



Investigation report

Variations in the delivery of palliative care services to adults

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Theme:

Access to care

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A note of acknowledgement

We would like to thank Dermot's family for sharing their experiences of his care. We would also like to thank the health and care organisations, third-sector organisations, and staff who engaged with the investigation for their openness and willingness to support improvements in this area.

Dermot and his family

About Dermot

Dermot was a fit, healthy and youthful 77 year old. He played tennis twice a week and was very active in his local community doing voluntary work with older people with disabilities. Dermot had been married for 52 years, and had three brothers who lived overseas and one sister. When Dermot got the diagnosis of his rare sarcoma he faced the challenge with characteristic courage and pragmatism. He did everything he could to get the best care he needed. He looked forward to months, even years, of healthy life after recovery from surgery in May 2020.

From Dermot's family

We welcome HSIB's investigation to support improvements in palliative and end of life care services across the country. The report highlights some of the difficulties faced by Dermot and his family during the palliative care for his sarcoma but is not able to fully reflect all the events and factors that contributed to his and his family's distress, nor the difficulties in meeting Dermot's needs and his and his family's expectations.

Dermot and his wife felt alone on their journey through his palliative care, particularly given his already rapidly deteriorating state of physical health and mental anguish at the point when palliative care services became involved. Exploration of Dermot's diagnosis of sarcoma, its recurrence, extensive metastases, and staff awareness of the condition were out of scope of HSIB's investigation. The family are separately exploring how the rare and aggressive nature of the cancer complicated Dermot's palliative care in current work with [Sarcoma UK](#).

Dermot's family did not feel there was continuity throughout his care, and this is highlighted in the investigation. Dermot did not have a "good death" despite the best efforts of services working with limited resources. From the family's experience and insight, this was due to issues relating to expertise and knowledge of how to assess and manage Dermot's illness in his last

weeks of life. It is hoped that the HSIB safety recommendation to build specialist workforce capacity and the action for integrated care boards will support staff to have the required knowledge and skills to look after patients with specialist palliative care needs, like Dermot, with conditions such as advanced metastatic sarcoma.

The family hope that the safety recommendations made by this investigation will play some part in the needed improvements in palliative and end of life care services to help provide effective holistic care in order that others do not have the same experience as Dermot.

Dermot's family (April 2023)

About this report

This report is intended for health and care organisations, policymakers and the public to help improve the experience of care of people and their families towards the end of a person's life. For readers less familiar with this area, terms are explained throughout.

There is variation in the terms used in palliative and end of life care (PEoLC). For consistency, this report uses PEoLC as an umbrella term which encompasses all types of PEoLC provided by health and care organisations, including those in the third sector (voluntary and charity). This includes specialist palliative care, and care provided by non-specialist staff, such as GPs and community nurses (sometimes termed 'general' or 'core' palliative care). Where relevant, the report will refer specifically to specialist palliative care (SPC).

Executive summary

Background

This investigation aims to improve the experiences of people accessing palliative and end of life care (PEoLC) services in England. Palliative care aims to improve the quality of life of people with life-threatening or life-limiting illnesses, and their families. It does this by taking a holistic approach, which means it addresses a person's physical, psychological, social, and spiritual needs.

In England the first national strategy for PEoLC was published in 2008 following recognition that people did not always die in their preferred location or receive high-quality care. Since then, national publications have described what people should be able to expect from PEoLC, but they have also highlighted continued concerns about the delivery of services in England.

To help explore the delivery of PEOLC in England the investigation considered the care and experiences of Dermot and his family. Those experiences are referred to as 'the reference event.' Due to the scope of HSIB's investigation, it focused on the PEOLC components of Dermot's care, and not the diagnosis and treatment of his sarcoma.

The reference event

Dermot was 77 years old and lived at home with his wife. He had been diagnosed with a myxofibrosarcoma (cancer of the soft tissues) in his armpit. Following surgery and radiotherapy, which were hoped would cure the cancer, the cancer returned and was found to have spread to other parts of his body. It was no longer possible to cure Dermot's cancer and so he was referred to specialist palliative care services.

Dermot initially received specialist palliative care at home from a team of specialist nurses. An assessment of his needs identified his main issues as nausea, anxiety, insomnia, and constipation. The assessment also resulted in a referral to a support organisation for Dermot's wife, but the referral did not progress and so support was not provided.

During the 9 days following his assessment, Dermot's health deteriorated, and it was not possible to control his symptoms at home. He was admitted for inpatient specialist palliative care at his local community hospital. The aim of the admission was to manage Dermot's symptoms and then discharge him home. However, his health rapidly deteriorated and he remained at the community hospital until the end of his life. Two days before Dermot died, his consciousness level decreased, and he became more settled and free of pain.

The national investigation

The investigation into Dermot's PEOLC found that his holistic care needs and those of his family were not always met by the services available to them. Several themes were identified that were considered in a national investigation, including:

- The needs of people and families, and what they are led to expect from PEOLC, cannot always be met by current services.
- The existing 'landscape' of PEOLC services in England is confusing, with multiple organisations involved in delivering care which is variable depending on where people live.

The national investigation visited PEOLC organisations across England, and engaged with people with lived experience, national bodies, and experts. The national investigation's findings echo those of several national publications relating to PEOLC since 2008, which highlight limited progress in improvements to PEOLC in England over recent years.

Findings

- Health and care services in England are not always able to provide individualised, equitable and co-ordinated PEOLC to meet the holistic needs of people and their families. They are unable to consistently provide what people have been led to expect from PEOLC.
- Holistic assessments for PEOLC may focus on physical care needs, with more limited attention to identifying, understanding and addressing other care needs, particularly psychological needs.
- The availability of PEOLC across England is variable and inequitable. This is influenced by the location of third-sector organisations, available charitable donations and NHS commissioning, and workforce shortages. There is no stated minimum standard for PEOLC that all people must be able to access.
- There is limited information to help the public and health and care staff to identify, access, and understand the roles of different aspects of PEOLC, with variation in words and definitions.
- PEOLC services are not always able to proactively plan care for people whose condition will deteriorate because of limited inpatient PEOLC and the unpredictability of some diagnoses.
- There is limited, specific guidance to support integrated care boards to identify the PEOLC needs of their populations in line with the expectations of the Health and Care Act 2022, and what could/should be done to address those needs.
- There is limited support available for health and care professionals to have honest conversations with people around death and what to expect, and to plan for the end of life.

HSIB makes the following safety recommendations

Safety recommendation R/2023/233:

HSIB recommends that NHS England specifies a palliative and end of life care data set to help integrated care boards to understand their populations' demographics and needs, in order to support commissioning and improvement of services.

Safety recommendation R/2023/234:

HSIB recommends that NHS England develops and promotes a minimum expected service specification for specialist palliative care in England to clarify the minimum services a person can expect to be available to them no matter where they live.

Safety recommendation R/2023/235:

HSIB recommends that NHS England commissions palliative and end of life care career pathways, ensuring that they include staff from the allied health professions, in order to build specialist workforce capacity.

HSIB suggests the following actions for integrated care boards

- Identify and describe the palliative and end of life care services in their areas through engagement with integrated care partnerships and third-sector organisations. This is to provide the public and health and care professionals with accessible and accurate information about available services.
- Support collaboration between health and care organisations to define clear routes of support for people in and out of normal working hours to ensure they know how to access help for palliative care and end of life needs.
- Work with integrated care partnerships to account for capacity and resource in social care when planning palliative and end of life care services.
- Support collaboration between health and care organisations, including those in the voluntary and charitable sectors, to encourage more open discussions about death and dying in their local communities, accounting for their population demographics.
- Include palliative and end of life care in strategic workforce plans to ensure staffing of services is appropriately capable and can provide the capacity needed to meet demand.

1 Background and context

This investigation aims to improve the experiences of people accessing palliative and end of life care (PEoLC) in England. HSIB began this investigation after a referral from a family describing concerns about the palliative care their relative received. For more information about the investigation process, see appendix A.

This section provides background information about the aspects of health and care considered in this investigation.

1.1 Palliative and end of life care

1.1.1 Palliative care aims to improve the quality of life of people with life-threatening or life-limiting illnesses, and their families (Marie Curie, 2022; World Health Organization, 2020). A life-limiting illness is one that cannot be cured and that someone is likely to die from, for example, advanced cancer. A person may receive palliative care for many years, and it does not necessarily mean that the end of their life is imminent (Marie Curie, 2022).

1.1.2 End of life care is sometimes seen as a component of palliative care, provided when a person is nearing the end of their life. In the NHS, people are considered to be approaching the end of their life when they are likely to die within the next 12 months (NHS, 2022). The National Institute for Health and Care Excellence (NICE) provides guidance on the care of adults in the last days of their life (National Institute for Health and Care Excellence, 2015) and a quality standard to support high-quality end of life care (National Institute for Health and Care Excellence, 2021).

1.2 Palliative care's 'holistic' approach

1.2.1 Palliative care seeks to take a 'holistic' approach to care by considering a person as a whole and addressing their physical, psychological, social, and spiritual needs (NHS, 2022). People's holistic care needs include the following (National Coalition for Hospice and Palliative Care, 2019):

- Physical – symptoms such as pain, breathlessness, nausea and vomiting.
- Psychological – such as anxiety, depression and anticipatory grief.
- Social – support for and communication with family and friends.
- Spiritual – spiritual, religious and existential needs.
- Cultural – such as language, rituals and dietary needs.

1.2.2 A person's care needs will vary as their life and illness progresses, and particularly as they approach the end of their life. Many of their symptoms can be managed with support from appropriate health and care services (see 1.4).

Gold Standards Framework

1.2.3 In England, the Gold Standards Framework (GSF) is often used to identify people nearing the end of their life (Gold Standards Framework International, n.d.). The GSF has three key steps – identifying people who may be in the last year of life and their needs; assessing their current and future needs; and creating a plan to support them to live and die well (Gold Standards Framework, 2011).

1.2.4 The GSF also provides a common language with the use of a 'prognostic indicator'. This is a set of trigger questions to help staff recognise when a person is nearing the end of their life. People are coded based on their needs such as amber ('weeks prognosis') or red ('days prognosis') (Gold Standards Framework, 2011).

1.3 National strategy for palliative and end of life care

1.3.1 In 2008 the [former] Department of Health published the first national strategy for end-of-life care in England (Department of Health, 2008). This followed recognition that people did not always die in their preferred location or receive high-quality care.

1.3.2 Following the 2008 strategy there have been several publications by governmental, policy, regulatory and third-sector (including voluntary and charity) bodies describing the ongoing need to address quality concerns in PEOLC (see appendix B), particularly as demand increases. Demand is increasing as the population grows and people live longer, and conditions such as cancer become more common (UK Parliament Post, 2022). PEOLC also has a role supporting people with multiple long-term conditions and/or frailty (Stow et al, 2019).

1.3.3 In 2021, the National Palliative and End of Life Care Partnership published 'Ambitions for palliative and end of life care: a national framework for local action 2021-2026'. This was a re-publication with the same ambitions as described in its framework for 2015 to 2020. The framework set out six ambitions to address ongoing gaps in PEOLC and describes what people should be able to expect to receive from services (see figure 1).

Figure 1 The six ambitions to address gaps in PEOLC, adapted from the National Palliative and End of Life Care Partnership (2021)

Each person is seen as an individual
Honest and timely conversations, and knowing what matters most to the person.
Each person gets fair access to care
Regardless of who a person is, where they live, or their circumstances.
Maximising comfort and wellbeing
Care is regularly reviewed and the person kept comfortable.
Care is co-ordinated
Right help at the right time from the right people.
All staff are prepared to care
Staff are competent and compassionate.
Each community is prepared to help

Everyone has a role to play in conversations about living and dying, and supporting each other.

1.3.4 The Health and Care Act 2022 established new NHS bodies, called integrated care boards (ICBs), to plan and deliver health and care to meet the needs of the population in their geographical footprints. The Act included a function to ‘arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility – such other services or facilities for palliative care as the board considers are appropriate as part of the health service ...’ (Health and Care Act 2022).

1.4 Palliative and end of life care provision in England

1.4.1 PEOLC provision in England is complex, with many organisations involved in the care of people and families. In general the NHS commissions (funds) fully or in part the following types of PEOLC (NHS England, 2016; 2023):

Core (also referred to as general, universal, or non-specialist targeted): delivered by all staff in health and care, and by non-specialist staff at specific PEOLC organisations. Core includes GPs and community nursing

Specialist: expert palliative care delivered by multidisciplinary teams with specialist knowledge and skills to meet people’s needs where they cannot be met by core services. Staff include consultants in palliative care and oncology, specialist palliative care nurses and allied health professionals (for example occupational therapists). People’s needs may be complex or require specialist consideration.

1.4.2 The above types of PEOLC are delivered to people and their families by the following sectors with the choice of care setting guided by various factors, including a person’s preferences:

- NHS healthcare – services delivered primarily by the NHS to people in hospital or community settings, including in their own homes. Organisations may deliver core and/or specialist PEOLC.
- Social care – services delivered by social care organisations. Organisations may include delivery of core PEOLC.
- Third sector – commonly voluntary or charity organisations that deliver health and/or social care in inpatient and outpatient settings. Some charities refer to themselves as hospices and may deliver core and specialist PEOLC.
- Private sector – not considered in this investigation.
- Other – including informal caring support provided by friends and family.

1.4.3 The funding sources for PEOLC vary depending on the sector providing the care. This investigation focused on PEOLC delivered by the NHS and third-sector (charity) organisations. The following is a simplified summary of the ways in which PEOLC may be funded:

- By the NHS – fully NHS-commissioned PEOLC services include core services provided via NHS general practices, community healthcare organisations, and hospitals, and specialist services via NHS-led community and inpatient units.
- Through charitable donations – charities that deliver both core and specialist PEOLC may do so with sole funding coming from charitable donations.
- A combination of NHS funding and charitable donations – core and specialist organisations that deliver PEOLC may also receive a mix of funding through NHS commissioning and charitable donations. Proportions of each can vary, but in general, for adult services with mixed funding, around 30% is from the NHS.

Hospice care

1.4.4 Hospice care is a 'style' of PEOLC which places a 'high value on dignity, respect and the wishes of the person who is ill' (NHS, n.d.). Hospice care may provide specialist and/or core PEOLC and is often primarily funded through charitable donations. Hospices are commonly located in areas where individuals have historically set up a charity to meet the PEOLC needs of a local community.

1.4.5 Following referral for care, hospices can often provide a wide range of services to meet the holistic needs of people and their families (Hospice UK, n.d.a). Most hospice care is now delivered in settings including day centres, care homes, and in people's own homes, rather than in inpatient facilities.

Hospice at home

1.4.6 Hospice at home is the provision of hospice-style care in a person's home. It aims to bring 'the skills, ethos and practical care associated with the Hospice movement into the home environment' (National Association for Hospice at Home, n.d.). Hospice at home may operate from a main hospice or through a specific hospice at home organisation. These services are again funded through charitable donations and/or NHS commissioning.

2 The reference event

The investigation used the following patient safety incident, referred to as 'the reference event,' to examine issues associated with palliative and end of life care (PEOLC). The reference event involved Dermot, who was diagnosed with a type of cancer known as sarcoma. The

investigation focussed on Dermot's PEOLC following diagnosis that the sarcoma had spread and was no longer curable. This section describes a timeline of the events affecting Dermot, with the investigation's analysis of the reference event described in section 3.

The investigation heard about the events affecting Dermot from his family, health and care staff involved in his care, and through access to his clinical records (see appendix A). There were several instances where the recollection of the family and staff, and what was stated in the clinical records, differed. The investigation was unable to reconcile all these differences. The investigation aimed to present the evidence objectively to reflect the views shared by different people, groups and organisations.

2.1 Initial diagnosis and management of Dermot's sarcoma

2.1.1 Dermot first found a small, hard, painful lump in his right armpit on 17 February. Following tests he was diagnosed on 26 March with a myxofibrosarcoma (a cancer of the fibrous tissues surrounding muscles). The sarcoma was classed as low-grade, which means slower growing/less likely to spread. Dermot's consultant surgeon, who he had seen in the independent sector (private healthcare), discussed the diagnosis with a local NHS sarcoma multidisciplinary team and referred Dermot to an NHS hospital which specialised in sarcoma management.

2.1.2 Dermot's care was taken over by the specialist hospital. The recommended treatment was surgery and postoperative radiotherapy, with an expectation 'to cure'. A sarcoma clinical nurse specialist (CNS) documented that they had introduced themselves and their role to Dermot and his wife and provided contact details for their team and the hospital helpline. The CNS role included the identification of any complications after the planned surgery, such as infection. Dermot's wife did not recall being introduced to the CNS nor information about their role.

2.1.3 Dermot underwent surgery on 13 May. The cancer was found to be more advanced than in clinic 2 weeks previously (measuring 10 cm). The whole cancer could be removed completely and there was no evidence of spread. A sample of the cancer taken at surgery subsequently showed that it was a grade three (high-grade, which means it was more likely to spread) myxofibrosarcoma. Given the findings, the surgeon considered that radiotherapy would be advisable and so they discussed this with clinical oncology colleagues. Dermot was later seen in a post-operative surgical clinic at the specialist hospital on 28 May.

2.2 Dermot's radiotherapy and postoperative monitoring

2.2.1 Dermot was referred for post-operative radiotherapy more local to his home at a dedicated sarcoma service. This service provided care to a large area/population and was staffed by specialist sarcoma oncologists. The plan was for Dermot to receive radiotherapy and

have local follow-up to evaluate his progress. Details of the local oncology (cancer specialist) CNS were given to Dermot as a point of contact; Dermot's wife did not recall this information being given.

2.2.2 Around 3 months after surgery, Dermot called the sarcoma CNS at the specialist hospital to say that he was experiencing nausea following completion of his radiotherapy. He was advised to contact the 'local team' (the oncology service where he was receiving radiotherapy) as they had current information on his care and he had been discharged by the specialist hospital. He spoke to the local oncology CNS and it was felt that the nausea was unrelated to the radiotherapy that he had previously received.

2.2.3 Ten days later Dermot had a telephone clinic appointment with the consultant oncologist at his local NHS hospital. They discussed Dermot's nausea, but as he was feeling fitter and wanting to get back to playing tennis, further investigation was not felt to be needed at that time. A plan was made for him to go to a follow-up appointment (in clinic) in 6 weeks' time, which coincided with a 3-month follow-up after radiotherapy.

2.3 Recurrence of Dermot's sarcoma

2.3.1 On 13 October, Dermot approached his GP for an appointment because he was experiencing pain on his right-hand side, just above his hip joint. Prior to seeing the GP later that week, Dermot saw an independent physiotherapist who found a possible mass in his abdomen.

2.3.2 Dermot contacted the independent consultant surgeon again and was seen on 14 October. Dermot had a computerised tomography (CT) scan in the independent sector on 15 October.

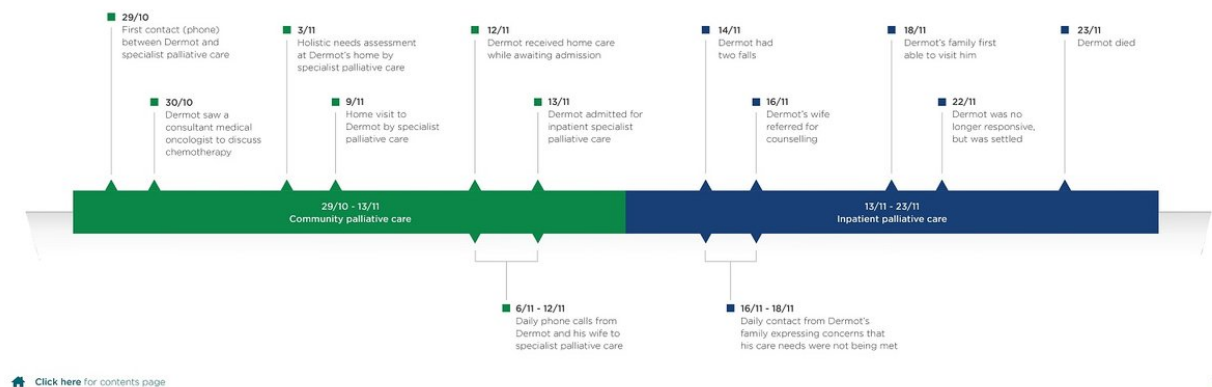
2.3.3 Dermot had a telephone consultation with the independent consultant surgeon on 16 October. He was told that the CT had shown a recurrence of the cancer in his right armpit, and that the cancer had spread to his lungs and abdominal tissues. Dermot was made aware that this was 'very bad news' and the focus would be on 'controlling the disease rather than cure'.

2.3.4 On 22 October, Dermot had a telephone consultation with the consultant oncologist at his local NHS hospital. Dermot was documented to have been told that his prognosis was such that his life expectancy was measured in months. The consultant oncologist discussed chemotherapy to slow disease progression and stressed that supportive care was important. A plan was made to ask Dermot's GP to refer him to community specialist palliative care (SPC) services.

2.4 Dermot's community specialist palliative care

2.4.1 Figure 2 provides a visual timeline of events affecting Dermot and his family following his referral to specialist palliative care.

Figure 2 A summary timeline of Dermot's palliative and end of life care after his sarcoma had recurred



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2.4.2 On 28 October, Dermot's GP referred him for community SPC for pain management, symptom management, emotional/psychological support, and assistance with carers' needs. An SPC CNS covering the area where Dermot lived telephoned him on 29 October to discuss the referral and his needs. Dermot told the CNS that he was 'struggling to sleep due to worry and not sure what to expect'. 'Extensive discussions regarding chemotherapy' were documented and Dermot and his wife were informed that his life expectancy was short and the cancer not curable. They were given an on-call support number and advice about pain relief.

2.4.3 Dermot had a clinic appointment with a consultant medical oncologist (specialist in chemotherapy) on 30 October. He was given some options to consider for future care/treatment. The appointment with the clinical medical oncologist was summarised in a letter to Dermot afterwards, including information about the potential benefits of chemotherapy and that without chemotherapy 'we would expect prognosis to be a short number of months'. Dermot decided to focus on management of his symptoms rather than chemotherapy treatment.

2.4.4 A SPC CNS documented carrying out a 'holistic needs assessment' of Dermot during a home visit on 3 November. This identified his main issues to be nausea, anxiety, insomnia, and intermittent constipation. It was also documented that Dermot was graded as 'amber' on the Gold Standards Framework (see 1.2.4) which suggested that he had weeks to live. Dermot's wife did not recall being told that he was graded as 'amber,' or that he had weeks to live.

2.4.5 The CNS emailed Dermot's GP with a care plan and asked them to prescribe anti-sickness medication. A plan was also made to refer Dermot and his wife for financial support, and Dermot's wife to a local family carers' organisation. The SPC CNS said they would review Dermot the following week, and if he was 'stable' would consider discharging him from SPC to core services (see 1.4).

2.4.6 Between 6 and 10 November there were daily telephone calls/contacts between Dermot's wife and health and care services, including the SPC CNS team, a local community healthcare organisation, and NHS 111. This was because Dermot was experiencing unresolved symptoms. An SPC CNS visited Dermot at home on 9 November. Counselling and psychological support were discussed, and Dermot's medications were changed as his symptoms were not resolving as anticipated.

2.5 Admission for inpatient specialist palliative care

2.5.1 On 11 November Dermot's wife and wider family called the SPC CNS team. They described that he was continuing to experience nausea, had deteriorated physically, was losing weight and was unable to eat. Dermot's wife also asked for support for herself and made enquiries about Dermot being admitted to an inpatient bed. The CNS team explained that they were trying to manage Dermot's symptoms at home and provide time for medications to work. The family asked to speak to the medical team for a review of Dermot's care and a telephone call was planned for later the same week.

2.5.2 On 12 November Dermot's wife rang the SPC CNS team asking for urgent help because of Dermot's worsening physical and psychological symptoms. There were no hospice beds available at that time in the region, and the family wanted to avoid Dermot being admitted via an emergency department to hospital. A CNS called Dermot's wife back and she was told that a bed would be available the next day at the local community hospital, which had six SPC inpatient beds managed by a hospice team. In the meantime, the plan was to provide support to Dermot and his wife at home via a local 'care at home team' (part of the community healthcare organisation).

2.6 Inpatient specialist palliative care support

2.6.1 On 13 November Dermot was admitted into an SPC bed at his local community hospital for symptom review, medication management and emotional support. Care was jointly provided by the community healthcare organisation (on site) and a hospice (located elsewhere). Initially Dermot's family were unable to visit him in the community hospital due to COVID-19 restrictions.

2.6.2 On 13 November Dermot was first seen by a consultant in palliative care who noted his main problems as anxiety and nausea. A falls prevention care plan was completed, and no concerns were noted. During the assessment a 'do not attempt cardiopulmonary resuscitation' recommendation was discussed, but that other care would still be considered. The plan was for Dermot to be discharged home if his condition stabilised.

2.6.3 On 13 to 14 November overnight Dermot was found to have fallen twice and had likely hit his head. He was unsettled and confused. A healthcare assistant was allocated to sit by his side-room door to prevent further falls.

2.6.4 Between 14 and 16 November Dermot was reviewed each day by medical and nursing staff from the community healthcare organisation and the hospice. Dermot's symptoms of anxiety, nausea and insomnia continued. He suffered from low blood pressure on standing, and shortness of breath on exertion, so received a blood transfusion. It became apparent that Dermot's health was rapidly deteriorating and that he may need to stay at the hospital for end-of-life care.

2.6.5 On 16 November Dermot's family raised concerns with the hospital that he was anxious and that his care needs were not being met. Dermot was then referred for counselling and was to be seen by a chaplain. It was also documented that Dermot's wife had been offered counselling and that she would consider it.

2.6.6 On 17 November Dermot's family telephoned the hospital to enquire about his wellbeing and to ask to speak to a consultant. The family also asked for Dermot to be transferred to a hospice; they were advised that Dermot was already 'in a hospice-funded bed'. The family were concerned that Dermot had not settled physically or psychologically.

2.6.7 On 18 November Dermot's wife and sister were able to visit him for the first time. Up until this point visiting restrictions due to COVID-19 had prevented the family from visiting. Following advice from a national cancer charity and a face-to-face meeting with the clinical team, the family were able to visit Dermot. It was also planned to offer Dermot counselling following family concerns that his anxiety had not been addressed. Dermot 'agreed that this may be beneficial'.

2.6.8 On 19 November a consultant in palliative care documented that Dermot appeared to be approaching the end of his life. On 20 November Dermot was again seen by the same consultant in palliative care. Dermot's main issues were constipation, anaemia, and insomnia (because of a fear of closing his eyes and dying alone). The family wanted Dermot to have someone with him continuously and so they arranged for a doula (a person trained to support people at the end of their life, including providing emotional and spiritual support) to be with Dermot during the daytime, while they stayed with him overnight.

2.6.9 On 21 and 22 November Dermot's condition continued to deteriorate, and he received further medication which helped relieve his symptoms. On 22 November Dermot was no longer responsive but appeared settled and pain free. Dermot died on 23 November with his wife and sister by his side.

3 Analysis and findings – the reference event

This section outlines the findings of the investigation's analysis of the reference event. Dermot's family told the investigation of the difficulties they had accessing the palliative and end of life care (PEoLC) that he needed. Dermot's wife told the investigation that they felt "completely alone", and the events had resulted in physical and psychological distress for Dermot, and psychological distress for the family.

The family shared concerns with the investigation around potential delays in the diagnosis of Dermot's initial sarcoma and its recurrence. Due to the focus of this investigation on PEoLC, Dermot's sarcoma diagnosis and management were outside of the scope of this investigation. The investigation was told by Dermot's family that these concerns influenced their later expectations and experiences. They considered that an earlier diagnosis may have supported earlier referral to PEoLC.

The investigation aimed to understand the gap between the PEoLC Dermot and his family described that they needed, and what was available and delivered. The investigation considered:

- the delivery of holistic palliative care to maximise a person's comfort and wellbeing
- access to inpatient specialist palliative care services
- the gaps between what was needed, expected, and received.

The events affecting Dermot and his family, and the undertaking of the investigation, occurred during the COVID-19 pandemic. During this period the delivery of health and care services in England were significantly affected with changes to practice to minimise transmission of the virus. The investigation found that the COVID-19 pandemic influenced Dermot's PEoLC.

3.1 Delivery of holistic palliative care

3.1.1 The investigation was told by Dermot's family that PEoLC services did not meet his and their holistic care needs. The family felt that Dermot's physical and psychological care needs were not fully met; the rapidity of his deterioration was not appreciated; and his wife's needs were not met. The following sections will explore these concerns.

3.1.2 Following Dermot's diagnosis of the recurrence of the sarcoma he was referred to specialist palliative care (SPC) services. SPC was provided by Hospice 1 (see figure 3), as it held the contract to deliver SPC in the area in which Dermot lived. Prior to Hospice 1's involvement in the area a local acute hospital trust had, for many years, provided a service to meet some of the PEoLC needs, but there had been no contracted hospice services.

Figure 3 Overview of Hospice

Hospice 1 is a charity-led service covering a geographical area spanning two counties. Around 70% of its funding is from charitable donations and 30% is provided by the NHS. It refers to itself as a 'hospice' which delivers palliative care. In the area where Dermot lived the hospice provides SPC community and inpatient services, along with a community SPC nursing service during working hours, and a 24-hour specialist advice line for patients, relatives, and healthcare professionals. It also provides commissioned care in a local hospital.

3.1.3 At Dermot's initial face-to-face SPC 'holistic' assessment with a clinical nurse specialist (CNS) in SPC he was documented to have pain, nausea, difficulty sleeping and anxiety. His family described him as "distressed" and that "no one was able to alleviate his suffering". Dermot's family told the investigation that the initial assessment did not lead to a holistic appreciation of his and their needs. They felt it did not appreciate their concerns about the earlier diagnosis of sarcoma, the particulars of managing sarcoma, and his deterioration to this point. They reported that the assessment was not able to "get to know Dermot" in a way to truly understand the "existential" crisis he was experiencing, and due to limited continuity of his care staff (see 3.1.14), no one was able to fully understand his individual needs.

3.1.4 The investigation considered the symptoms that someone with a palliative diagnosis of sarcoma may experience. Sarcoma is a rare diagnosis and so health and care professionals may see very few cases in their professional career. A subject matter advisor told the investigation that the palliative care of people living with sarcoma, and other conditions such as melanoma (skin cancer), can be particularly complex. This is due to the nature of the symptoms and the rapidity with which these cancers can progress. Regular review of a person is important and a range of medications are likely to be needed alongside non-medication treatments to control symptoms; sometimes symptoms may only be partially controlled. Sarcoma UK further described the complexity of sarcoma and how this can make it difficult to predict how someone's condition may deteriorate.

Psychological support for Dermot

3.1.5 Dermot had physical and psychological symptoms that required management as part of his PEOLC. An SPC CNS had recorded that his anxiety may have been exacerbating his insomnia and nausea. The investigation explored how SPC CNSs address both physical and psychological symptoms in their interactions with people. Hospice 1 told the investigation that every contact with a person includes a psychological component. In Dermot's case counselling and psychological support were documented as having been discussed with Dermot and his wife. Based on the CNS's assessment it was documented 'I don't think they wanted this' (see 3.1.22).

3.1.6 Dermot's family expressed concerns that his PEOLC had focused on his physical rather than psychological symptoms. They felt his psychological distress was underappreciated because he was seen as 'always a worrier' and there was limited acknowledgement that he had gone from a 'curable' diagnosis to receiving palliative care in a short period of time. Dermot's wife described that it was not counselling that was needed, rather continuity in the support received from PEOLC (see 3.1.14).

3.1.7 The investigation looked for other psychological support options that would have been available to Dermot. These potentially included emotional wellbeing through Hospice 1, through the GP, and via national charities. Dermot's family described longstanding concerns with the care they had received from their GP practice which had affected their trust and had led to a reluctance to approach them for support. The investigation did not explore these concerns further as they were outside scope of the investigation. With regards to national charities, several SPC staff told the investigation that some charities may advertise themselves as available, but they are not available in all parts of the country, including in the area Dermot lived.

3.1.8 The investigation met with Dermot's GP practice to discuss psychological support options. A GP told the investigation that they had been specifically asked by Hospice 1 to refer complex psychological needs to the Hospice and therefore had limited involvement once SPC services were involved.

Recognition of deterioration

3.1.9 Dermot was cared for at home by community-based SPC staff for 10 days until his admission to the community hospital on 13 November. During his period at home his family described how he had deteriorated physically and mentally to a point where he needed urgent admission to address his needs.

3.1.10 The SPC CNS team told the investigation that Dermot's health had deteriorated quickly, and more rapidly than they expected. The complexity of sarcoma can mean people deteriorate in different ways and limited face-to-face opportunities for the CNS team to see Dermot meant his deterioration may not have been as visible to them, reducing opportunities to proactively plan his treatment and care.

3.1.11 Hospice 1 told the investigation that the need for Dermot to be admitted had not been considered by the SPC CNS team until the day before he was admitted. Hospice 1 was aware that Dermot's family wanted him to be admitted to a hospice, but that it was a challenge to proactively plan for potential admissions because of issues with the availability of SPC beds. They also did not want to create expectations of a bed when there were often waiting lists. In Dermot's case Hospice 1 also described wanting to keep Dermot at home because this had been documented as his preferred place of care and death.

3.1.12 Dermot's family challenged the documentation in his clinical records that his preferred place of care and death was at home. The family questioned whether the decisions around preferred place were made without accounting for his wife's feelings and without honest discussion about what dying at home could mean. Dermot's wife did not recall discussions about preferred place of death, and he had not told her of his preferences. The family also reported that the conversations occurred at a time when they were still trying to understand Dermot's prognosis.

3.1.13 Hospice 1's records stated that place of care had been discussed between the SPC CNS team and Dermot. The investigation was told by Hospice 1 that a holistic needs assessment should account for the home and family situation, and by a family care organisation that all family members should be consulted on their feelings about a family member dying at home.

Continuity in Dermot's care

3.1.14 A recurrent theme found by the investigation was that there was limited face-to-face contact between SPC services and Dermot, and no consistent member of the SPC team who liaised with Dermot and his family at home (see below) or when he was admitted to the community hospital (see 3.1.23).

3.1.15 During his SPC at home, Dermot had two face-to-face visits from CNSs. All other contacts were by telephone including via Hospice 1's 24/7 helpline, responding to calls first from Dermot and then his wife. Between 29 October and 12 November they had contact with seven different SPC CNSs from Hospice 1. Hospice 1 had no SPC home visiting service in Dermot's area out of hours.

3.1.16 Dermot was unable to build a rapport with any specific member of the SPC team. Dermot's wife also described concerns, with hindsight, that the holistic needs assessment "misread" how unwell he was. She described that he had looked "OK" and that because he was "stoical" his true feelings may not have been expressed to the SPC CNS. The CNS who saw Dermot in person at his initial needs assessment did not see him in person again; there was therefore no opportunity to compare how he looked.

3.1.17 Hospice 1 told the investigation that the limited in-person contacts between Dermot and the SPC CNS team were the result of 1) measures to minimise COVID-19 transmission, and 2) the team-based approach Hospice 1 used. Dermot would not have been assigned a specific CNS because the team-based approach meant teams of CNSs were assigned a group of patients. The aim of this was to manage demand and distribute workload, while attempting to provide some continuity for people and their families in terms of the staff who cared for them.

3.1.18 The investigation also considered the role of Dermot's GP in the continuity of his care while he was receiving SPC. A subject matter advisor told the investigation of the important role a GP has in the continuity of a person's care in the community. Dermot's GP confirmed that Dermot was on their palliative care register and so 'would have been discussed' at their monthly multidisciplinary team meeting. This may have happened once as Dermot was under community care for just over 2 weeks. Otherwise, Dermot's GP had limited involvement in his care after the referral to community SPC.

Managing Dermot's family's care needs

3.1.19 During a call to Hospice 1 on 11 November it was recorded that Dermot's wife 'needs help also'. She described to the investigation feeling "alone" and said that she had not received support during Dermot's time at home.

3.1.20 Following Dermot's assessment a plan was made to refer his wife to a local 'family carers' organisation which provides charity-funded support to carers, including emotional support. The clinical records described that a SPC CNS contacted the organisation on 4 November and the referral was made following a call-back on 10 November. The investigation contacted the family carers organisation and found that the referral had been sent and received by the palliative care centre at a local acute hospital rather than themselves.

3.1.21 The palliative care centre told the investigation that normal practice would be to complete a referral sheet and document an initial phone contact with the family member. The palliative care centre was unable to find any documentation to suggest that contact had been made with Dermot's wife and was unable to explain this. The investigation was unable to ascertain why no progress was made with the referral, but it resulted in no support being

offered to Dermot's wife via that route. These findings were shared with Hospice 1, which confirmed that it had addressed issues with its local process for referring families to support services.

3.1.22 The SPC CNS team also documented discussing counselling and psychological support with Dermot and his wife, but this had not been pursued. Dermot's wife recalled the conversation but told the investigation that it was not counselling that she needed. Rather she wanted help for Dermot and a consistent person to ask questions to who could help them "navigate this new world". As stated in 3.1.14, she also described wanting "continuity" rather than counselling, but this was not received.

During Dermot's inpatient care

3.1.23 On 13 November Dermot was admitted to a community hospital bed in his home town which was managed by the community healthcare organisation and Hospice 1. During Dermot's inpatient care the family described a limited ability to provide information about his condition before he was admitted, challenges accessing information about his progress, and not being able to visit him for the first 5 days. They felt he needed significant inpatient psychological support and wanted someone to be with him at all times to comfort and support him.

3.1.24 Staff at the community hospital told the investigation that the COVID-19 pandemic had changed their ways of working in efforts to reduce the risk of transmission to patients who may already be vulnerable. However it was recognised that this had had a negative impact on family experiences because it had reduced face-to-face visiting and had resulted in the closure of rooms in which meetings with staff would normally take place. In Dermot's case, Hospice 1 told the investigation that restrictions for visiting would have been lifted as Dermot approached the end of his life. The decision making around COVID-19 restrictions was outside the scope of this investigation and therefore is not explored further.

Organisation of palliative care services

3.1.25 The investigation's findings suggested that PEoLC services in the area in which Dermot lived did not meet all of his, or his family's needs. Several PEoLC and commissioning staff in and around the area told the investigation that the availability of services was limited. The investigation was made aware of both positive and negative experiences of PEoLC services in the area.

3.1.26 Hospice 1 gave the investigation a service evaluation undertaken by a university which covered a 2-year period which included the time of Dermot's PEoLC. The evaluation considered the delivery of SPC in the wider area around where Dermot lived and found evidence of positive experiences of services. It also highlighted some potential areas for improvement, including

admission to inpatient SPC beds. A further annual audit from 2021 was shared which demonstrated positive patient and family experiences, and some areas for improvement based on feedback from individuals.

3.1.27 The investigation was told by a local acute hospital that there was “woeful commissioning of [palliative care] services outside of [the hospital]” in the area Dermot lived. The area is rural and is on the border of two counties and therefore two [former] clinical commissioning groups (CCGs). The [former] CCGs described to the investigation that the area was a “gap” which affected the commissioning of PEOLC and created confusion about what services were available.

3.1.28 The local community healthcare organisation told the investigation that this “gap” was a result of very limited funding in the area for PEOLC. Hospice UK described that PEOLC services in an area often evolve from where a charitable hospice had been historically set up. No charitable hospice had been set up in the area where Dermot lived, but due to public concerns about the lack of SPC a case was made for a charitable specialist PEOLC organisation to extend services into the area. This ultimately resulted in Hospice 1 providing care through a community-based SPC CNS team and by providing SPC input for up to six people admitted to beds at the community hospital.

3.1.29 Staff at Hospice 1 and the local community healthcare organisation told the investigation that the Hospice’s involvement was welcome in the area where Dermot lived and they provided an SPC provision where it had not previously existed. However, staff said that because Hospice 1’s original site (the base for its specialist community, outpatient and inpatient services) was some distance from the area, some people had to travel or “go without” the additional services available at the original site. The geography of the area also meant SPC CNSs had to travel long distances which limited the number of people they could see in a shift.

3.1.30 The investigation met the newly formed integrated care board (ICB, a statutory body responsible for planning and funding NHS services within a geographical footprint) for the area in which Dermot lived. It shared its PEOLC strategy which described that all patients should have access ‘to specialist, enhanced and generalist [core] palliative and end of life care’. The strategy described that SPC provision should include access to inpatient SPC beds, community SPC, psychological support, and a 24/7 professional and carers advice line. The strategy also included a ‘hospice at home’ (see 1.4.6). However, the investigation was told by the community healthcare organisation that the area in which Dermot lived had previously had a hospice at home service, but that it had been decommissioned in 2016 due to insufficient evidence of its value. The investigation was unable to obtain further information about its decommissioning.

Summary

3.1.31 Dermot and his family did not receive all of the PEOLC that they felt they needed. In comparison with the National Palliative and End of Life Care (2021) 'Ambitions for palliative and end of life care: a national framework for local action 2021-2026' (referred to in this report as the 'Ambitions Framework') (see 1.3.3) the investigation found evidence that some aspects of care were not available or not co-ordinated in a way to maximise Dermot's and his family's 'comfort and wellbeing'. Several factors contributed to the situation, including historical factors relating to the evolution of charity-based PEOLC services, and limited commissioning of PEOLC services from the NHS. COVID-19 also limited face-to-face care opportunities and access to services as the NHS and charities attempted to minimise the risk to vulnerable patients.

3.2 Access to inpatient palliative care services

3.2.1 Dermot's family described challenges finding information about the different inpatient PEOLC services in his area and having to 'push' for him to be admitted. When Dermot was admitted for SPC, they also felt he would have received better care if he had been admitted to a 'hospice'. The following sections explore these concerns.

3.2.2 In the region where Dermot lived there were three hospices delivering PEOLC. There was also a hospice under development. The three hospices were Hospice 1 (see figure 3) which provided SPC in the local community hospital and whose original site was more than 1 hour's drive away; Hospice 2 (see figure 4) around a 30-minute drive away; and Hospice 3 (see figure 4) also more than 1 hour's drive away. Each of the hospices had different catchment areas, received different amounts of NHS and charitable funding, and had varying waiting lists.

Figure 4 Overview of Hospices 2 and 3

Hospice 2 is a fully NHS-commissioned (funded) hospice that describes itself as delivering specialist inpatient services for people with complex palliative care needs. It does not use the term 'hospice' in its title or descriptions. Care is provided by a multidisciplinary specialist team and is available when a person's current place of care is unable to meet their PEOLC needs.

Hospice 3 is a local charity-funded hospice that describes itself as providing support to people living with long-term and life-threatening illnesses. It refers to itself as a hospice. It provides care in the community, inpatient services and support for families.

Availability of inpatient palliative care for Dermot

3.2.3 The ICB told the investigation of a shortage of inpatient SPC beds in the area in which Dermot lived. This was the result of the historical situation and lack of a charitable hospice in the area, as described in 3.1.28. As a result, there was a planned hospice in development, but challenges raising charitable funds had limited its progress. Parts of the ICB area were described as “deprived” which may have affected charitable donations.

3.2.4 The hospices described in figures 3 and 4 were funded in different ways. Hospice 1, for example, was mostly charity funded and Hospice 2 was entirely NHS-commissioned/funded. The hospices described how the sources of their funding influenced what they delivered. The investigation was told by charitable hospice leads that where the NHS was more involved in the design of services, there was potentially less flexibility in what the hospices were able to deliver. Where the NHS was less involved, hospices reported being able to be more innovative and provide a wider range of holistic services.

Access to information about available services

3.2.5 When Dermot was admitted for SPC his family described that they had wanted him to be in a hospice bed such as those provided by the three hospices described above. Their reasons for this are explored in 3.3.7. However, they struggled to find information about what inpatient services were available and how to access them. This led them to seek help from a local cancer charity for advocacy with the [former] CCG. It took several hours to determine which inpatient beds Dermot could access, the length of waiting lists and what support was provided.

3.2.6 PEO LC and [former] CCG staff told the investigation that they were “not surprised” that the family struggled to find information because it was unclear and not always available. Staff described a lack of clarity about the PEO LC services available in the area, which made it difficult for staff and the public to know what they could access. This was exemplified by some staff telling Dermot’s family that Hospice 3 was an option when it was not because Dermot did not live in its catchment area, and other staff not being aware of the capabilities of the SPC facilities in the local community hospital.

3.2.7 The investigation found that for patients, families, and health and care staff there was limited clarity around available PEO LC services, the care they provided, and how they could be accessed. The areas in and around where Dermot lived were described by PEO LC staff as a “postcode lottery” for the availability of SPC services because of the way they were organised, as described in 3.1.25. The investigation heard that where multiple ICBs were responsible for commissioning PEO LC, navigation of services could be challenging.

Summary

3.2.8 When Dermot needed inpatient SPC there was not a bed immediately available. In comparison with the Ambitions Framework (see 1.3.3) the investigation found that, due to where Dermot lived, access to some care was limited. The investigation also found that PEOLC in the area was confusing for the family and for staff, with limited clarity on what organisations and services were available and where.

3.3 Care needs versus care received

3.3.1 The investigation found a recurrent theme relating to a mismatch between the PEOLC Dermot's family felt he required, and what was available and delivered by local services. They described that this added to their feelings of isolation, and the perceived lack of support.

Dermot's prognosis

3.3.2 Dermot's family were not sure what to expect following his diagnosis of the recurrence of the sarcoma. They described how they had been given limited information about the progression of sarcoma, risks of recurrence, and associated symptoms. The investigation was advised by the specialist hospital that it is impossible to predict which patients will develop rapid metastases and which will not. Therefore most surgeons will focus on the fact that many patients will receive curative treatment. The specialist hospital also shared a calculator with the investigation which supports prediction of the risk of metastasis; for a patient of Dermot's age this suggested that 26% of patients at 5 years will have developed metastases, and 30% at 10 years.

3.3.3 Dermot's health deteriorated quicker than his family (and potentially staff, see 3.1.9) expected. The family were under the impression that he had months to live rather than weeks. They did not recollect being told that he had 'weeks to live' after he had been graded as 'amber' on the Gold Standards Framework (see 1.2.3). The family felt that a poor relationship with their GP (see 3.1.7) and the short time between diagnosis and deterioration reduced opportunities for honest conversations about Dermot's prognosis.

3.3.4 The investigation reviewed correspondence sent to Dermot describing his poor and uncertain prognosis, and the potential symptoms that may arise from the sarcoma. Dermot's family reported that they were not always aware of the contents of correspondence. The family highlighted the difficulty of taking in such information, particularly at a time when they were trying to come to terms with the diagnosis. The consultant oncologist also told the investigation about the challenges of sharing distressing information, such as timing, the volume of information, knowing whether people have understood the information, and whether it is shared by the patient with wider family members.

3.3.5 Sarcoma UK told the investigation that the sharing of information about sarcoma with patients and families was a recurrent issue in the complaints they received. The charity told the investigation that information was challenging to share because of:

- the variability of the types of sarcoma
- the different parts of the body it can affect
- the complexity of symptoms
- the variations in prognoses.

Sarcoma UK described how some people's health deteriorates rapidly after diagnosis, while others remain well for a long time. However, once a person's condition starts to deteriorate it is often rapid and unpredictable.

3.3.6 The investigation explored the family's understanding of Dermot's prognosis and identified several factors that meant they thought he had a longer life expectancy. The family recalled being told that Dermot's surgery was expected to be curative, and that radiotherapy was "belt and braces".

3.3.7 They also did not recall being told about the potential for recurrence or the prognosis of a high-grade sarcoma. The family felt they had been misled by care planning that suggested a longer life expectancy (for example, Dermot had been encouraged to go on holiday in his caravan), and by the plans to 'discharge' Dermot from SPC when his symptoms were under control.

3.3.8 The investigation did not further investigate the effects of optimism on the PEOLC experiences of people and their families. There is evidence that healthcare staff may overestimate prognoses and this can limit people accessing PEOLC (for example, Enzinger et al, 2015).

Dermot's inpatient specialist palliative care

3.3.9 Following Dermot's admission to the community hospital his family explored opportunities for him to be transferred to Hospice 1's original inpatient unit or another hospice. This was because of Dermot's continuing symptoms that had not been alleviated. Ultimately transfer was not possible because of the catchment areas of the various hospices, waiting lists, and Dermot's deterioration. Hospice 1's original inpatient unit was in a different county and was not part of the commissioned service for the area where Dermot lived.

3.3.10 Exploring the SPC available in the community hospital and at Hospice 1's original inpatient unit highlighted differences in terminology and expectations around the roles of hospices and other SPC organisations. Hospice 1 told the investigation that it was

commissioned to deliver SPC at the community hospital, and both SPC and end of life care in its original inpatient unit, but that it called itself a hospice. The investigation found public and staff confusion around the similarities and differences between hospice care and SPC. Some PEOLC staff described hospice care and SPC as the same care, while others described them as different.

3.3.11 A subject matter advisor told the investigation that hospice models had changed since they were established. The traditional hospice model was one of a non-hospital environment where people from the local community could be admitted for care at the end of their lives. However, as health needs and preferences have changed, the hospice model has changed with many now delivering SPC in line with the NHS's definition (see 1.4.1). The title 'hospice' is often used to maintain the link with the original charities that set up units.

3.3.12 Hospices told the investigation that they are often not able to meet the public expectations that have been created of the care they deliver. This mismatch was reported to be due to limited public awareness of how the hospice model has evolved. In Dermot's case the bed he was in at the community hospital was described by different staff as an 'SPC bed' and 'hospice-funded bed'.

3.3.13 Hospice 1 told the investigation that they were commissioned to deliver six SPC beds at the community hospital where Dermot was admitted. The care it delivered in the community hospital was described as similar to the care in Hospice 1's original inpatient unit. Consultants from Hospice 1 visited the SPC beds and provided support via a 24/7 advice line. The nursing staff caring for Dermot were described by Hospice 1 as 'generalists' who cared for all the patients in the community hospital with additional professional development in PEOLC. At Hospice 1's original inpatient site they had dedicated or enhanced 'specialist' palliative care nurses, on-site medical staff, and wider input from a multidisciplinary team.

3.3.14 Dermot's family also wanted him to be transferred to an inpatient hospice so he could receive regular medical input and specialist care out of hours. The family were particularly concerned that Dermot had not received an assessment from SPC consultants while he was at home; the investigation found that the SPC CNS team had discussed his care with SPC consultants on two occasions, but this was not apparent to his family. At the time of Dermot's admission to the community hospital, SPC consultant staff cover was not available 7 days a week; this has changed since. Dermot was seen by a medical or nurse consultant specialising in SPC on 7 of 9 days and the family recall seeing three different medical consultants.

Summary

3.3.15 The investigation found that Dermot's deterioration was rapid and in contrast with what the family thought they were told by, or had inferred from, healthcare staff. The gaps between needs, expectations (as described in the Ambitions Framework (see 1.3.3)) and reality are explored in the next section of this report, with consideration of how the expectations around PEOLC have been created and why they may not always be met.

4 Analysis and findings – the national investigation

This section provides an overview of the analysis and findings from HSIB's national investigation. The national investigation focused on the delivery of palliative and end of life care (PEoLC) in England and why that delivery does not always meet people's needs or what they should expect to receive.

The methodology for the national investigation is described in appendix A.

4.1 Palliative and end of life care in England

4.1.1 National policy, strategy and the National Palliative and End of Life Care (2021)

'Ambitions for palliative and end of life care: a national framework for local action 2021-2026' (the 'Ambitions Framework') (see 1.3.3) describe what people should be able to expect from PEOLC in England (see appendix B). National experts and policy bodies told the investigation that the Ambitions Framework is the primary document setting out what a person should receive. These ambitions have been used in support of 'Statutory guidance for integrated care boards [ICBs]' (NHS England, 2022b) to help ICBs meet the requirements of the Health and Care Act 2022.

4.1.2 The investigation was further told of historical influences on people's expectations of PEOLC, and that marketing from local and national charities create expectations of services that they may not be able to meet. National and local charities, and PEOLC staff, described that people often expect traditional hospice care to be available in their area, often because it had been previously accessed by other family members. However, modern PEOLC is different to the traditional model. For example, subject matter advisors told the investigation of perceptions that when a person is dying the best place to be is in a hospice, and that this care will be readily available. The reality is that PEOLC can be provided anywhere and it is not possible to admit everyone who is dying to a hospice; palliative care services have very limited capacity due to 'long-term underfunding'. Inpatient PEOLC (whether in acute or community hospitals, or hospices) therefore focuses on those with the most complex needs that cannot be met elsewhere.

4.1.3 During the investigation's visits to regions and their PEOLC services (summarised in figure 5), and meetings with people with lived experience (see figure 6), an understanding of PEOLC in different parts of the country was developed. Organisations delivering PEOLC and their staff described the difficulties meeting the national Ambitions Framework (see 1.3.3) and the challenges involved in delivering services that meet the needs of their populations. People with lived experience described care that did not meet individual needs and wishes; care that could not be accessed due to the location in which someone lived; confusing PEOLC; and poor co-ordination leading to duplication of work by organisations.

4.1.4 The investigation did not challenge the national Ambitions Framework for PEOLC, which describe and aim for high-quality and accessible services. Rather the investigation sought to understand the gap between the Ambitions Framework for PEOLC and current service delivery, and how the delivery and understanding of PEOLC services may be improved across England.

Figure 5 Examples of palliative and end of life care organisations seen during the national investigation



Figure 6 Quotes from the investigation's meetings with people with lived experience

"It's okay dealing with physical symptoms, but [they] should listen to individuals and their families and consider their emotional needs."

"He needs somebody at the end of a phone who can supply him with the information that can put him down the right pathway."

"He is sitting there with no one to turn to ..."

"She would have got better care if we lived in a different bit of [the county]."

Palliative and end of life care for sarcoma patients

4.1.5 The national investigation did not focus on PEOLC for a specific diagnosis. Rather it aimed to inform learning for the care of patients and families who receive any palliative diagnosis. However, the reference event highlighted the challenges associated with care of people with specific, rare and aggressive cancers, such as sarcoma, and the need to co-ordinate their care.

4.1.6 Staff working in PEOLC told the investigation that, in general, the principles of palliative care management of people with sarcoma are the same as for other cancers. However, Sarcoma UK highlighted that there are nuances about the progression of sarcoma and the intractable nature of some symptoms that may not be known to some staff because it is rare. It was described that people with sarcoma may remain well for a period of time, then suddenly and quickly deteriorate.

4.1.7 The investigation has not investigated the specifics of PEOLC for people with sarcoma. However, the findings of this investigation and particularly Dermot's case suggest potential benefit in ensuring early, specialist support and collaboration between different services to help address a person's symptoms rapidly. There is evidence to suggest that 'specialised palliative care intervention leads to significant symptom relief in patients with advanced [soft-tissue sarcoma]' (Brandes et al, 2021). The investigation was also told by an Honorary Professor of Palliative Medicine that there are potential benefits in oncology and palliative care services working in a more integrated way. For example, close working relationships and a unified clinical record 'meant that continuity of care was far easier to maintain'.

4.2 Access to and co-ordination of palliative and end of life care services

4.2.1 The Ambitions Framework (see 1.3.3) describes that people should be able to expect fair access to care that is co-ordinated and individualised. Individualised care means considering all of a person's needs, including their psychological needs (National Institute for Health and Care Excellence, 2015). The investigation found that individualised care was not always being provided. This was due to confusion about the roles and responsibilities of organisations, variation in the availability of services, and difficulties identifying the needs of populations.

Unclear roles and responsibilities

4.2.2 The investigation found variation in the way common PEOLC terms were defined. This variation was described by national bodies and experts, organisations, staff, and the public. They reported that this variation meant some services were different to what people expected. This was exemplified in the reference event in relation to the perceived differences between a hospice and specialist palliative care (SPC) organisation.

4.2.3 National experts told the investigation that terms and definitions in PEOLC were “troublesome” and had become “medicalised.” This has led to PEOLC being seen as a specialty, rather than recognising it as everyone's responsibility. When this investigation began, NHS England referred to core and specialist palliative care (NHS England, 2016), while organisations and staff used various terms. In January 2023 publications by NHS England started to refer to specialist, targeted, and universal palliative care (NHS England, 2023).

4.2.4 The definitions of SPC (NHS England, 2016) and hospice care (Hospice UK, n.d.a) were found to be sometimes used interchangeably. However, some PEOLC staff described how the two types of care were distinct and different. Some SPC organisations call themselves hospices, and there are hospices that do not see themselves as delivering SPC. The investigation was further told by staff and people with lived experience that it was unclear whether SPC and hospice services are the same or different.

4.2.5 The similarities and differences between SPC and hospice care is a long-standing and international debate (Hui et al, 2013). A hospice at home service told the investigation that it is the level of expertise that determines the type of care, not the location. The investigation found a need for greater clarity for the public and health and care staff on which services PEOLC services deliver. This finding has contributed to the actions for ICBs described later in this section.

Visibility of available services in an area

4.2.6 The investigation found that available PEOLC services were not visible to the public and health and care staff. This made it difficult to find out what services a person could access and what those services could deliver. This is reflected in the reference event, when Dermot's family sought help from an advocacy group to help navigate the system.

4.2.7 Factors that contributed to the limited visibility of services included the variation in definitions discussed in 4.2.2 and the fact that ICBs were not always aware of what was available in their geographical footprints. One ICB visited by the investigation was attempting to map PEOLC services in its footprint, but described problems identifying services and the areas they covered. Hospice UK and national experts further told the investigation that charitable and voluntary sector involvement in PEOLC means that there may be multiple third-sector services in an area, but it may not be clear who they are.

4.2.8 National charities and a subject matter advisor described the importance of ICBs understanding the roles, responsibilities, boundaries, capability and capacity of PEOLC services in their geographical footprints. This understanding is necessary to support commissioning and co-ordination of services to meet the expectations of the Health and Care Act 2022.

4.2.9 The investigation also found that where services were known about, in some areas there had been limited engagement between ICBs and the third sector. This was particularly where there was minimal NHS commissioning of, and therefore involvement in, the design and monitoring of these services. The investigation was told by some third-sector leaders that limited engagement was due to some ICBs not knowing the services in their footprints or not inviting them into discussions, or because some third-sector services did not want to engage. Leaders perceived that more scrutiny from NHS commissioners of hospices and PEOLC services meant more of a focus on 'numbers' rather than 'experiences'.

4.2.10 The investigation found that available PEOLC services were not always visible to those who needed them or needed to know about them to co-ordinate care. Visibility included awareness of information about the types of care offered by different organisations, their catchment areas, and their capacity, particularly those in the third sector. The investigation also found that information needs to be presented in meaningful ways for different communities.

HSIB suggests the following action for integrated care boards

HSIB suggests that integrated care boards should identify and describe the palliative and end of life care services in their areas through engagement with integrated care partnerships and third-sector organisations. This is to provide the public and health and care professionals with accessible and accurate information about available services.

Care co-ordination and out-of-hours support

4.2.11 As described in the previous section, visibility of PEOLC services affected the ability to plan and co-ordinate care across a geographical footprint. Co-ordination was also found to be affected by the number of organisations involved in a person's care and poor interoperability of digital systems containing patient records. In the reference event Dermot's family did not know who was co-ordinating his care as this was not apparent to them. The investigation was told of similar experiences by people with lived experience; not knowing who to contact out of hours if support was needed was a particular concern. The investigation observed that some areas did not have a single helpline number to call for PEOLC. This is in the context of evidence suggesting that community PEOLC is best delivered via a single point of access and 24/7 signposting (RM Partners, 2018).

4.2.12 National experts told the investigation that when multiple organisations are involved in a person's care it can be difficult to know who has overall responsibility and who to go to when urgent help is needed. The investigation heard varying views from organisations and staff about whether a person's GP was responsible for co-ordinating a person's care or whether that responsibility passed to an SPC team once the person had been referred. SPC organisations were supportive of people contacting them for help while under their care but did not necessarily see themselves as having overall responsibility for a person's care.

4.2.13 PEOLC staff told the investigation that assumptions were often made about who was co-ordinating a person's care and this led to missed or duplicated referrals and care. Unclear responsibilities for the co-ordination of patient care has been identified as a theme in other HSIB investigations (Healthcare Safety Investigation Branch, 2021). The formation of ICBs creates an opportunity to develop improved co-ordination of PEOLC services across a geographical footprint; this has also been identified by The King's Fund (2023).

HSIB suggests the following action for integrated care boards

HSIB suggests that integrated care boards support collaboration between health and care organisations to define clear routes of support for people in and out of normal working hours to ensure they know how to access help for palliative care and end of life needs.

Variable availability of services

4.2.14 The Ambitions Framework (see 1.3.3) states that PEOLC should be available to everyone, irrespective of who they are or where they live. The investigation found that availability of PEOLC services varied depending on where people lived in England and this has

affected the services available. For example, in two of the regions visited by the investigation, no inpatient SPC or hospice care facilities were available. Inequalities in PEOLC have also been identified by other national publications (The King's Fund, 2023).

4.2.15 From the regional visits the investigation found several factors that contributed to service variability. These included the location of third-sector organisations (such as local and national charitable hospices); funding of services; and workforce shortages in social care and PEOLC. The variation was also noted by people with lived experience, who were concerned that those commissioning services did not appreciate their populations' needs.

Location of third-sector organisations

4.2.16 National bodies and charities told the investigation that the location of third-sector PEOLC organisations was "haphazard". This was because of the way in which hospice charities had originally been set up. Different ICB footprints therefore had different third-sector provision available. In the reference event there had been no third-sector provision in the area in which Dermot lived (see 3.1.28).

4.2.17 The number of third-sector organisations was not the only geographical challenge for PEOLC identified by the investigation. During visits to different regions, the investigation observed how location affected ease of access to services and heard how it affected staff recruitment.

4.2.18 The investigation visited several large, rural areas with low population densities. These demonstrated the long distances people needed to travel to reach services, or for community SPC staff to reach people in their homes. These issues were also identified by people with lived experience and in the reference event. SPC nurses said that the rurality of areas limited the number of patients they were able to see in a day. Staff also described how large amounts of travelling and rurality meant some could not or did not want to work in those areas. The investigation was told that this highlights the importance of care planning.

4.2.19 Urban areas, in contrast, were described by PEOLC staff as having higher concentrations of organisations delivering services, and potentially attracted more staff to work there. However, capacity of services was still a concern because of demand and workforce shortages in PEOLC and social care.

4.2.20 With regards to national PEOLC charities, the investigation found parts of England where those charities were not available or only provided limited services. The absence of a charity was not always apparent until explored. For example, in one area community SPC nurses were referred to as 'Macmillan Nurses', but they were employed by the NHS with no involvement with the charity. The investigation was told by a national expert that this was the case in other parts of England as well.

Funding of organisations and services

4.2.21 The investigation explored how PEOLC charitable organisations are funded. A national charity told the investigation that inpatient hospice beds are often high cost with a funding 'black hole' (Kirby, 2023). Funding is commonly via charitable donations and through NHS commissioning. While proportions from each source vary, in general around 30% of funding for adult hospices is from the NHS and the rest is charitable. Local hospice charities told the investigation that having minimal funding from the NHS meant they were able to be more autonomous, holistic and focused on the needs of their local population. However, charitable donations vary, particularly in areas of deprivation and during times of economic downturn, such as during a pandemic.

4.2.22 Hospice leaders told the investigation that where the NHS commissions and funds a larger proportion of PEOLC this results in more NHS scrutiny and a more 'medical' focus. This was felt to limit their ability to broaden services beyond a core set, with less consideration of factors such as wellbeing. In contrast, ICBs told the investigation that the involvement of multiple third-sector organisations in PEOLC made it difficult to manage and co-ordinate, and could "leave gaps". This was thought to be because population needs were not recognised, and because of capacity within services. The view of hospice leaders and ICBs again highlighted the importance of ICBs and third-sector organisations working together to deliver for the needs of a population (see 4.2.29).

4.2.23 The investigation explored the reasons why NHS commissioning of PEOLC organisations/services commonly relies on charitable donations. Hospice UK and national experts told the investigation that limited funding was provided by the NHS because historically charities had provided PEOLC services, so there had been no need for the NHS to commission services. There was also thought to be limited impetus to fund PEOLC because it is "niche", "rarely in the media" and generally receives positive reviews.

Social care

4.2.24 PEOLC relies on a co-ordinated approach across 'health, social care and the wider system of public services and community support' (The King's Fund, 2023). However, the investigation found that the capacity of SPC services was affected by the availability of other parts of the system, including social care and other core PEOLC services. In all regions visited there was limited social care resource, district nursing resource, and increasing demand on primary care. In one region the investigation was shown lists of people who needed packages of social care but were unable to receive them due to capacity issues.

4.2.25 The lack of core PEOLC and social care capacity was described by some community SPC organisations as having an impact on services. SPC teams were being required to address extra social, core and specialist needs during home visits. This was observed to be increasing demand on SPC and was thought by nursing teams to be reducing their ability to deliver timely and holistic SPC.

4.2.26 Investigation of the capacity of social care in England was out of scope for this investigation. However, the findings demonstrate how closely linked the roles of health and social care are, and therefore how variation in one sector impacts on the other.

HSIB suggests the following action for integrated care boards

HSIB suggests that integrated care boards should work with integrated care partnerships to account for capacity and resource in social care when planning palliative and end of life care services.

4.2.27 Inequitable access to services may also be influenced by factors outside of the scope of this investigation. The investigation met with Age UK which described that older people may not have the same access to hospice care as those who are younger. Age UK also stated that, despite people with advanced dementia having multiple palliative care needs, they are less likely to be referred to SPC than people with cancer (Quinn et al, 2021).

4.2.28 Hospice UK also told the investigation that there are other groups who are at risk of being discriminated against when attempting to access PEOLC. These groups include people without cancer and the 'oldest old, racialised communities' (Hospice UK, 2021). Other groups such as those from the LGBTQ+ community and people experiencing homelessness may also be at risk (Tobin et al, 2022).

Understanding the needs of a population

4.2.29 The investigation found that ICBs had concerns about meeting the expectations of the Health and Care Act 2022. The Act calls for all ICBs to commission PEOLC services that meet the needs of their populations; guidance from NHS England (2022a) has called for those services to align with the Ambitions Framework (see 1.3.3). In response ICBs and national experts told the investigation that they had questions about 1) how best to seek to understand the needs of their populations, and 2) what PEOLC models best fitted with those needs.

4.2.30 To support the requirements of the Health and Care Act 2022, national guidance and service specifications have been published (NHS England, 2022a; 2022b; 2023). However, the publications do not describe what data ICBs should collect to understand population needs. The

investigation was also told by national experts that there is no 'national data set' for PEOLC to help understand populations' demographics and needs. A national body advised that in 2016 Public Health England piloted a data set, but it was not taken forward due to the associated costs.

4.2.31 As observed by the investigation, this meant each ICB was taking a different approach to collecting data and evaluating needs. The King's Fund (2023) identified similar in their work focusing on end of life care at home, noting that ICBs are not 'making good use of the data' and that there should be more support for ICBs to help collect and understand data about their populations.

4.2.32 ICBs agreed that they needed more support to achieve the expectations of the Health and Care Act 2022 and to understand the needs of their populations. The investigation engaged with NHS England's National Programme Team for Palliative and End of Life Care to make the following safety recommendation. Any data set would likely include quantitative and qualitative data to ensure the experiences of people are included.

HSIB makes the following safety recommendation

Safety recommendation R/2023/233:

HSIB recommends that NHS England specifies a palliative and end of life care data set to help integrated care boards to understand their populations' demographics and needs, in order to support commissioning and improvement of services.

Models of care

4.2.33 Across the regions visited the investigation saw different approaches to the delivery of PEOLC. Some regions had inpatient hospices, specific services for families and informal carers, and hospice at home (see 1.4.6) services, while others did not. The investigation was told by ICBs and community SPC organisations that hospice at home was a potentially beneficial model, particularly as care becomes increasingly delivered in people's homes. However, the investigation heard about a mismatch between the move to deliver care at home and investment in home-based services. There were also concerns about the value of hospice at home and the variety of potential models (Butler and Holdsworth, 2013). During the period of the investigation the National Institute for Health and Care Research published research into the optimum models for hospice at home (Butler et al, 2022).

4.2.34 The different models of PEOLC led the investigation to explore whether there was a minimum set of services which all people could expect to receive, no matter where they lived. The investigation found several sources of guidance, including from the National Institute for Health and Care Excellence (2015; 2019), but no minimum, fundamental level of care or standard has been described. ICBs and organisations therefore have no guidance about the PEOLC services that they must deliver for everyone in their footprint. The investigation was told by ICBs that the previous Ambitions Framework (see 1.3.3) for PEOLC set out useful principles, but did not give the detail they needed, further contributing to the variability seen in services across the country.

4.2.35 During this investigation NHS England (2023) published a service specification for specialist palliative and end of life care for adults. The specification sets out an 'adult service model', but several national bodies told the investigation that it does not provide the required detail to support ICBs to commission adequate services for a local context, nor the minimum services that must be provided. The investigation engaged with NHS England's National Programme Team for Palliative and End of Life Care to make the following safety recommendation.

HSIB makes the following safety recommendations

Safety recommendation R/2023/234:

HSIB recommends that NHS England develops and promotes a minimum expected service specification for specialist palliative care in England to clarify the minimum services a person can expect to be available to them no matter where they live.

4.3 Societal expectations of death and dying

4.3.1 The Ambitions Framework (see 1.3.3) describes that communities should be prepared to help at times of 'crisis and loss'. This includes supporting people to have open discussions around 'living and dying well'. Across the regions visited, the investigation found public beliefs that health and social care will provide for people at their times of need with access to care such as admission to a hospice (see 4.1.2).

4.3.2 The investigation found limited community-focused efforts to involve the public in conversations around PEOLC. One region visited had developed a 'social contract' between the [former] clinical commissioning group and the public. This aimed to clarify what PEOLC organisations and services were available, what the public could do to help support health and social care, and what they could expect from services. The investigation was also told of the role the contract had in supporting people to talk about death.

Supporting discussions about death and dying

4.3.3 The investigation was told by PEOLC staff that talking about death is seen by some of the public as “taboo” and there is limited support to talk about it honestly (Hospice UK, n.d.b). Seeing death as a taboo subject was described by Lofland (2019) to be because of the way dying has changed. More people now die from long-term rather than sudden problems and there is greater involvement of healthcare at death. These changes have resulted in families and communities losing ‘familiarity and confidence in supporting death’ (Sallnow et al, 2022).

4.3.4 The investigation was told by hospice leaders that advances in medicine and the development of specialist services for PEOLC had led to care becoming increasingly ‘medicalised’. This means that death may be seen as an illness rather than an outcome. Medicalisation was described by some hospices to have contributed to the public seeing death as something that can be “fixed”.

4.3.5 PEOLC staff called for the need to “normalise death and dying”. To do this requires increased community-based support for people. The investigation became aware of the ‘compassionate community’ concept which is orientated around building supportive, community environments to help with health promotion and support (Dumont et al, 2022). This concept may increase discussion in communities around death and dying, and lead to the development of greater mutual aid.

4.3.6 The investigation also met with the charities Compassion in Dying and Age UK to explore how discussions around dying and a person’s wishes can be supported. Compassion in Dying referred the investigation to various sources of evidence that suggest that death may not always be a taboo subject for people, but rather people are not given opportunities by healthcare professionals early following a diagnosis to discuss death and their plans (Care Quality Commission, 2021; YouGov, 2019). It further told the investigation about how it had reframed conversations around death and dying as “important” rather than “difficult”. Age UK has also developed a resource to support people of all age groups to open up conversations about death and dying (Age UK, 2020); it describes coping with death as an ‘intergenerational challenge’.

HSIB suggests the following action for integrated care boards

HSIB suggests that Integrated Care Boards should support collaboration between health and care organisations, including those in the voluntary and charitable sectors, to encourage more open discussions about death and dying in their local communities, accounting for their population demographics.

4.3.7 Compassion in Dying agreed that there was a need for a public campaign to raise awareness around death and dying. This has been echoed by the Care Quality Commission (2021). However, to undertake a campaign requires widely publicised and accessible information on a national scale in partnership with third-sector and advocacy services. The investigation was told that national efforts to undertake this public-focused work had stalled and required “re-invigorating”.

4.4 Workforce competency and preparedness to care

4.4.1 The Ambitions Framework (see 1.3.3) describes that people should expect to receive care from staff who are competent and ‘prepared to care’ (that is, they have empathy, skills and expertise). The investigation found no national competency-based training package for the development of specialist non-medical staff in SPC. Hospice 1 in the reference event told the investigation that it had developed its own bespoke course.

4.4.2 The investigation was told by national bodies that the lack of a training package limited recruitment into SPC, particularly from the allied health professions (for example, physiotherapists and paramedics). The investigation heard from PEoLC organisations that demand for their services was often greater than the capacity of their workforces.

4.4.3 NHS England told the investigation that there is a Palliative Care Career Development Programme currently under consideration. The programme will aim to initially develop foundational and fundamental knowledge for staff, and then to implement a career pathway and capabilities framework for the PEoLC workforce. The investigation was told that this will help to address the identified gaps around a competency-based approach to developing SPC practitioners. It was agreed by NHS England that it would be beneficial to ensure the development of the career pathway progresses and that it is accessible to all relevant healthcare professionals, not solely nursing, and that training includes insights from people with lived experience.

HSIB makes the following safety recommendation

Safety recommendation R/2023/235:

HSIB recommends that NHS England commissions palliative and end of life care career pathways, ensuring that they include staff from the allied health professions, in order to build specialist workforce capacity.

4.4.4 NHS England also told the investigation that, with the Health and Care Act 2022 placing responsibility on ICBs to provide appropriate PEOLC services, there is a need to ensure that the workforce has the required knowledge and skills. ICBs should be clearly evidencing PEOLC in their strategic workforce plans.

HSIB suggests the following action for integrated care boards

HSIB suggests that integrated care boards include palliative and end of life care in strategic workforce plans to ensure staffing of services is appropriately capable and can provide the capacity needed to meet demand.

5 Summary of findings, safety recommendations and actions for integrated care boards

Health and care services in England are not always able to provide individualised, equitable and co-ordinated PEOLC to meet the holistic needs of people and their families. They are unable to consistently provide what people have been led to expect from PEOLC.

Holistic assessments for PEOLC may focus on physical care needs, with more limited attention to identifying, understanding and addressing other care needs, particularly psychological needs.

The availability of PEOLC across England is variable and inequitable. This is influenced by the location of third-sector organisations, available charitable donations and NHS commissioning, and workforce shortages. There is no stated minimum standard for PEOLC that all people must be able to access.

There is limited information to help the public and health and care staff to identify, access, and understand the roles of different aspects of PEOLC, with variation in words and definitions.

PEOLC services are not always able to proactively plan care for people whose condition will deteriorate because of limited inpatient PEOLC and the unpredictability of some diagnoses.

There is limited, specific guidance to support integrated care boards to identify the PEOLC needs of their populations in line with the expectations of the Health and Care Act 2022, and what could/should be done to address those needs.

There is limited support available for health and care professionals to have honest conversations with people around death and what to expect, and to plan for the end of life.

HSIB makes the following safety recommendations

Safety recommendation R/2023/233:

HSIB recommends that NHS England specifies a palliative and end of life care data set to help integrated care boards to understand their populations' demographics and needs, in order to support commissioning and improvement of services.

Safety recommendation R/2023/234:

HSIB recommends that NHS England develops and promotes a minimum expected service specification for specialist palliative care in England to clarify the minimum services a person can expect to be available to them no matter where they live.

Safety recommendation R/2023/235:

HSIB recommends that NHS England commissions palliative and end of life care career pathways, ensuring that they include staff from the allied health professions, in order to build specialist workforce capacity.

HSIB suggests the following actions for integrated care boards

- Identify and describe the palliative and end of life care services in their areas through engagement with integrated care partnerships and third-sector organisations. This is to provide the public and health and care professionals with accessible and accurate information about available services.
- Support collaboration between health and care organisations to define clear routes of support for people in and out of normal working hours to ensure they know how to access help for palliative care and end of life needs.
- Work with integrated care partnerships to account for capacity and resource in social care when planning palliative and end of life care services.
- Support collaboration between health and care organisations, including those in the voluntary and charitable sectors, to encourage more open discussions about death and dying in their local communities, accounting for their population demographics.
- Include palliative and end of life care in strategic workforce plans to ensure staffing of services is appropriately capable and can provide the capacity needed to meet demand.

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7 Appendices

Appendix A Investigation approach

Decision to investigate

The national issues relating to access to, and the quality of, palliative and end of life care (PEoLC) were assessed against HSIB's investigation criteria, as follows:

Outcome impact – what was, or is, the impact of the safety issue on people and services across the healthcare system?

Dying is inevitable and should be dignified; the holistic needs of people who are dying and their families should be met. Intelligence received by HSIB has shown that PEoLC is not always of high quality, with variation in services across England. Care may fall below the expectations and needs of people and their families, resulting in physical and psychological harm.

Systemic risk – how widespread and how common a safety issue is this across the healthcare system?

National publications since 2004 have suggested that there are limitations in the delivery of PEoLC in England. These limitations may be more noticeable in areas where funding for services is limited or where care is being delivered across wide geographical areas. The need for PEoLC is increasing as the population grows and people live longer.

Learning potential – what is the potential for an HSIB investigation to lead to positive changes and improvements to patient safety across the healthcare system?

National publications have described the limitations of PEoLC for several years. This investigation adds to learning to support improvements in PEoLC in England through the lens of a systems-based investigation.

Evidence gathering and verification of findings

Evidence gathering

The investigation:

- visited Dermot's wife, and met his sister and brother-in-law via video call
- received submissions in writing from the family describing their experiences
- interviewed staff from health and care services involved in Dermot's care and visited the community hospital where Dermot was cared for

- visited several hospices in and outside of the area where Dermot lived
- gathered further evidence from Dermot's clinical records; relevant local and national policy and guidance; and academic literature.

For the national investigation, the investigation:

- examined PEOLC in five regions of England which included areas with large geographical footprints, in both rural and urban areas
- visited, either in person or virtually, hospices, community hospitals, primary care organisations and clinical commissioning groups/integrated care boards
- gathered further evidence from national publications and academic literature
- gathered the experiences of people with lived experience of family members who had required PEOLC
- engaged with national stakeholders and experts as shown below.

Analysis of the evidence

The following methods/frameworks were used:

- Systems Engineering Initiative for Patient Safety (Holden et al, 2013)
- AcciMap (Svedung and Rasmussen, 2002).

Stakeholder engagement and consultation

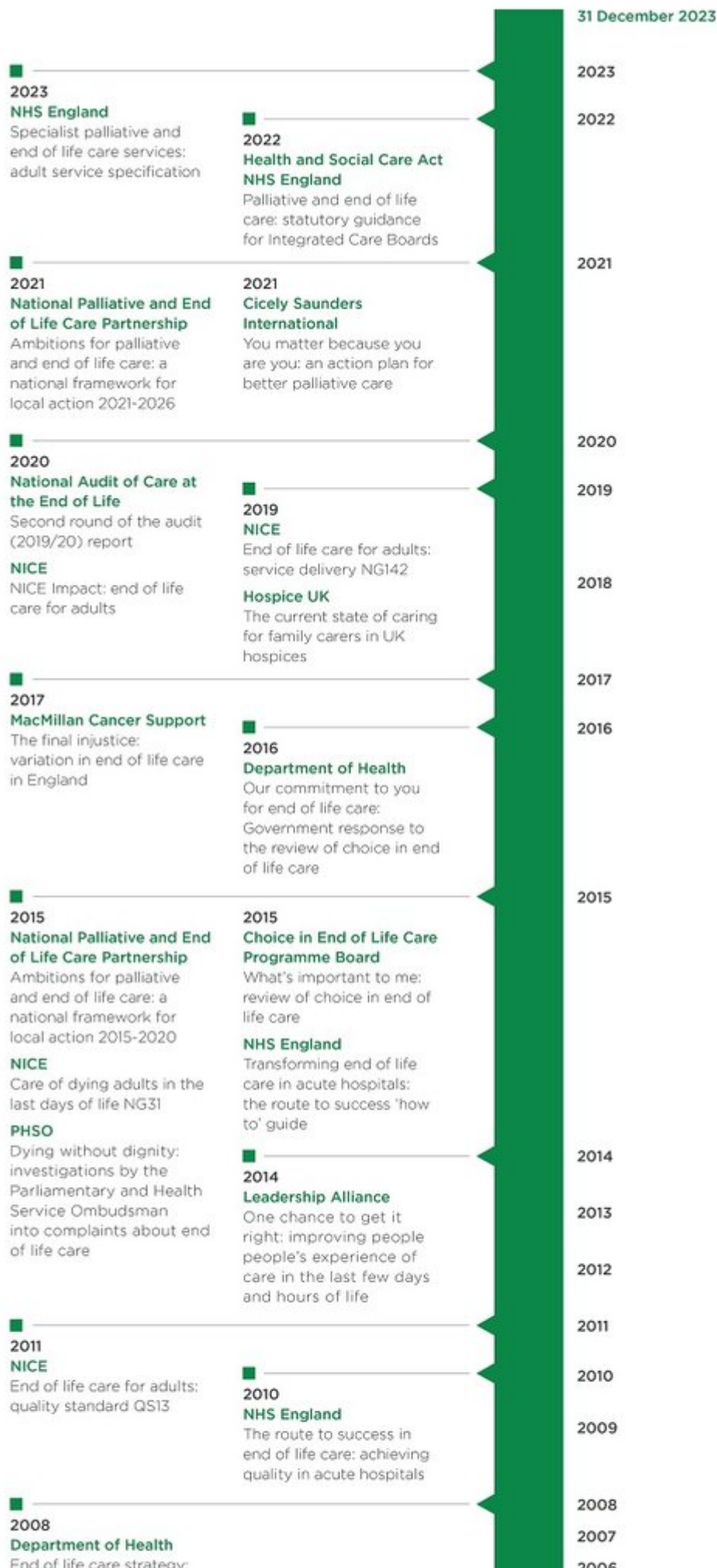
The investigation engaged with stakeholders and subject matter advisors to gather evidence during the course of the investigation. This also enabled checking for factual accuracy and overall sense-checking. The stakeholders contributed to the development of the safety recommendations based on the evidence gathered.

Stakeholders included:

Regions engaged with	National organisations	Other stakeholders
Region 1 (reference event region): large area, small population, mainly rural	NHS England (clinical directorate and education leads)	Subject matter advisors
Region 2: large area, small population, mainly rural	Department of Health and Social Care	Consultant in palliative care
Region 3: large area, small population, mainly rural	Association of Palliative Medicine	Member of UK Parliament

Region 4: small area, large population, mainly urban	National Institute for Health and Care Excellence	Honorary Professor of Palliative Medicine
Region 5: medium area, medium population, mix rural and urban	Choice Support	People with lived experience
	Sarcoma UK	
	Hospice UK	
	Marie Curie	
	Age UK	
	Compassion in Dying	

Appendix B National publications considering palliative and end of life care between 2004 and 2023



CQC: Care Quality Commission

NICE: National Institute for Health and Care Excellence

PHSO: Parliamentary and Health Service Ombudsman

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