Report to	Brighton and Hove Health Overview and Scrutiny Committee (B&H HOSC)
Meeting date	23 April 2025
Report Title	NHS Palliative Care Offer to Brighton and Hove residents
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Summary:

This paper has been developed following a request by the Brighton and Hove HOSC.

The paper outlines the ICB's statutory responsibilities in relation to Palliative and End of Life Care (PEoLC) and the Palliative Care offer to B&H residents by Providers working in the B&H system that receive NHS funding and how these organisations work collaboratively to support patients with PEoLC needs.

NHS Palliative Care offer to Brighton and Hove residents

1. Introduction/ Background

As a system in 2022 we agreed our system strategy *Improving Lives Together* building on the Health and Wellbeing Strategies we have in place across Brighton and Hove, East Sussex and West Sussex that focus on the priorities across our local populations. Our five-year strategy sets out our ambition for our population and the areas that will make the biggest positive difference to people's lives that can be best achieved by working across the whole of Sussex.

These are:

- A new joined-up community approach to health and care
- Growing and developing our workforce
- Improving the use digital technology and information
- Maximising the power of partnership working

We now have a better opportunity to make our ambition a reality because of the different way that we – the organisations responsible for planning, providing, supporting and influencing health and care - are working together. This includes Palliative End of Life Care (PEoLC)

The ICS has a key role to play in ensuring that people with palliative and end of life care needs can access and receive high quality personalised care and support. Health and care partners have a responsibility to ensure that the palliative and end of life care needs of people of all ages, with progressive illness or those nearing the end of their lives, and their loved ones and carers, receive the care and support they need to live and to die well. This includes addressing health inequalities for PEoLC, by improving equity of access to services and reducing inequity of outcomes and experience.

2. Overview

In Brighton and Hove there are, on average, circa 2,100 deaths per year.

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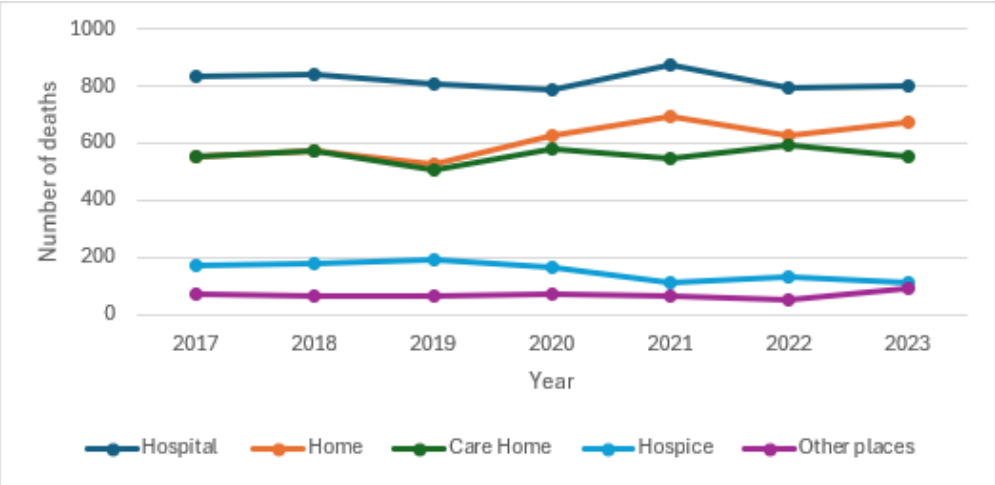
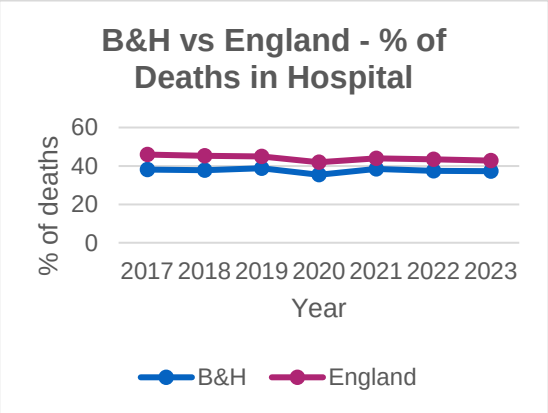
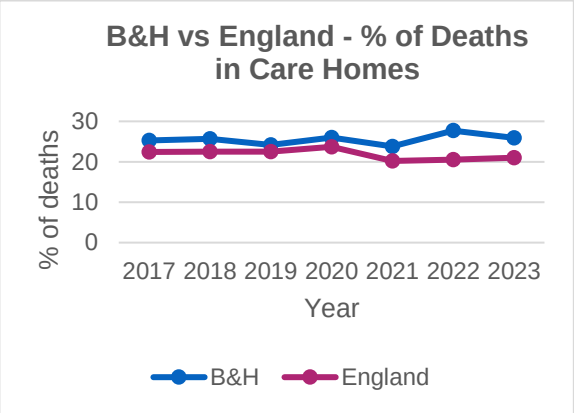
Annual deaths by place of death: Brighton and Hove:







It is widely recognised that people prefer to die at home or in a community setting of their choice. These graphs demonstrate that Brighton & Hove benchmarks well against the England average at providing PEoLC outside hospital, which therefore means people are more likely to die in their preferred place of death.

Despite this, we always recognise that more can be done to improve PEoLC and coordinate care across system partners.

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3. Priority Focus

In 2022, health and care partners recognised the PEoLC programme as a priority area of focus and a Sussex Palliative and End of Life Care (PEoLC) all age Programme Oversight Group was established. This is a multi-stakeholder group with wide reaching representation across the Sussex system.

A Strategic Action plan covering 2022-25 was developed with the following vision:

'Our collective aim in Sussex is to make the last stage of a person's life as good as possible, through working together confidently, honestly, and consistently to help each individual and the people important to them'

The NHS England (NHSE) Ambitions framework was developed by a partnership of national organisations across the statutory and voluntary sectors. It sets out NHSE's vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England.

There are six ambitions:

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is co-ordinated
- All staff are prepared to care
- Each community is prepared to help

In 2022 an exercise was undertaken to map the Sussex system against these ambitions. This was used to inform the development of the Sussex ICS PEoLC Programme Strategic Action Plan for 2022-2025.

2. Current Services

2.1 Primary Care

NHS Sussex commissions a Frailty and End of Life Locally Commissioned Service (LCS), which supports the identification of people with severe frailty and those living in the last year of life. Those identified should be offered personalised care and support planning, including Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) where appropriate.

Following the introduction of the LCS over 95% of Brighton & Hove GP Practices have signed up to provide this LCS, and the number of people on a GP practice palliative care register in B&H has increased from 321 in 2009/10 to 983 in 2023/24.

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The LCS encourages discussion regarding the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) at an earlier stage.

The ReSPECT process aims to ensure that a person's clinical care wishes are known, so that in a future emergency where they may not have capacity or be able to express their choices these are already known in the person's ReSPECT plan. The ReSPECT process is intended to respect both patient preferences and clinical judgement.

There have been a variety of educational and training events regarding ReSPECT. There are resources available on the ICS website at: https://www.sussex.ics.nhs.uk/professional-guidance/carers/care-planning/respect/ which are accessible to patients and system partners/providers. There are resources specifically for patients and their families at: https://www.sussex.ics.nhs.uk/your-care/emergency-care-plan/#h-respect-resources These pages contain information about the ReSPECT process and how it supports patient care.

The aim is to support the involvement of patients, carers and families, and system partners in the use of ReSPECT in practice, and in training and education around ReSPECT and its place in End-of-Life care. There is a focus on admission avoidance for end-of-life patients.

2.2 University Hospitals Sussex NHS Foundation Trust

End of life care (EoLC) is one of the core services provided by University Hospital Sussex NHS Foundation Trust (UHSx). EoLC 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

The UHSx SPCT provides support for:

- multiple, complex or refractory physical symptoms
- complex end of life 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 end of life

- 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

UHSx has recently implemented a digital end-of-life-care plan which ensures that patients nearing the end of life 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.

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 Martlets hospice for patients with specialist palliative care needs

The SPCT has a daily MS Teams meeting with Martlets to discuss and triage referrals for specialist palliative care on Martlets in-patient unit.

In Q3 2024/25 the SPCT supported 1196 newly referred patients within the hospital. During this time the SPCT provided specialist support for the care of 546 patients who died in UHSx.
In the same period the SCPT supported 410 discharges:

- 53% returned home
- 20% to a care home
- 12% to a hospice in-patient unit
- 15% to other destinations

Approximately 40% of the UHSx SCPT caseload is at Royal Sussex County Hospital.

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2.3 Sussex Community NHS Foundation Trust (SCFT)

SCFT provides palliative and end of life care in people's own homes, for those who are approaching end of life and are likely to die within the next 12 months. Sussex Community NHS Foundation Trust (SCFT) strives to ensure the last few months, weeks, or days of a person's life are as dignified and comfortable as possible.

Our end-of-life strategy is aligned to national ambitions with the following objectives:

- each person is seen as an individual
- each person gets fair access to care
- maximising comfort and wellbeing
- care is co-ordinated
- all staff are prepared to care
- each community is prepared to help

SCFT provides palliative care in B&H in collaboration with partner agencies including general practice, Martlets, UHSx, 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 B&H 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 end of life 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. The Martlets community palliative care team meets the SCFT community nursing teams every Thursday afternoon. SCFT community teams also attend Gold Standard Framework (GSF) meetings led by Primary Care to discuss and plan for patients approaching end of life.

Patients receiving end of life care from SCFT have an individualised end of life 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 & End of Life 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 end of life training facilitator provides palliative care training to nursing staff in nursing homes in Brighton and Hove.

2.4 Martlets Hospice

Martlets is the sole provider of both community and hospice in-patient-based specialist palliative and end of life care to adults living in Brighton & Hove.

Martlets receives a grant towards their running costs from NHS Sussex, but the majority of their income comes from community fund raising, retail and major donors.

Martlets offers specialist assessment, advice and support to patients who are 18 years and over and who have advanced, progressive and life-limiting illness (whether due to cancer or a non-cancer diagnosis) and who require complex pain or other physical symptom control. Martlets also offers complex psychosocial assessment and support to patients and their families/carers, specialist help with rehabilitation or adjustment to deteriorating function and/or specialist end of life care and support.

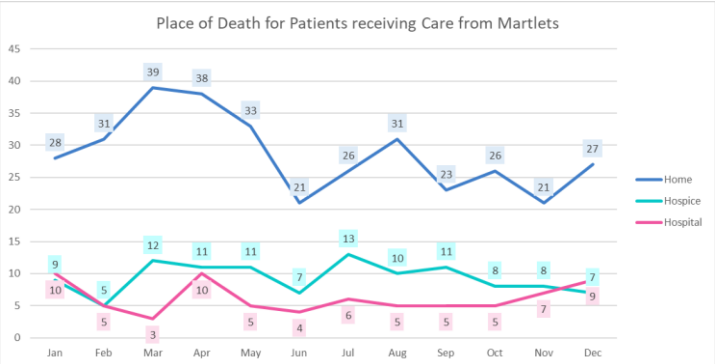
This includes supporting complex advance care planning discussions by working with the primary care clinical team in charge of care to facilitate avoidance of admission to the acute setting.

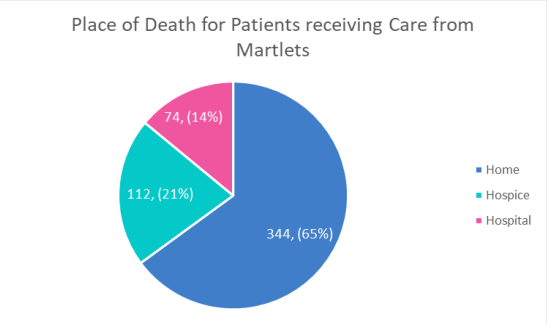
Martlets' specialist multi-disciplinary team, comprising doctors, nurses, physiotherapy and occupational therapy team, social workers, counsellors, spiritual care lead, clinical admin and volunteers, conduct face to face holistic, patient-centred assessments in the home setting, including care homes, in their out-patient clinic, or on the specialist in-patient unit. They also provide 24/7 specialist clinical telephone advice, with access to a Consultant in Palliative Medicine, via their Hub for patients and their families and for health care professionals.

In addition, Martlets provides Well-Being and Supportive Services to enable patients and their families to manage the social, emotional and practical impacts of their illness, and to prevent the development of a crisis situation. Martlets offers pre- and post-bereavement

support to families and carers of all patients who are or have been under their care.

Place of death for patients receiving care from Martlets, 2023:





Whilst referrals largely come from GPs, PCN teams and the hospital team at RSCH, Martlets also works closely and effectively with other providers such as SECAmb, IC24, care home teams and social care.

The service aims to work in collaboration with colleagues in primary and community care and across hospital and other care settings to enable people with complex needs to die in their preferred place of care with dignity and with optimal symptom control.

Martlets is now part of Sussex Hospice Group (with St Barnabas House and Chestnut Tree House) and their subsidiary company, Martlets Care, provides personal care to a range of clients across Brighton & Hove, both privately and state funded. Home care is centred around the needs of the client, and adults of all ages and life stages are supported.

2.5 All-Age Continuing Care (AACC), NHS Sussex

Background

In the context of NHS Continuing Healthcare (CHC), "Fast Track" funding refers to a streamlined process for individuals with a rapidly deteriorating condition, typically those nearing the end of their life. The purpose of CHC Fast Track funding is:

- to expedite the process of securing NHS Continuing Healthcare funding for individuals in urgent need of care
- to ensure that people with rapidly deteriorating conditions receive the necessary care and support without unnecessary delays
- To ensure rapid funding, and the provision of care in the most suitable environment. This is decided taking into account the patient's wishes, best interests, safety, sustainability and resource.

The provision of Fast Track (FT) CHC funding is either in a 'placement' or provided in the person's home.

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Placements
AACC commissions Nursing Home beds for those with FT CHC funding and has a robust marketing and contracting framework in place, to ensure the safety, quality and best use of resources, when commissioning these beds.

The NHS Sussex All-Age Continuing Care Service has a Sussex wide Nursing Home Any Qualified Provider (AQP) Contracting Framework in place. For providers to have access to this framework, they must demonstrate:

- High quality, safe provision of care. This includes regulator ratings, such as the CQC, and any provider concerns
- Providers agree to sign up to a fair, and affordable weekly charge for a bed – this ensures placements are sustainable and best value for the taxpayer

In late 2024, AACC agreed to block purchase bed capacity at Martlets, to provide non-specialist nursing care services for CHC Fast-track funded EoLC patients, as a proof-of-concept approach. 6 beds were commissioned for this purpose. This arrangement supports faster transfer of patients, from hospital/community to a hospice bed.
Following the success of this proof-of-concept pilot this will be rolled out to other hospices across Sussex.

This approach ensures, high quality provision of end-of-life care, for patients in a rapidly deteriorating phase of life, whilst providing a stream of long-term financial security for hospices, by providing funding guarantees through long term contracts.
This agreement ensures a rapid, streamlined process, from the community/hospital to the hospice setting – improving patient experience and outcomes.

Domiciliary 'Home-based' care
CHC commissions domiciliary, home care, packages for patients who are rapidly deteriorating. Once a patient is confirmed as eligible, CHC 'broadcast' to domiciliary care providers, who will assess whether they can meet the needs of the patient.
CHC has a robust quality assurance framework in place for providers, to ensure they meet the highest standards of quality and safety.

In a recent development, CHC are working on a proof-of-concept with the subsidiary arm of Martlets Hospice, Martlets Care, to provide a high quality, safe and effective service to those Brighton & Hove residents with CHC FT funding in place, requiring care at home. Being based at Martlets, this benefits from close working with the Hospice teams, with rapid transfer from home to the hospice if required. A plan is in place for Martlet's Care to provide care to more patients, as they grow a sustainable workforce to meet the need.

3. Volunteers

The Royal Sussex County Hospital, supported by the Friends of Brighton and Hove Hospitals, has launched "*A Friend In Need"*, a new volunteer service dedicated to providing companionship and emotional support to patients, and their loved ones, at the end of their life. In the first three months, 13 volunteers visited nearly 100 patients, offering a comforting presence and a listening ear to those in need. The initiative has received overwhelmingly positive feedback, with patients and families expressing profound gratitude for the comfort and companionship provided. Volunteers, including retired individuals and professionals, find the experience fulfilling and the service is highly valued by hospital staff for enhancing the quality of end-of-life care. For more information, visit: www.uhsussex.nhs.uk/news/selfless-volunteers-bring-comfort-to-end-of-life-patients-in-brighton/.

At Martlets, volunteers play a vital role in the delivery of counselling, therapy and wellbeing, spiritual care and chaplaincy services. Currently this includes several volunteer counsellors who provide 10 additional sessions per week to patients and their families, a bereavement support home visitor, the Compassionate Neighbours scheme with 32 volunteers across Brighton & Hove, 21 Wellbeing Group Volunteers supporting a variety of complementary therapies being delivered to Martlets patients and their carers,10 volunteer drivers who support patients and their carers to access groups and complementary therapy services, and 2 volunteers who support Martlets' chaplain to provide patients on the inpatient unit with spiritual support. Martlets could not provide all these services to patients and their families without their volunteer workforce, and are looking at further opportunities across their hospice sites to further utilise their volunteers' vital input.

4. Clinical Case Study

Clinical Case Study illustrative of the joint working between providers of PEoLC in Brighton and Hove.

A patient with advanced cancer underwent intensive treatment during 2021, the patient responded to treatment and was stable until early 2023 when a recurrence was diagnosed.

The patient expressed a wish to remain at home for as long as possible.

Over a period of 3 months the patient had multiple hospital admissions for falls, sepsis, acute kidney injury, and self-neglect, however a wish to remain at home as much as was possible remained strong. To facilitate this, SCFT Community Nursing, Rehab Services, and Urgent Community Response were involved, the patient had inpatient rehab, and CareLink installed.

During their regular visits SCFT Community Nurses continued to build a relationship with the patient, enabling advance care planning discussions to take place. A ReSPECT plan

was completed confirming the patient's wish to be cared for at home with preferred place of death (PPD) being at home.

Following a subsequent hospital admission, the ReSPECT plan was updated with preferred place of death as hospice in-patient unit and, remaining at home for her on-going care.

Martlets and SCFT agreed that SCFT's community nurses provided ongoing face-to-face care with Martlets 24/7 Hub providing specialist clinical advice regarding complex pain control to the SCFT Community Nurses and GP as needed, due to the patient's reluctance to engage with new services. Subsequently the patient was admitted to hospital and was reviewed by the Hospital Palliative Care Team (HPCT). In line with patient wishes, discharged back home Dec 2024, with an increased package of care.

Despite these plans a further A&E attendance was clinically indicated. Following review by the HPCT and discussion with the patient, it was agreed that the patient be discharged to Martlets for specialist pain and symptom management, as well as social, psychological and spiritual support, as the most appropriate treatment environment aligned to the patient's wishes.

The patient was cared for and the family supported appropriately during the hospice admission. The patient died peacefully, in their preferred place of death, and the family member was offered bereavement support and follow up by Martlets.

Despite the clinical and social challenges presented, the patient's wishes and preferences regarding their end-of-life care were respected by all services (hospital, community and hospice), and through collaboration and close partnership-working, care was individualised and preferred place of death achieved. An awareness of, and respect that an individual's wishes and preferences can change over time were reflected in the changes to the Care and ReSPECT plans.

5. Looking to the Future

Organisations within the Sussex Health and Care Partnership commenced their journey to work in a joined-up way to better meet the needs of each local community in 2022 when collectively we agreed our system strategy, *Improving Lives Together*.

Aligned to the system strategy *Improving Lives Together*, the six hospice charities in Sussex have come together strategically to work alongside the NHS and statutory partners. The charities are:

- St Wilfrid's Hospice, Chichester
- Southern Hospice Group (St Barnabas House, Martlets, Chestnut Tree House)
- St Peter and St James's Hospice

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- St Catherine's Hospice
- St Wilfrid's Hospice, Eastbourne
- St Michael's Hospice, Hastings and Rother

September 2024 the six hospice charities formed the Sussex Hospice Alliance (SHA) supported by NHS Sussex.

The key strategic drivers for the Sussex Hospice Alliance are:

- Meeting the goals of *Improving Lives Together*, the strategy for NHS Sussex, with specific reference to end-of-life care and support, and its delivery within Integrated Community Teams – Multidisciplinary Teams working across organisations
- Achieving the goals of the Sussex Health and Care PEoLC Strategic Action Plan
- Meeting statutory responsibilities for Integrated Care Boards (ICB) for PEoLC set out in the Health and Social Care Act (2022)
- Achieving strategic goals and charitable aims of individual Sussex hospices in serving their local communities
- Reducing health inequalities in PEoLC

In 2024/25 the Sussex Hospice Alliance successfully trialled 3 'proof of concept' models:

- Bedded care for Discharge-to-Assess Pathway 2 patients
- Bedded care for patients eligible for AACC Fast-track funding
- Provision of AACC funded domiciliary care

In 2025/26 the SHA plans to:

- Commission AACC fast-track funded beds across the hospices in the Alliance
- Assist in the development of virtual health for PEoLC patients
- Embed as a key partner in Integrated Care Teams (ICTs)

NHS Sussex focus for 2025/26 is to improve system working and enable greater impact with partners by delivering integrated care at Neighbourhood level.

6. Conclusion

This paper has outlined the ICB's statutory responsibilities in relation to Palliative and End of Life Care (PEoLC) and the Palliative Care offer to Brighton & Hove residents, illustrating how these organisations work collaboratively to support patients with PEoLC needs.

The ambition is to continue to work in partnership to provide high quality care, where possible in the care setting of the patient's choosing, delivering personalised and joined-up End of Life care. This approach aligns into the developing Neighbourhood and Integrated Community Teams.