of their life. It is currently only available at the Royal Sussex County Hospital in Brighton, but we hope to extend this across all our sites in the near future.

UHSx has recently implemented a digital EoL care plan which ensures that patients nearing the EoL are assessed, their symptoms reviewed, and appropriate care provided in a timely manner, with support from the SPCT.

UHSx PEoLC Strategy 2021 27:

Patient	Improve SPCT's response to those recognised as dying and symptomatic, thus improving Patient/Carer experience.
People	Improve parent teams' confidence in managing care of the dying and associated symptoms, thus improving staff commitment to excellent care
Quality	Improve UHSx's ability to recognise deterioration from life-limiting illness and acknowledge unavoidable death and how this impacts on mortality rates.
Sustainability	Improve SPCT productivity, in triage and allocation of workforce.
Systems & Partnerships	Earlier recognition of deterioration from life-limiting illness, with the potential to promote earlier EoLC transfer of care to community setting.

Research & Innovation	Create an innovative and evidence-based approach to improve care of the dying in an acute setting that is replicable in other organisations.

Access

Any hospital patient with unmet palliative or EoL care needs can be referred by their medical or nursing team. Occasionally, patients or carers may refer directly, and we then coordinate with the relevant ward.

PEoLC is provided on the basis of patient need irrespective of diagnosis.

Referrals to the specialist palliative care team (SPCT) are accepted for patients who:

- Have active, progressive, advanced disease of any diagnosis with a probable prognosis of less than 12 months.
- Have a complex level of need exceeding the skills and/or capacity of the current caring team and are over 18 years of age
- Patients that are within the last days of life

Hours of Operation

- We offer a Clinical Nurse Specialist service for patients in hospital, available 7 days a week from 9am to 5pm and supported by 24 hour medical advice from palliative medicine consultants.

Links to published information:

Palliative care University Hospitals Sussex NHS Foundation Trust

EoL Palliative Care Research Group University Hospitals Sussex NHS Foundation Trust

Hospital Palliative Care Team University Hospitals Sussex NHS Foundation Trust

UHSussex quality account reports 2023 24 University Hospitals Sussex NHS Foundation Trust

Trust Board in Public 01 August 2024 PAPERS v2.pdf Board papers contain Palliative and EoLC Annual Report 2023/24

NHS+Palliative+Care+Offer+to+Brighton+and+Hove+residents+HOSC+23+April+2025final.pdf

East Sussex Healthcare NHS Trust

Service Summary

East Sussex Healthcare NHS Trust is an integrated provider of acute and community care. Our extensive health services are provided by over 8,700 dedicated members of staff working from two acute hospitals in Hastings and Eastbourne, three community hospitals in Bexhill, Rye and Uckfield, over 100 community sites across East Sussex, and in people's own homes.

We take the provision of care to patients and those closest to them at EoL very seriously. In the community, we deliver services that focus on people with long term conditions living well outside hospital, through our integrated locality teams working with district and community nursing teams. Community members of staff also provide care to patients in their homes and from a number of clinics, health centres and GP surgeries.

For some patients dying in hospital is their choice for others they would rather explore other options. We work very closely with community colleagues to ensure that wherever possible the co ordination of care enables the individual to die in their place of choice.

We aim to support both the patient and their carers with respect and dignity at all times, including clear communication, excellent symptom control and provision of the best environment we can deliver.

Although every member of the multi disciplinary team is responsible for the provision of excellent care, the hospital supportive and palliative care team will support the ward teams and will endeavour to review as many patients as possible on the Last Days of Life Personalised Care Plan.

We understand that this is a difficult time for everyone and can appear to be very confusing.

We would encourage people to ask ward staff for support and information if they feel it is lacking, as we know staff will do their best to provide the correct level of care and will ask for support from the palliative care team if the situation is beyond their skill or experience.

The Supportive and Palliative Care Team (SPCT)

Who we are:

The Supportive and Palliative Care Team (SPCT) at East Sussex Healthcare NHS Trust is a hospital based team working within Conquest Hospital in Hastings and Eastbourne District General Hospital. The team provides a service to adults with

palliative care needs within both acute hospitals and also in the outpatient clinic setting.

The Supportive and Palliative Care Team (SPCT) comprises palliative care consultants and clinical nurse specialists, all with experience in working with patients with life limited illnesses.

What we do:

The team provides an advisory and advocacy service to patients and staff including:

- Evidence based, individualised symptom control
- EoL care
- Complex psychosocial care
- Liaison with other specialist palliative care services for people with advanced disease and those close to them
- EoL care education programmes and support
- Monitoring practice and supporting the organisation to provide best evidence based care
- Developing and innovating person-centred care

How we work:

The team does not take over the overall management of patients who are referred but works alongside the medical and surgical teams in the hospitals caring for that patient and offering specialist advice and assessment.

We are committed to delivering a high quality service that promotes quality of life, informed patient choice and treats patients and their carers with respect and dignity at all times.

We work closely with the providers of community specialist palliative care which is delivered via our local hospices and have established joint medical roles working across St Michael's Hospice, St Wilfrid's Hospice and ESHT to enable our teams to work flexibly around patients.

Access

If you are concerned about a patient in the hospital and feel palliative care input would be beneficial, please discuss with the ward looking after the patient and ask them to make a referral to the team.

The team will also accept referrals from patients and family members via telephone (Eastbourne Hospital 0300 131 5899 / Conquest 0300131 5271) or email (esht.palliativecare@nhs.net).

Hours of Operation

Monday to Friday – 8.00am to 4.00pm

Community services supporting Palliative and EoL Needs

How do our teams integrate and work together?

- Daily Capacity Call with PEoLC patients reviewed and staffing resource considered for supporting urgent needs across UCR, DN and Hospice teams.
- Shared EPR on SystmOne with cross service notes visible within tabbed journal.
- Direct phone call referrals from Hospice / DN, the Daily Capacity Call, as well as HSCC referrals.
- PEoLC MDT meetings at each GP surgery with representatives from DN team lead assigned.
- Prescribing capabilities of a broad range of medications across the community service teams.
- Locality based bi monthly Palliative and EoL Collaborative meetings with team leads from across UCR, Hospice and DN, to discuss patient requirements, service needs review and improvement opportunities.
- SPCT link with DN for those being supported home from hospital on syringe drivers, often with UCR social support as part of their holistic management.
- SPCT link with UCR clinical teams for prescribing training and ongoing mentorship for those prescribing PEoLC medications.

Urgent Community Response (UCR) and Integrated Night Service (INS) Team Symptom Control and Clinical Assessment

Who we are:

The UCR and INS teams provide patients with symptom control and clinical assessment for acute medical deterioration in the place they call home, with a 2 hour response or same day referral to treatment (RTT).

The team includes Advanced Practitioners, Clinical lead / senior and junior nurse and paramedics, clinical support workers, associate practitioners, trainee/registered nurse associates led by Head of Nursing, Matron and Service Manager, Team Managers and broad administrative coordinators.

What we do:

If patients are experiencing a deterioration in their health, our clinical care team can support with symptom control administration, acute deterioration assessment and treatment management including prescribing.

How we work:

A member of the team will complete a clinical assessment and establish a treatment management plan. This may be a one off intervention, completing the episode of care. Where further treatment / assessment or monitoring is required beyond 24hrs, patients are discussed and transferred to the Virtual Ward (VW) for continued care or stepped up to acute if agreed and their acuity and complexity is beyond VW threshold.

Access

Referrals can be made via Hospice, Health and Social Care Connect, NHS 111 / 999 or through escalation from ESHT community teams (DN primarily).

UCR have a self referral pathway for patient experiencing difficulties with their catheter.

Hours of Operation

Service available 24 hours a day, 365 days a year.

Urgent Community Response (UCR) Social and AHP Support

Who we are:

The UCR social and therapy team provides patients with short term support for up to five days either following a hospital discharge or to prevent hospital admission.

The Therapy team includes Occupational Therapists, Physiotherapists and Advanced Practitioner, Dietitian and Speech and Language Therapists alongside rehabilitation support workers, OT apprentices and AHP associate practitioners. Social support is provided through senior support workers and an extensive team of support workers, overseen by operational and administrative leads.

What we do:

Therapy – We support those requiring urgent (2 hour response / same day) review following functional decline (incl. swallow/nutrition concerns), fall without serious injury, or urgent equipment provision for those in crisis. Short term management within the service up to 5 days with close collaboration with onward care teams

such as joint community rehabilitation/reablement, community AHP services or adult social care therapists.

Social We provide a short term package of care to maintain patients at home for up to five days. Through working in close collaboration with external agencies, Continuing Health and Adult Social Care during a patients' time with us, we can determine any ongoing care needs and support seamless transition when necessary.

How we work:

A member of our team will work with you to agree what support you need at home. They will write a care plan, which will be delivered by the member of our team with the most relevant skills and experience. While receiving care from the UCR team your care plan will be reviewed and adjusted as needed. Many of the staff have cross competencies, with a number of senior support workers able to prescribe basic functional needs equipment, alongside support workers who facilitate a reablement approach to care delivery and can lead exercise programmes with patients.

Access

Referrals are received through Health and Social Care Connect or internal through ESHT acute and community teams.

Hours of Operation

Service available 08:00 – 22:00, 7 days a week, 365 days a year.

Virtual Wards

Who we are

The Virtual ward (or Hospital at Home) supports people at the place they call home, including in care homes, allowing appropriate patients who would otherwise be in hospital to receive the level of care, monitoring and treatment they need using straightforward medical and technological devices. Virtual wards help prevent avoidable admissions into hospital and allow for an earlier supported discharge back into patient's own homes.

The team shares a core delivery workforce with UCR, working interchangeably across the service teams, with workforce as described. In addition to this core delivery team, we have a Virtual Ward Hub team that consists of Lead Co ordinator, remote monitoring clinicians (nurses) and CSWs who support caseload coordination and home monitoring (Doccla), and administrative support. Pivotal to delivery are also Pharmacists and Pharmacy Technicians, Virtual Ward GPs lead the General Ward, and Specialist Clinicians and Consultants in Respiratory, Heart

Failure and Frailty working very closely as part of their integrated community services.

What we do

Respiratory VW focuses on patients with both acute exacerbations of chronic respiratory conditions such as COPD and asthma, and those with new respiratory infections. Patients receive remote monitoring of vital signs, medication management, oxygen weaning and respiratory specialist nursing and physiotherapy support.

Heart Failure VW Designed for patients with heart failure experiencing acute decompensation. The service provides intensive monitoring of fluid balance, medication optimisation, and holistic support particularly if moving into EoL phase.

Frailty VW pathway caters to older adults with frailty who are at risk of hospital admission due to acute illness or deterioration, as well as an opportunity to reduce hospital length of stay. It offers comprehensive geriatric assessment, medication review, in addition to coordinated care and therapies to optimise ongoing management at home.

General VW supports a broad spectrum of patient's and is diagnosis agnostic, providing medication delivery, monitoring, holistic support and cohesive care plan oversight.

Personalised care plans identify what matters to the person to ensure that the support they receive is designed around their desired outcomes. Treatment and management may involve face to face care, remote vital sign monitoring / questionnaires or a blend of both. Patients are holistically supported with access to social and therapy team support to maintain/improve or support plan functional changes due the impact of the acute illness.

A daily General board round is led by the VW GP and supported by the MDT, with speciality board rounds also occurring separately across the week. Acuity and complexity of the caseload is measured using the Guys and St Thomas Tool (GSTT) – Table 1. For an example of the patient needs we support please see below.

Tier 1	Tier 2	Tier 3	Tier 4	Tier 5
Patient does not require any medical or therapy interventions but remains under at home for bridging of care and ongoing social interventions.	Tier 1 criteria exceeded and Urgent care at home. However, patient needs are met through routine once daily typically carried out by band 5 nurse. Low level therapy interventions.	Tier 2 criteria exceeded and Urgent care at home. Patient requires more than a routine visit, clinically stable but at risk of deterioration. This would be typically carried out by senior band 5 and band 6 clinicians, with up to twice daily medical/nursing visits. Therapy input where deterioration is a risk factor.	Tier 3 criteria exceeded and Urgent care at home, clinically unstable with higher risk of deterioration. These visits would typically be carried out by senior Band 6, Band 7 and doctors, with up to 3 visits daily or a joint visit requiring Multidisciplinary Team input	Tier 4 criteria exceeded and Urgent care at home requiring external expertise and staffing level. Patient with an advance care plan/ceiling of care to be provided in place of residence. These visits would typically be carried out by band 7 clinicians and doctors.

Access

Direct referrals can be made for patients that have had a healthcare professional assessment with clear management and escalation plan.

For the General and Frailty VW call the Virtual Ward Hub to complete an SBAR handover and/or discuss a potential referral with a senior clinician.

Virtual Wards Hub
Ext: 734455
Tel: 0300 131 4455

Respiratory VW contact the team directly as below:

- We are available from 8am 16:00pm Monday to Friday. 07974842068.
- Should you require an admission out of our hours please contact the Virtual Ward Hub.

Heart Failure VW contact the team directly: EHS – 07717 138690 / H&R – 07855 964894

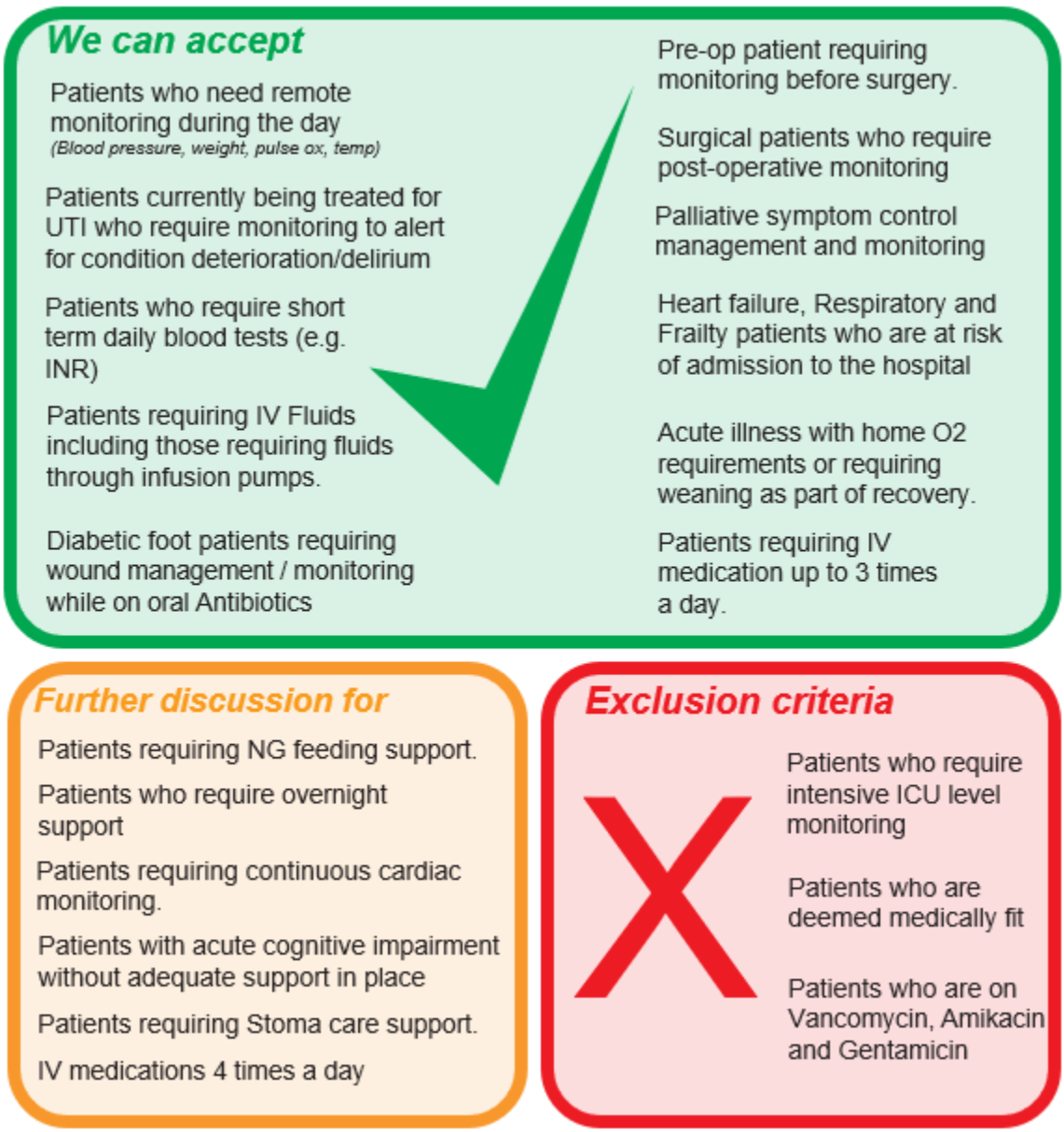
Patients who have not had an initial healthcare professional assessment but are identified as being at risk of admission can be referred via HSCC for an initial UCR Clinical assessment (2 hr / same day) where they can determine suitability for onward management under the Virtual Ward service.

Hours of Operation

Virtual Ward Hub operates 08:00 – 18:00, 7 days a week with the phoneline covered 18:00 – 22:00 by core delivery team.

Core delivery service available 08:00 – 22:00, 7 days a week, with urgent clinical support from the INS team overnight on an ad hoc basis.

Specialty support is available 08:00 – 16:00 Monday – Friday with Core VW service covering outside of these hours.



Primary Care Network Community Teams

Who we are

The teams are made up of a variety of roles including senior staff nurses, district nurses, clinical facilitators, nurse associates and associate practitioners, health care assistants and admin staff.

What we do

The teams provide a wide range of nursing care and support in the home and clinical setting. The team provide ongoing support for patients with short term or complex health needs, long term conditions or palliative care needs, as well as nursing care interventions to individuals assessed as being housebound.

Access

GP referral via PEoLC MDT

Hospice

Hours of Operation

08:00 – 16:00 with skeleton cover 16:00 – 20:00 at each locality.

7 days, 365 days a year.

Links to published information:

Information about us – East Sussex Healthcare NHS Trust

Hospitals and hospices join forces to enhance local palliative care services – East Sussex Healthcare NHS Trust

EoL Care – East Sussex Healthcare NHS Trust

Urgent community response – East Sussex Healthcare NHS Trust

Quality Account 2024 25.pdf Contains section on NACEL trust results from 2024 audit.

https://www.esht.nhs.uk/2023/03/02/supporting each other at hailsham health centre/

Surrey and Sussex Healthcare NHS Trust (SASH)

Service Summary for PEoLC Needs Assessment October 2025.

Who we are:

The specialist palliative care team at SAH provides support for adult patients with progressive, non-curative illnesses.

We are a multi professional team, comprising specialist nurses and doctors.

What we do:

The team provides holistic assessment, advice and support to inpatients with illnesses that are not curable.

Our aim is to maximise quality of life by addressing the physical, psychological, spiritual and social needs of patients and their relatives or carers.

The main activities of the hospital palliative care team are:

- Pain control
- Symptom control
- Psychological, social and spiritual support for patients
- Support for families and carers
- Liaison with community and hospice based palliative care teams
- Liaison with other specialist teams both within and external to SASH
- Advance care planning
- EoL care
- Education and training
- Research
- Strategic input into delivery of palliative and EoL care at SASH.

How we work:

We see patients admitted to the wards and to the Emergency Department. Patients are generally seen on the wards, although they can be seen in other settings within the hospital.

The team is made up of specialist palliative care doctors, clinical nurse specialists and administrative staff. We act as an advisory service working alongside your medical team. You remain under the care of your own ward-based consultant for your treatment, and we provide additional help, advice and support when needed. We meet regularly with other teams, including discharge co coordinators and spiritual care, as relevant to each individual patient.

A booklet ‘Information for relatives and carers when someone is dying.’ is available. This explains the changes that happens to an individual when they are dying and how you might best support them.

We regularly undertake surveys to ensure that we are providing a good service for our patients. You and your family members may be asked to take part in one of these surveys, but your care will not be affected if you choose not to take part.

We also take part in national audits.

Access

We take electronic referrals from any healthcare professional within SASH and telephone or email referrals from external healthcare professionals, patients and relatives via the contact details provided below. However, we do need the agreement of the patient and the treating medical team to become involved in care. We will endeavour to contact the referrer by telephone on the same day to gather further information, give urgent advice if needed, signpost to other services (if relevant) and plan face to face review, usually within 24 72 hours.

The team does not make home visits. These are undertaken by specialist palliative care teams in the community. We work with SASH inpatients only.

Hours of Operation

The hospital palliative care team work 7 days a week 9am 5pm.

However, there is always specialist palliative care advice available for healthcare professionals 24 hours a day. Please contact the ward team in the first instance if you feel specialist palliative care team advice is needed for inpatients outside of normal working hours.

If you are a patient or relative at home and need out of hours palliative care advice, please contact your community palliative care team, out of hours GP and/or your district nurse in the first instance.

Frailty Virtual Ward overview

Surrey and Sussex Healthcare have developed virtual wards for people experiencing a deterioration in their respiratory, frailty or those with a general medical acute illness. Virtual wards will provide additional capacity to our existing hospital beds enabling more patients to receive the care they need. By being in their own home, people are also supported to be as independent as possible.

Personalised care plans identify what matters to the person to ensure that the support they receive is designed and coordinated around their desired outcomes. Support may involve face to face care from multi-disciplinary teams based in the community too when needed.

The frailty virtual ward is a 'hospital at home' service with the acute hospital frailty team. It delivers the same level of treatment and care you need in hospital but can safely be supported at home. Stay on the ward is up to 14 days and may include virtual technology to aid monitoring of basic observations such as temperature, blood pressure and heart rate.

2024/25 Quality account breakthrough objective: Deliver integrated frailty models of care with our community. We have worked with partners on the development of our frailty model of care and the implementation of the SDEC unit. We have also reviewed the work of the virtual ward to support admission avoidance pathways in addition to early supported discharge, held workshops with system partners to review our collective approach to EoL care, and we have trialled new models of care for our community services in Surrey. We have also shared our best practice models with system and regional partners to share learning and support our continuous improvement journey. **Links to published information:**

Palliative care: Surrey and Sussex Healthcare NHS Trust

https://www.surreyandsussex.nhs.uk/our services/cancer services/palliative care

https://www.surreyandsussex.nhs.uk/latest news/introducing virtual wards surrey and sussex healthcare nhs trust

https://www.surreyandsussex.nhs.uk/our services/medicine emergency/medicine elderly

https://www.surreyandsussex.nhs.uk/application/files/6917/5404/4774/2.2__Quality_Account_2024 25.pdf

Sussex Community NHS Foundation Trust (SCFT)

Community Services, Midhurst MacMillan, ECHO EoL Care Hub

Service Summary for PEoLC Needs Assessment October 2025

Who we are

Sussex Community NHS Foundation Trust (SCFT) provides palliative and EoL care in people’s own homes, for those who are approaching EoL and are likely to die within the next 12 months. SCFT strives to ensure the last few months, weeks, or days of a person's life are as dignified and comfortable as possible.

How we work

SCFT provides palliative care in Sussex in collaboration with partner agencies including general practice, hospices, UHSx, SASH, Macmillan, South East Coast Ambulance Service (SECAmb), Continuing Healthcare and Adult Social Care to

enable patients to return home from hospital as quickly as possible and to avoid unwanted admissions to hospital where possible.

Palliative patients in Sussex who are referred to SCFT are supported by a 24/7 service including community nurses, homeless health inclusion team, Urgent Community Response, overnight nursing, Virtual wards, SCFT specialist services, Enhanced Health in Care Homes matrons (if the patient lives in a care home) and our intermediate care units.

These teams work collaboratively to ensure patients receive individualised and coordinated care, in their preferred place of care wherever possible.

All adult community nursing teams in SCFT have a weekly meeting with their local hospice to discuss palliative patients on their caseloads. This allows EoL care to be provided by the most appropriate team and ensures that these organisations are able to mutually support one another. This ensures that palliative patients always receive an excellent service tailored to their needs.

SCFT community teams also attend Gold Standard Framework (GSF) meetings led by Primary Care to discuss and plan for patients approaching EoL.

What we do

Patients receiving EoL care from SCFT have an individualised EoL care plan, ensuring advance planning is in place and the patient wishes and preferences are clearly documented. This holistic assessment document supports teams to identify the needs of a person at the end of their life and respond to these needs appropriately.

SCFT work alongside colleagues in primary care to ensure that patients at the end of their life have a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) plan detailing what matters to them. This plan contains important information about preferred place of care as well as any preferences regarding admission to hospital and resuscitation. Staff at SCFT receive training in both understanding of the ReSPECT process and how to respond appropriately to a patient with a ReSPECT plan in an emergency. SCFT have a dedicated ReSPECT Lead who delivers level 2 ReSPECT training, which is mandatory for all band 6 and above clinicians including all community nursing teams.

SCFT has a dedicated Nurse Consultant in Palliative & EoL Care (PEoLC) who sets the local agenda for PEoLC across the SCFT localities, aligned to the national ambitions document. They ensure high quality care is delivered working in partnership with other organisations and service users.

The SCFT EoL training facilitator provides palliative care training to nursing staff in nursing homes in Sussex.

Community Services Supporting Palliative and EoL Needs

Urgent Community Response (UCR) and Virtual Wards

Urgent Community Response (UCR) teams provide urgent care to people in their homes which helps to avoid hospital admissions and enable people to live independently for longer. Through these teams, older people and adults with complex health needs who urgently need care, can get fast access to a range of health and care professionals within two hours. This includes access to physiotherapy and occupational therapy, medication prescribing and reviews, and help with staying well fed and hydrated.

Patients who are referred into UCR may receive further clinical support in their homes on a General Virtual Ward to prevent and monitor deterioration, with General Practitioner medical oversight.

Who we are

UCR teams are made of GPs, Nurses, Paramedics, Pharmacists, Occupational Therapists, Physiotherapists and Health and Therapy Assistants who work to help reduce avoidable hospital admissions.

What we do

UCR supports patients to remain in their home (usual place of residence) to avoid attendance and/or admission to an acute hospital and/or Intermediate Care Unit, in line with the national UCR guidance.

UCR provides a two-hour crisis response delivered by a multi skilled team of professionals. Support is provided at home or usual residence for people who are concerned their health or mobility is declining and are therefore at risk of admission to hospital. The service also provides a two-day response for patients who require support to regain their skills, confidence, and independence to remain safely in their home or usual place of residence, following an illness.

Patients who require higher levels of care are closely monitored on a virtual ward, receiving appropriate medical intervention at home. Technology is also used to support, by enabling remote monitoring of patients vital signs and allowing virtual consultations between the team (medical, nursing and therapy) and the patient whilst at the place they call home.

Patients on the virtual ward are reviewed daily by a clinical team and the ‘ward round’ may involve a home visit or take place through video technology. SFCFT

contracted GP's will have medical oversight of the patients on the caseload and respond to escalations as necessary.

Access

The UCR Service accepts referrals from: patients and carers, general practitioners, paramedics, NHS 111 services, health and social care professionals, residential and nursing homes, hospital (to minimise prolonged stay/s), voluntary services, Unscheduled Care Navigation hubs (UCNH), SECAmb web portal.

To access our service, patients must meet the following criteria:

- be over the age of 18
- have consented to UCR service provision
- be able to manage safely at home or their usual place of residence with time limited contact
- be safe at home in between visits and overnight
- anticipate treatment required is short term.

Hours of Operation

Urgent Community Response runs 8am to 8pm, 7 days a week, 365 days a year.

Primary Care Network Community Nursing Teams, Brighton and Hove and East Sussex

Who we are

We are district nurses, community nurses, healthcare assistants, nursing associates and administrators who work in local teams across East Sussex.

What we do

We actively promote health and wellbeing in the community, and where possible prevent admission to hospital for patients in their own homes.

Access

To access our community service you must be housebound, which means you are unable to leave your home, or live in a Care Home. You must be an adult aged over 18 years and be registered with a Brighton and Hove GP or a GP in the High Weald, Lewes and the Havens area.

If you meet the above criteria, you can ask your GP or other health care professional to refer you.

We are not an urgent response service and do not respond to urgent referrals.

Hours of operation

All Brighton and Hove Nursing Teams work from 8:00am to 8:00pm and High Weald Lewes and Havens Nursing Teams work from 8:00am to 10:00pm.

Primary Care Network Community Teams, West Sussex

Who we are

We are a team of healthcare professionals in West Sussex who work closely as part of a multi-disciplinary team, which is made up of nurses, Care Home Matrons, health care support workers, physiotherapists, occupational therapists, social workers, mental health practitioners, psychological therapists and organisations which provide voluntary services.

What we do

The Primary Care Network Community team has three functions. It provides community nursing, Proactive Care and promotes Enhanced Health in Care Homes. If you are housebound or in a Care Home and unable to get to your GP practice or any other healthcare setting, our community teams will visit you at home and provide a personalised assessment of your health needs with an agreed plan of care to support you. We have a proactive approach which aims to help you stay as healthy as possible and to live independently in the community for as long as possible. If you have a long-term condition (chronic illness) our Proactive Care team will help you to plan for the future, enabling you to stay as well and independent as possible for as long as possible. If you are a resident in a Care Home setting our Care Home Matron will work with you and the Care Home to ensure you can access the same services that would be available to you if you still lived in your own home.

We offer face to face visits at home, and telephone appointments.

Access

To access our community service you must be housebound, which means you are unable to leave your home, or, in a Care Home. You must be an adult aged over 18 years and be registered with a West Sussex GP.

If you meet the above criteria, you can ask your GP or other health care professional to refer you via OneCall into our community service. For proactive care the referral process is the same. Once you are under our services, you can liaise directly with the teams via one call.

Hours of Operation

Our service runs 7 days a week, from 8:00am to 6:00pm. However, you can contact OneCall 24 hours a day and they will direct you to the most appropriate services depending on your needs.

Midhurst MacMillan Service

The Midhurst MacMillan Service is a community-based team who offer specialist palliative care support to patients and families affected by complex life-limiting illness.

We provide specialist palliative care support to patients and families affected by complex life-limiting illness.

Specialist palliative care services are required for people living with more complex and/or long-term conditions which are life-limiting or life-threatening. The needs of this group cannot be met by their core team alone. Our team provides specialist advice and support to the wider care team providing direct palliative care to the patient.

Who we are

Our Midhurst Macmillan service team includes:

- service managers
- doctors
- clinical nurse specialists
- clinical support team
- counsellors
- occupational therapists
- physiotherapists
- bereavement support team and volunteers

What we do

- Provide patients with holistic care, addressing their physical, spiritual, social and psychological needs.
- Support carers in their important role.
- Provide patients with nursing care to support them to stay at home in comfort, with good symptom control.
- Where possible, offer appropriate clinical interventions at home.
- Provide access to consultant and doctor support for patients with complex needs.

- Link in effectively with NHS, social care and other services involved in patient care and to complement and support these services in a patient centred approach.
- Provide patients and their carers with strategies to manage their condition where possible.
- Prevent unnecessary and inappropriate admissions and expedite discharge from hospital.
- Work as a multi-disciplinary team in partnership with service users, families and carers to promote and facilitate optimal health, independence and disease/condition management for individuals.

Access

We accept patients 18 years and over who are registered with a GP within our catchment area. We accept patients with any diagnosis and a need for specialist palliative care.

Please contact your GP, district nurse or hospital consultant if you would like to be referred to our service.

Hours of operation

We are open from 8:00am to 8:00pm, 7 days per week.

Contact is made within 24 hours for urgent referrals.

ECHO EoL Care Hub

ECHO provides a telephone service to people who have a life-limiting illness, advanced terminal diagnosis or are approaching and entering the end phase of their life.

Who we are

ECHO is a telephone service where you can access support and advice 24 hours a day, 7 days a week.

What we do

We know it is likely that you will be supported by several services and health care professionals and that contacting the right person can sometimes be complicated and time consuming, sometimes you might not be sure who the right person to contact is.

Our aim is to improve your care by acting as a single point of contact for you, so that if your needs or situation change, you only have to call one number.

The ECHO team will be able to give you advice and support over the telephone. If we are not able to advise you ourselves, we will consult with other specialist nurses and doctors. We will also be able to ask other services to respond to your care needs or will advise and direct you, your relative or carer to other services that can help you.

We will also record your views and wishes within a confidential electronic personalised care plan. This plan will be shared with doctors, nurses, social care providers, ambulance services, out of hours GP services and other professionals involved in your care to help them understand the choices you have made.

ECHO will not replace or impact your relationship with your GP, community nurse, hospice, palliative care service, hospital, or any other health care professional. Instead, we work alongside those services to improve communication and make it easier for you to access the right care.

Access

We support people aged over 18 who live in the **Coastal West Sussex area**. We will also support older teenagers who choose to be supported by adult services. You, your relative or carer can contact ECHO 24 hours a day, every day of the year, if you need advice or support. Contact us if:

- your condition or needs change and you or your relative or carer are not sure what to do
- you need advice about accessing equipment or practical care support
- you need to know how to access bereavement support.

Hours of operation

We are open 24 hours a day, 7 days a week.

Links to published information:

- Home | Sussex Community NHS Foundation Trust
- NHS+Palliative+Care+Offer+to+Brighton+and+Hove+residents+HOSC+23+April+2025final.pdf
- Primary care network community nursing teams brighton and hove and east sussex
- Primary Care Network Community Teams West Sussex
- Midhurst Macmillan Service
- Surgeries We Work With | Midhurst Palliative Care
- https://www.sussexcommunity.nhs.uk/patients and visitors/services/echo EoL care hub
- Life Stage Service Frameworks 2022 2026 Ageing Well

- Patient Experience Report 2024 2025 | Sussex Community NHS Foundation Trust

The Voluntary, Community and Social Enterprise (VCSE) sector

A wide range of local and national VCSE sector organisations also provide PEoLC. This can include national condition specific organisations such as Cancer and neurodegenerative diseases such as Motor Neuron Disease (MND) and Parkinson's, and national EoL charities such as Marie Curie. Other VCSE organisations can be local organisations providing practical, emotional and spiritual support and care at the EoL in a variety of ways. This could also be supporting carers, and other family members experiencing the EoL care and bereavement of a loved one.

The Sussex Voluntary Leaders Alliance (SVLA) established in Sussex, to promote partnership working similarly to SHA.

Families and carers

Families and carers play a central role in ensuring dignity and comfort during EoL care. They often act as advocates for the person's wishes, helping healthcare professionals understand personal values and preferences.

Initial analysis has provided the first estimate of the number of end of life carers in the UK, with a minimum of at least 150,000–180,000 people providing care to some one within their household at the end of life each year. The total number of end of life carers is likely to be much higher, and could be as high as 775,000. (199)

This suggests that over 1% of the UK population may be providing end of life care. Our methods could be adapted for other countries which routinely collect health survey data, providing a mechanism for identifying and characterising end of life carer populations worldwide. Many end of life carers are living in poverty, and there is a notable rise in poverty in the first year of bereavement, showing a need for policy initiatives to provide support. Future research should further investigate the financial impact of end of life caring, in order to identify where support is most needed and to inform policy

Beyond practical support, they provide emotional reassurance and continuity, which can ease feelings of isolation for the patient. Effective involvement of families requires clear communication, access to information, and recognition of their own emotional needs. When carers are supported and included in decision making, it strengthens trust and promotes a more compassionate, person-centred approach to care.(200,201)

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