Palliative and
End of Life Care

West Yorkshire
Health and Care Partnership

NHS
NHS West Yorkshire
Integrated Care Board

West Yorkshire Palliative and End of life Care Health Needs Assessment

Contents

Acknowledgments

We extend our sincere gratitude to everyone who contributed to the development of this Health Needs Assessment (HNA). Each contribution has been invaluable, playing a crucial role in shaping its findings and recommendations.

A special thank you to the NHS West Yorkshire Integrated Care Board contributors, whose expertise and support have been instrumental in guiding this HNA to completion:

Nazreen Iqbal, Kulvant Sandhu, Michelle Bennett, Amy Kenyon - West Yorkshire Integrated Care Board, Palliaitve and End of life Care Programme

We would also like to thank our wider colleagues who generously contributed their time and expertise throughout the development of this HNA:

Deborah Penfold - Bradford Integrated Care Board / Shipley Medical Practice

Elizabeth Price - Bradford Teaching Hospitals NHS Foundation Trust

Rebecca Owen - Marie Curie

Michael Crowther - The Kirkwood

Adam Hurlow - Leeds Teaching Hospitals NHS Trust

Diane Boyne - St Gemma's Hospice

Jamilla Hussain - Bradford Teaching Hospitals NHS Foundation Trust

Emily Parry-Harries - Public Health Team Kirklees Council

Ross Smith - Leeds Teaching Hospital NHS Trust / Martin House Children's Hospice

Jo Rooney - West Yorkshire Integrated Care Board, Children and Young People Programme

Helen Laird - Public Health Team Leeds Council

Alison Harwood - Wakefield Hospice

Hazel Pearse and Paul Ashwood - Mid Yorkshire Teaching NHS Trust

Eloise Kane - Sue Ryder

Julie Williams - Locala

Thank you to our lived experience partners who were also part of our Task & Finish group. We deeply appreciate the time, trust, and openness they brought to this process, enriching our work with their invaluable insights.

Finally, we would like to offer a heartfelt thanks to the patients, carers and relatives of the bereaved who took part in the Healthwatch case studies and to Healthwatch staff who delicately navigated discussions around this sensitive topic with people in our communities.

Foreword

Palliative and end of life care is about far more than clinical treatment, it is about dignity, choice, and ensuring that every individual, regardless of their background or circumstances, can experience care that is compassionate, personalised, and equitable. In West Yorkshire, we are committed to improving palliative and end of life care for all, ensuring that individuals and their families are supported through some of life's most challenging moments.

This Health Needs Assessment (HNA) is a vital step towards that goal. It provides a comprehensive overview of the current landscape of palliative and end of life care across West Yorkshire, highlighting both the progress made and the areas where improvement is needed. It identifies disparities in access, experiences, and outcomes, particularly among groups facing health inequalities, and offers key recommendations to address these challenges.

At the heart of this assessment are the voices of those with lived experience - patients, carers, families, and professionals who have shared their stories, insights, and expertise. Their contributions have shaped our understanding and will guide our efforts in building a system that is inclusive, responsive, and sustainable.

This work aligns with NHS England's Ambitions Framework for Palliative and End of life Care, reinforcing our commitment to ensuring that:

- Every person is seen as an individual
- Everyone has fair access to care
- Comfort and wellbeing are maximised
- Care is well co-ordinated
- All staff are prepared to care
- Each community is ready to support those at the end of life

I want to express my sincere gratitude to everyone involved in developing this HNA, from the dedicated professionals across our healthcare, voluntary, and hospice sectors, to the individuals and families who have shared their experiences. Your insights and commitment will be instrumental in shaping the future of palliative and end of life care in West Yorkshire.

By working together, we can create a future where everyone receives the care they need at the end of life, in the place of their choosing, and with the support they deserve.

Rob Webster
Chief Executive

1.0 Executive summary

Introduction

West Yorkshire Integrated Care Board's (WY ICB) Palliative and End of life Care (PEoLC) programme is committed to developing a vision for PEoLC that allows individuals in West Yorkshire to die in their preferred location, surrounded by loved ones and with their end-of-life wishes respected. To help develop this vision, we commissioned Healthwatch between 2023-2024 to engage with residents of West Yorkshire about their current experiences of end of life care services. The experiences are captured within a Healthwatch report, this then followed by conducting an all-age Health Needs Assessment (HNA) to evaluate the current palliative care needs across West Yorkshire to identify gaps in services, accessibility, and overall care delivery for individuals in the palliative and end stages of life, with a particular focus on those who experience health inequalities. The HNA analysed data from many sources and was done in collaboration with key palliative care stakeholders including hospital, hospice and care home staff, individuals with lived experience and voluntary sector partners.

This HNA is structured around how we are making progress against NHSE's Ambitions Framework for Palliative and End of life Care, the outcomes will be used to identify areas for improvement and implement our vision for more equitable provision of PEoLC in our region. During the development of this HNA, some Places have also begun to prioritise their own population's PEoLC needs, highlighting them within their Director of Public Health (DPH) annual reports. Place refers to one of the five areas that make up West Yorkshire: Leeds, Bradford, Wakefield, Kirklees, and Calderdale

Additionally the WYICB PEoLC programme presented the findings and recommendations of this HNA to the WYICB Board in December 2024, seeking a system-wide commitment to reducing health inequalities for those requiring PEoLC in our region. We recommend using this HNA as a foundation for PEoLC services across the region to collaborate on a transformation programme, driving quality improvement and more equitable care.

Findings

These HNA findings will be used to guide the development of equitable PEoLC services across West Yorkshire, ensuring compliance with statutory duties. The HNA aimed to address health inequalities affecting protected characteristic groups and populations significantly impacted by health disparities, including those living in poverty, individuals with learning disabilities, those with serious mental illness, unpaid carers, ethnic minority groups and homeless people. The HNA findings are centred on NHSE's six ambitions for PEoLC framework and are summarised below;

Ambition one - Each person is seen as an individual

- The Quality and Outcomes Framework (QOF) encourages GPs to maintain accurate registers of patients with long-term conditions, including those requiring palliative care, yet data accuracy and completeness remain challenging.
- Advance care planning (ACP) discussions are crucial for ensuring patients' end-of-life wishes are respected, yet workforce confidence in having these conversations varies, highlighting the need for further training and support.

- Many relatives of deceased adults experienced unclear communication regarding diagnosis, prognosis and end-of-life expectations.
- Parents of children with life-limiting conditions generally found health and care professionals to be supportive and attentive to their needs. However, some relatives of adults described poor experiences in care homes and hospitals, citing a knowledge gap in some staff and issues with dignity and care. There were instances where ACPs were not implemented, causing distress for relatives. Conversely some care home staff were praised for their emotional support to both residents and their families.

Ambition two - Each person gets fair access to care

- The HNA highlighted that health inequalities are evident within PEoLC across West Yorkshire. West Yorkshire faces significant deprivation challenges, indicated by various metrics such as the Index of Multiple Deprivation (IMD), income deprivation, child poverty, older people in poverty, fuel poverty and overcrowding. These indicators show that West Yorkshire performs worse than the national average, highlighting widespread deprivation across nearly all areas.
- The HNA also highlighted inequalities related to protected characteristics and vulnerable populations impacted by health disparities. These groups include individuals living in poverty, those with learning disabilities, individuals coping with serious mental illness, unpaid cares, people in contact with the justice system, ethnic minority communities and homeless individuals. The average age of death in these groups is significantly lower than the general population.

Ambition three - Maximising comfort and wellbeing

- The Healthwatch report highlighted inconsistencies across West Yorkshire in terms of whether staff always checked care met the patient's needs.
- Some people reported poor experiences in care homes, including repeated falls and staff not knowing where emergency buzzers were. Delays in cancer diagnosis and inadequate care during in-patient stays, such as the use of degrading equipment and lack of communication about prognosis, were also highlighted.
- Issues with timely delivery of necessary equipment, like commodes and beds caused significant distress for families trying to care for their loved ones at home.
- Some case studies highlighted issues with pain management at the end of life, including over-medication and inconsistent pain relief, causing significant distress for patients and their families. Relatives often found themselves caught between care homes and GPs, chasing necessary medications and dealing with delays in receiving pain relief.
- Positive experiences included personalised support from hospice staff and the opportunity for relatives to stay overnight with their loved ones. However, there is a widespread fear of hospices and a lack of public awareness about the comprehensive services they offer. Ensuring appropriate environments and addressing workforce issues are crucial for improving end of life care.

Ambition four - Care is co-ordinated

- The HNA revealed variability in 24/7 PEoLC provision. While many services offer elements of 24/7 PEoLC, they are not uniformly available across West Yorkshire and typically serve only known patients, though they do provide support and advice when contacted.
- A significant issue identified is the lack of full interoperability between electronic patient records for EPaCCS or ReSPECT. Various providers (including primary care, community nursing, hospitals, hospices, out-of-hours GPs, Yorkshire Ambulance Service (YAS), adult social care, and mental health trusts) use multiple systems beyond SystemOne and EMIS. The degree of challenge varies by area, and West Yorkshire-wide providers, such as Leeds Teaching Hospitals NHS Trust (LTHT) as a tertiary provider and YAS, add another layer of complexity.
- Parents of children and young people reported that care was well-coordinated, with examples of effective collaboration between schools and other services.
- In contrast, Healthwatch case studies from adults revealed issues with coordinating care, emphasising need for a single point of contact and better communication among medical teams before speaking with patients. Patients felt more supported when hospices were involved as they helped navigate the healthcare system more effectively.

Ambition five - All staff are prepared to care

- The HNA stakeholder survey highlighted that across West Yorkshire all five Places have established boards. These boards play a crucial role in reporting and escalating issues, facilitating collaboration among relevant agencies, and ensuring good governance and accountability.
- Patient-Centred Care: The HNA highlights that personalised care empowers individuals to make their own decisions and maintain some control during their PEoLC journey. According to the Healthwatch report, 80% of respondents felt that staff were kind and caring and 71% believed that staff possessed all the necessary skills. Additionally, 59% of respondents reported that staff consistently checked to ensure that care met the needs of both patients and their relatives. However, the report also highlighted areas needing improvement. Only 40% of respondents had discussed their end-of-life wishes with services and just 39% were consistently informed about what to expect from their end of life care. These findings indicate a need for further development in communication and personalised care planning.

Ambition six - Each community is prepared to help

- The HNA highlighted the importance of living in a community where everybody is ready, willing, and confident to have conversations about living and dying well and to support each other in emotional and practical ways.
- Many areas of good and innovative practice were described, including community outreach projects, death cafes and an NHS pilot involving end of life doulas. Funding is hard to obtain, as shown by the closure of the highly regarded Leeds Bereavement Forum after 28 years.

- The HNA showed that more work is needed to raise awareness and build resilience within communities. People described the fear their loved ones experienced at the end of life and the need for more support and open discussions, as well as access to bereavement support.

Key Recommendations

- **Ensure equity and access for all:** Tackle health inequalities by utilising local expertise to create accessible and inclusive pathways and services tailored to the needs of marginalised groups. Preserve exemplary practices, such as Leeds St. Gemma's PEoLC inclusion service, which stands out as an effective model providing critical PEoLC support to health inclusion groups.
- **Strengthen partnership working:** Develop collaborative relationships across the system to create equitable and financially sustainable PEoLC services for the future. This includes our VCSE and hospice sectors, which play a vital role in delivering PEoLC.
- **Strategic use of data:** Promote the consistent collection and application of data across West Yorkshire to guide decision-making and enhance service planning.
- **Service coordination:** Improve integrated system working where services collaborate seamlessly, alleviating the burden on families and improving the overall care experience.
- **Workforce education and training:** Offer comprehensive training and professional development opportunities to equip the workforce with the skills needed to deliver high-quality PEoLC.
- **Advance care planning (ACP):** Enhance personalised PEoLC, particularly for individuals with multimorbidity, by promoting ACP. This ensures that professionals are aware of and can respect individuals' preferences and wishes for their end of life care. This includes ensuring the workforce is equipped with the skills to confidently and effectively initiate ACP discussions.
- **24/7 access to care:** ensure equitable, round-the-clock access to responsive and timely PEoLC for all patients and their families.
- **Improve public awareness and education:** Promote greater awareness of death, dying, and the role of palliative care in West Yorkshire, while providing clear information on how individuals can access these vital services when required.
- **Enhance community and family support:** Strengthen community and family engagement by developing care models that allow people to receive care closer to home, including improved access to bereavement support.

2.0 Background

West Yorkshire Integrated Care Board's (WY ICB) Palliative and End of life Care (PEoLC) all age programme has an ambition for PEoLC in our region that allows individuals to die in their preferred location, surrounded by loved ones and with their end-of-life wishes respected. Our PEoLC programme objectives are aligned to NHS England's (NHSE) "Ambitions for Palliative and End of life Care" framework (2021) and NHS England's ICB statutory guidelines for commissioning of PEoLC services.

A task and finish group of key stakeholders set up to oversee, advise and support the development of the findings and recommendations. The outcomes will be used to identify areas for improvement and implement our vision for more equitable provision of PEoLC in our region.

2.1 Aim of the HNA

The aim of this HNA is to identify how the West Yorkshire region is making progress against NHS England's (NHSE) Ambitions Framework for Palliative and End of life Care: A national framework for local action (2021). The core purpose of the HNA is to guide the future development of equitable PEoLC services across the West Yorkshire footprint. The HNA will also assist us in meeting the statutory responsibilities of the WY ICB in this area.

Outcomes from the HNA will be used to implement an equitable delivery of PEoLC services in line with our vision and identify areas for improvement. This will be undertaken by working with people with lived experience and their carers, the public, the voluntary sector, Place colleagues and regional programmes.

The HNA will focus on inequalities for individuals who fall under the protected characteristics and populations that are greatly affected by inequalities in health. This includes those living in poverty, people with learning disabilities, those living with serious mental illness, unpaid carers, those in contact with the justice system, ethnic minority groups and homeless people.

The ICB has a duty to report on health inequalities, including reducing health inequalities in accessing health services, and reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services (NHSE, 2024).

The HNA work has been completed through the analysis of data from a variety of sources and collating the experiences of local people and communities to identify and address local avoidable health inequalities specific to PEoLC. The HNA has taken a combination of epidemiological and corporate approaches.

2.2 National policy and guidance

End of life care is on the national agenda and there are some key policies and drivers for this work. The first 'End of life Care Strategy', published in 2008, highlighted the challenges society faces around death and dying. This contained three key findings:

- People did not die in their place of choice
- The need to prepare for larger numbers of dying people
- Not everybody received high quality care.

This is still relevant today as we know these issues are still applicable and programmes of work are in place in varying forms to rectify them across the region. In 2009 the 'Dying Matters Coalition' (Department of Health, 2012) was the first comprehensive framework aimed at promoting high quality care across the country for all adults approaching the end of life. It was set up to increase the profile of end of life care and to change attitudes about death and bereavement in society. In addition, it focused on commissioning, funding, research, care planning and coordination in identifying people approaching the end of life.

For several years, the National Institute for Health and Care Excellence Quality Standard (QS13, 2011) for end of life care has used 'place of death' as a quality indicator for PEoLC. This was initially published to provide comprehensive guidance on what high quality end of life care should look like. It sets out 16 markers of high-quality care for adults who require end of life care that will help result in an increased length of time spent in their preferred place of care during that last year of life, a reduction in potentially avoidable admissions and reduction of deaths in hospitals.

The independent review 'Choice in End of life Care' (2015), shared the views of patients, explaining, patients wanted choice in their place of care and death; others said they wanted choices over other aspects of their care, such as pain control and involvement of family and those close to them. The document offers a blueprint for how greater choice in end of life care can be achieved. The advice focused on a 'national choice offer' - a simple expression of what should be offered to everyone who needs end of life care.

In 2016 the government response to the above independent review made six commitments to end variation in end of life care by 2020:

1. Have honest discussions with care professionals about their needs and preferences.
2. Make informed choices about their care.
3. Develop and document a personalised care plan.
4. Discuss their personalised care plans with care professionals.
5. Involve their family, carers and those important to them in all aspects of their care as much as they want.
6. Know who to contact for help and advice at any time.

Source: *Department of Health. (2016). Choice in end of life care: government response.*

In 2015 the 'Ambitions for Palliative and End of life Care: A national framework for local action' was published, building on the 2008 'Strategy for End of life care'. There has been a refreshed version of this, a reminder that more must be done. Monitoring who dies and where is important in delivering high quality palliative and end of life care. The 'Ambitions for Palliative and End of life Care Framework' highlights that this is not just about distribution of appropriate services, but that personal choice needs to be respected in place of care and death. This is fundamental to the lived experience of the dying and their families.

The updated 'Ambitions Framework for Palliative and End of life Care' (2021) provides a framework for each Integrated Care System (ICS) to evaluate commissioning and delivery of their palliative and end of life services. This builds upon the NHS Long Term Plan (2019) commitment for PEoLC including increasing identification for people likely to be in their last 12 months of life and those people being offered personalised care and support planning, alongside ensuring workforce training. This differs for children and young people, the Specialist Palliative and End of life Service specification (B1675, 2023) states 'Access to palliative care should not depend on diagnosis or overall prognosis and can be provided at any stage of a child or young person's illness.

The NHS England 'Palliative and End of life Care National Delivery Plan' (2022–2025) sets out a three-year trajectory for PEoLC, focusing on improving access, quality, and sustainability. It explains that palliative care services are included within the Health and Care Act 2022 and specifies that ICBs have a legal duty to commission palliative care services within Integrated Care Systems, guidance has been developed by NHS England to support that duty. The guidance is statutory and ICBs must have regard to it. The ambitions are listed below and the HNA findings will be structured around these.

Six Ambitions for Palliative and End of life Care:

- **Each person is seen as an individual.**
- **Each person gets fair access to care.**
- **Maximising comfort and wellbeing.**
- **Care is coordinated.**
- **All staff are prepared to care.**
- **Each community is prepared to care.**

Source: *National Palliative and End of life Care Partnership (2021). Ambitions for Palliative and End of life Care: A national framework for local action.*

The Health and Care Act (2022) placed a statutory duty on ICBs to commission PEoLC provision to adequately meet their local population need. This role sits alongside the requirement to commission hospital services and other important core elements of healthcare. It is recognised that a proportion of PEoLC is provided by charitable hospices and that only around one third of their funding currently comes from statutory sources. However, the current commissioning process for hospices is not fit for purpose. The commissioning guidance recommends that ICBs prioritise PEoLC in joint strategic needs assessments to guide commissioning decisions. Additionally, it suggests that hospices should be offered multi-year contracts, with contract uplifts that are equitable with both NHS-run services and other hospices in the region.

2.3 Current delivery of PEoLC

The NHSE Commissioning and Investment Framework (2022) classifies PEoLC services into three tiers:

- Core - Basic provision required across all healthcare settings.
- Specialist - Advanced services requiring expert knowledge and skills.
- Enhanced - Additional services that complement core and specialist provision.

Currently across the region, the majority of patients will be receiving 'core' PEoLC provided by NHS primary care, community nursing teams, hospital teams and some hospices. PEoLC patients with more complex needs will receive 'specialist' input from hospices, community specialist teams and hospital-based specialist teams. The majority of 'enhanced' provision is provided by third sector organisations offering other components of support, for example complementary therapies and bereavement counselling. ICBs have a statutory duty for commissioning of 'core' and 'specialist' PEoLC provision.

For children in the West Yorkshire region, those identified patients receive specialised PEoLC provided by NHS hospital teams or the two children's hospices in the region. It is not currently known how many children would be eligible or would wish to access support from dedicated children's palliative care or hospice services. However, it is expected that all children with PEoLC needs would benefit from some elements of the palliative care approach and their families being aware of the support available from children's palliative care services (Fraser et al 2021).

2.4 Definitions

At this point, it is helpful to clarify some key terms commonly used in the PEoLC field.

Dixon et al (2015) defined **palliative care** as active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. Palliative care aims to ensure the best possible quality of life for individuals at end of life or with advanced illness, and their families.

They went on to explain **end of life care** as referring specifically to care provided in the last phase of life. This is often defined as approximately the last year, but end of life care can also sometimes be used to refer to the last weeks or even days of life. For 'carers' this can include care into bereavement.

Care of the dying patient is generally referring to care in the last days or hours of life to ensure comfort and dignity.

One key difference between **paediatric palliative care** and adult palliative care is the World Health Organisation recommendation which states that paediatric palliative care "begins when illness is diagnosed and continues regardless whether a child is treated for the disease or not". This means that children and their families may require care and support for a prolonged period of time, experience shows us this may be more than 25 years in some instances.

Rietjens J et al. (2017) describe Advance care planning as enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.

Furthermore, The Universal Principles for Advance care planning (2022) describe Advance care planning as a:

'voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care. These are likely to involve a number of conversations over time and with whoever the person wishes to involve. When advance care planning is done well, people feel they have had the opportunity to plan for their future care. They feel more confident that their care and treatment will be focused on what matters most to them in a personalised, holistic way and helps them to live as well as possible.'(p4).

2.5 Local policy and guidance

Locally NHS WYICB's Joint Forward Plan (2024) includes a commitment for this HNA to be conducted, and the work being focused on the six ambitions for PEoLC framework. This coordinated and joined up approach will ensure the findings from this HNA are implemented in practice with key stakeholders in the PEoLC system within West Yorkshire.

2.6 Existing evidence

As part of this HNA an extensive literature review was conducted to identify key themes and relevant research specific to the West Yorkshire region. The full literature review can be found in Appendix 1.

3.0 Epidemiology - Demographics

This section presents the data on the population of West Yorkshire and on palliative and end of life care where it is available. Several data sources have been used to present this information. For the purpose of this HNA where Places are referred to, Bradford will be identified as Bradford District and Craven, since from a health perspective the boundaries identify this as one Place. However, some of the data sets available such as the census use local authority data which excludes Craven within the West Yorkshire data.

The 2021 census data shows the West Yorkshire population is 2.35 million, made up of the following district population;

- Leeds - 812,000.
- Bradford - 546,000.
- Kirklees - 433,000.
- Wakefield - 353,000.
- Calderdale - 206,000.

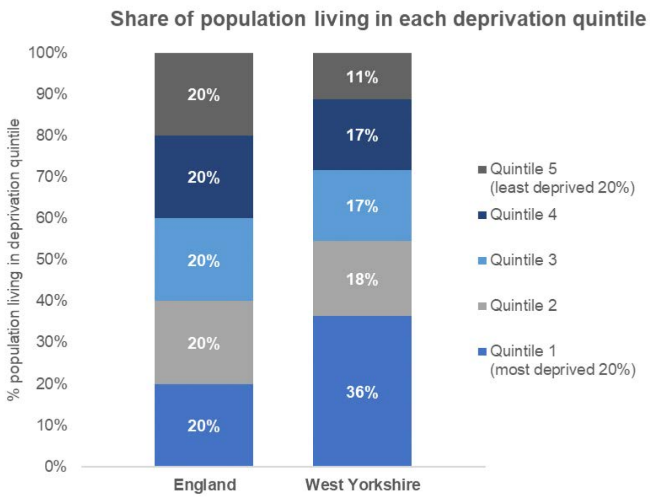
Since 2011 the population structure of West Yorkshire has changed. The under 5-year-old population fell by 6.9% compared to a 7.2% fall in England as a whole (ONS, 2021). The under 16-year-old population has grown by 5.6% compared to a 4.6% growth in England as a whole. The over 65 population grew by 18.7% compared to 20.1% in England as a whole. This suggests that we have a younger population when compared nationally, however this does vary by Places, for example Craven has a much older population.

3.1 Deprivation

The Index of Multiple Deprivation (IMD) is the official measure of relative deprivation in England. It ranks areas based on various factors that contribute to deprivation, including income, employment, education, health, crime, housing, and access to services. The IMD divides England into small geographical areas called Lower-layer Super Output Areas (LSOAs) and assigns each a deprivation score. Areas are then ranked from the most (IMD1) to the least deprived (IMD10) deciles.

The graph in figure 1 highlights the higher levels of deprivation in West Yorkshire compared to the national average. While England's population is evenly spread across all five deprivation quintiles (20% each), West Yorkshire has a much larger proportion (36%) living in the most deprived areas and significantly fewer (11%) in the least deprived areas. This suggests that socioeconomic inequality is more pronounced in our region, with a greater share of residents experiencing poverty and limited access to opportunities compared to the national distribution.

Figure 1 - Map showing IMD deciles in West Yorkshire



Source: *English indices of deprivation 2019 - GOV.UK, & 2022 mid-year population estimates from the Office of National Statistics.*

Figure 2 shows the IMD map of West Yorkshire, with darker areas indicating higher levels of deprivation and lighter areas representing less deprived regions. Deprivation levels vary widely across our region, with higher deprivation concentrated in urban areas such as Bradford, Leeds, Wakefield, Huddersfield, and Dewsbury. In contrast, less deprived areas are found in suburban and rural locations, including north Leeds, parts of Calderdale, and rural Wakefield, where socioeconomic conditions are generally better. This pattern highlights the need for targeted interventions and resource allocation to address disparities and improve outcomes in the most affected communities.

Figure 2: IMD deciles map of West Yorkshire

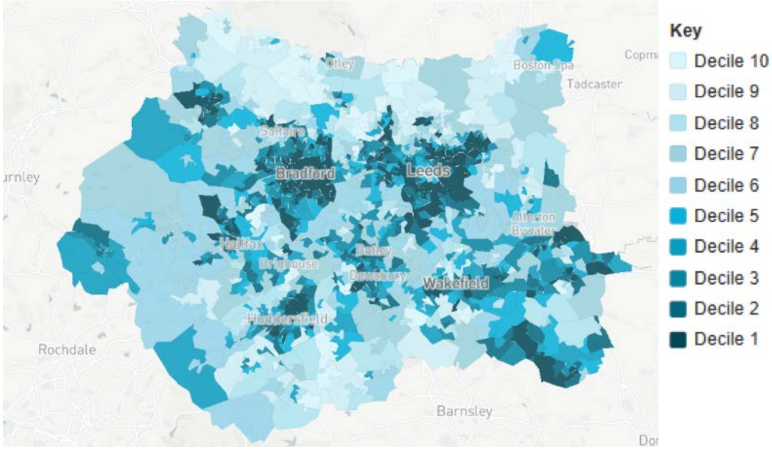
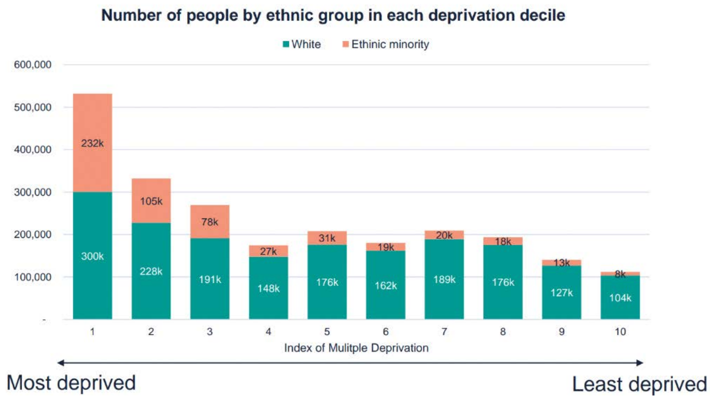


Figure 3 also shows a noticeable correlation between ethnicity and deprivation in West Yorkshire; 42% of ethnically diverse individuals reside in the 10% most deprived neighbourhoods. This figure rises to 61% in the 20% most deprived neighbourhoods. Living in deprivation is a well-documented determinant of poor health outcomes, disproportionately affecting access to healthcare, healthy living conditions, and overall quality of life.

Figure 3: Number of people by ethnic group in each deprivation decile in West Yorkshire.



Source: *West Yorkshire Combined Authority (2023): westyorks-ca.gov.uk*

3.2 Ethnicity

The consideration of ethnicity in PEoLC is vital to delivering culturally competent services that address the diverse needs of various populations. Ethnicity influences perspectives on health, illness, and care preferences, which makes understanding and respecting cultural nuances a cornerstone of equitable care. Research highlights the link between ethnicity and disparities in accessing services, these gaps may arise from factors such as language barriers, cultural misunderstandings, mistrust of healthcare systems, or systemic inequities in healthcare delivery. Addressing these barriers requires intentional efforts.

Figure 4: Ethnic group share of West Yorkshire from Census 2021

Source: *West Yorkshire Combined Authority (2023): westyorks-ca.gov.uk*

The 2021 Census highlights that 23% of West Yorkshire's population is ethnically diverse, a notable increase from 18% in 2011. This figure surpasses England's overall ethnically diverse population, which stands at 19%. The distribution of ethnic diversity within West Yorkshire varies significantly: Bradford has the highest proportion of individuals identifying as Asian or Asian British. Kirklees and Calderdale follow, also reflecting significant Asian and Asian British communities.

The 2021 Census data also shows that the 'White Other' category includes a significant Eastern European presence in West Yorkshire. This includes a Polish population of 27,000, forming a substantial part of this group, Romanian population of 6,000, and a notable concentration of Slovakians, with 18% of the UK Slovakian population (over 1,000 individuals) residing in West Yorkshire, predominantly in Bradford.

3.3 Religion

Religion also plays a pivotal role in shaping end of life care preferences, rituals, and needs. The region's religious diversity emphasises the importance of culturally and religiously competent care.

From the 2021 Census, 40.6% of West Yorkshire residents identified as being Christian, a fall from 54.6% in 2011, this is similar to England overall. 36.7% said they had no religion, an increase from 25% in 2011. 14.5% identified as Muslim which is double England's overall Muslim population, with Bradford having a significant proportion (30% of its population).

19,000 residents identified as Sikh, 18,000 identified as Hindu and just under 7,000 identified as Jewish (0.3% of the West Yorkshire population and 90% of these live in Leeds.)

Recent legislative changes of introducing a new Medical Certificate of Cause of Death (MCCD), have raised concerns among some religious groups that these changes could potentially delay burials, which are a vital aspect of their religious practices. The changes were introduced in September 2024, we are carefully monitoring feedback from the communities most impacted by these changes.

3.4 Language proficiency

In West Yorkshire, 91.3% of residents aged three and over speak English as their main language, with Calderdale having the highest proportion at 95.4%. In contrast, Bradford has the lowest proportion, with 88.6% of residents reporting English as their primary language. Across the region, 8,700 residents (0.4% of the population) are unable to speak English. Of these, 44% (3,800 individuals) live in Bradford, equating to 1 in every 136 Bradford residents- 2.5 times higher than England's overall average.

Urdu is the most commonly spoken non-English language in West Yorkshire, followed by Punjabi and Polish. Bradford has a particularly high concentration of Urdu and Punjabi speakers, with 2.9% of the population speaking Urdu and 2.6% speaking Punjabi. In contrast, Polish is the most widely spoken non-English language in Leeds, reflecting the city's distinct linguistic diversity.

The census data analysed thus far on ethnicity, religion, and languages spoken, is invaluable for ensuring that PEoLC services are culturally competent. Additionally, services must address health literacy by providing written materials in the most commonly spoken non-English languages, ensuring that patients and carers are fully informed about their healthcare options in the final stages of life.

3.5 Disability

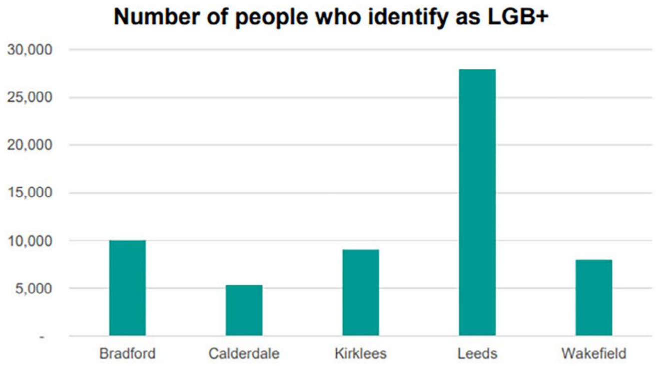
The 2021 Census also shows an increase in the number of disabled people in West Yorkshire, rising from 400,000 in 2011 to 414,000- a 3.6% growth which compares to the 4.5% increase across England. Additionally, 1 in 3 households in West Yorkshire now include at least one disabled person (312,000 households in 2021, up slightly from 310,000 in 2011). Wakefield has the highest proportion of disabled residents, and all Places in West Yorkshire (except Leeds) exceed England's average proportion of people classified as disabled under the Equality Act (2010).

Children with palliative care needs often have multiple complex disabilities and may require lifelong care support beyond specialised medical care and coordination (NICE, 2019).

3.6 Sexual orientation

According to the 2021 Census, 89.3% of West Yorkshire residents aged 16 and over identified as straight or heterosexual, closely aligning with the national figure of 89.4% for England. In England, 7.5% of people did not respond to this question, with a higher non-response rate in Bradford (8.8%). A total of 60,368 people (3.2% of West Yorkshire residents) identified as LGB+, with nearly half (46%) residing in Leeds, where 4.2% of those aged 16 and over identified as LGB+. Overall, West Yorkshire is home to 4.1% of England's LGB+ population.

Figure 5: Number of people who identify as LGB+ across West Yorkshire from Census 2021



Source: *West Yorkshire Combined Authority (2023): westyorks-ca.gov.uk*

3.7 Mortality Data

This data comes from the Fingertips website, a comprehensive public health data collection organised into themed profiles. The table below presents the age-standardised mortality rate for all deaths per 100,000 from 2018 to 2020. An upward arrow indicates a rate worse than the England average. Mortality rates in West Yorkshire are rising, showing a worsening trend compared to the national average. This upward trajectory highlights the need for targeted public health interventions alongside expansion of PEoLC services to address the increasing demand.

This data item does not include Craven as the data source aligns to local authority boundaries, Craven's data forms part of North Yorkshire local authority data which could not be separated.

Figure 6: Standardised age mortality rate for all deaths per 100,000 from 2018 to 2020.

	2020	2019	2018
Bradford	1274↑	1072↑	1094↑
Wakefield	1219↑	1059↑	1077↑
Leeds	1170↑	1046↑	1070↑
Kirklees	1136↑	979↑	1031↑
Calderdale	1099↑	951↑	1029↑

Source: *Fingertips 2024*

3.7.1 Cause of death

The three leading causes of death across our region are cancer, circulatory diseases, and respiratory diseases as shown in Figure 7 by each of our Places. Cancer is the primary cause of death in West Yorkshire, accounting for an average of 23.2% of all deaths, closely aligned with the England average of 24.3%. This pattern is consistent across all Places. The highest proportion of cancer-related deaths occurs in the 65–74 age group, making up 35% of these deaths.

Circulatory diseases are the second leading cause, with West Yorkshire's percentage (21.1%) closely matching the national average of 21.8%. This trend is equally distributed across all age groups.

Respiratory diseases show a higher prevalence in Calderdale and Kirklees, with death rates of 11.8% and 11.2%, respectively. The West Yorkshire average stands at 10.3%, comparable to the England average of 10.2%. The 2023 Health Needs Assessment on Air Quality in Leeds highlights that unplanned hospital bed days are significantly high for respiratory diseases among individuals receiving end of life care, with the highest rates observed in residents from the most deprived areas (Index of Multiple Deprivation decile 1- IMD1).

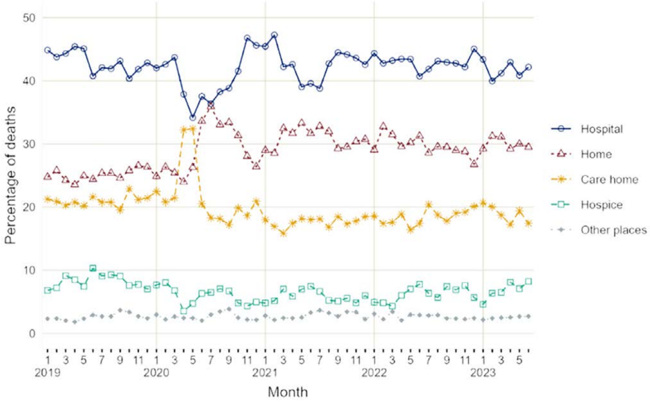
Figure 7: Three most common underlying causes of death by Place

Source: *Palliative and End of life Care Profiles - Data - OHID (phe.org.uk)*

3.7.2 Place of death

The location of death is a crucial factor in understanding the alignment between where people pass away and their expressed preferences for end of life care. Figure 8 shows in West Yorkshire approximately 44% of deaths occur in hospitals, making this the most common setting, followed by deaths at home. Notably, home deaths increased in early 2020 and have remained above pre-pandemic levels, correlating with a reduction in deaths in care homes and hospices.

Figure 8: West Yorkshire Place of Death from 2019-2023



Source: *Fingertips 2023*

A breakdown of death locations provides further insights in figures 9, 10, 11 and 12. In West Yorkshire around 44% of deaths occur in hospitals, consistent with the England average. Deaths at home slightly exceed the national average across all Places in the region and for care home death rates, two Places align with the national average. However, Wakefield, Calderdale, and Leeds report lower care home death rates compared to England overall.

Craven, Wakefield and Calderdale have fewer care home beds per capita than the national average. Additionally, hospice deaths are above the national average in Leeds, Calderdale, and Wakefield, whereas Kirklees and Bradford are comparable to the national average. The latter two Places, with their more diverse populations and higher proportions of ethnic minorities, may be influenced by cultural preferences regarding end of life care.

Figure 9: Percentage of deaths in hospital by place in 2021

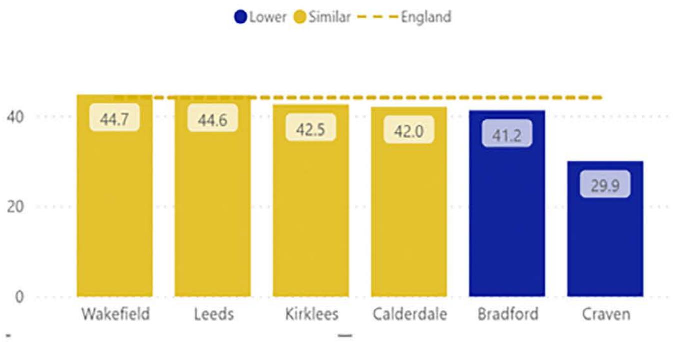


Figure 10: Percentage of deaths at home by place in 2021

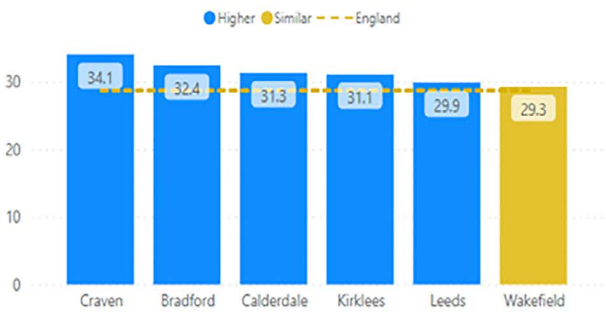


Figure 11: Percentage of deaths in care homes by place in 2021

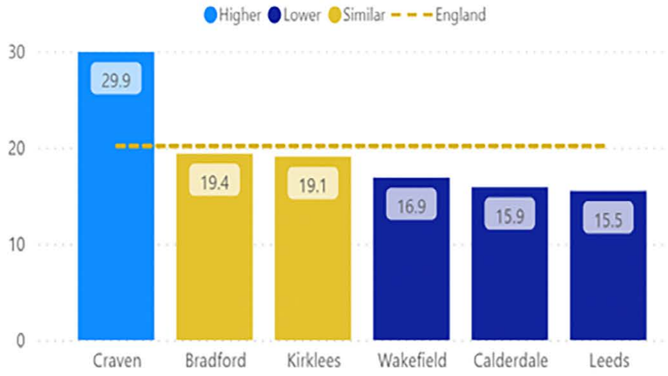
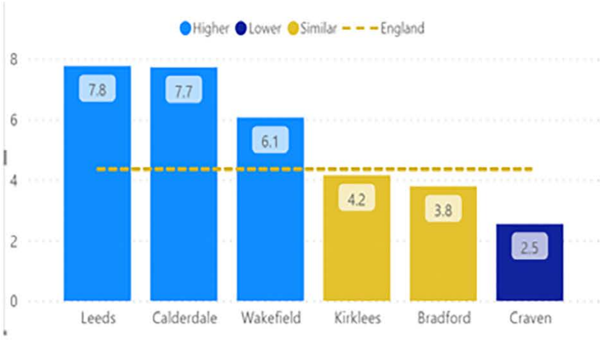


Figure 12: Percentage of deaths in hospice by place in 2021



Source: *Fingertips 2021*

The tables below present the age distribution of deaths based on the location of death. Deaths in hospitals are spread relatively evenly across all age groups. However, as age increases, fewer individuals die at home. In contrast, care homes account for a significant proportion of deaths among those aged 85 and older, with over 30% of deaths occurring in this age group. Deaths at home span a wide range of ages, reflecting diverse circumstances. A small proportion of deaths, approximately 3.5%, occur in other locations, including incidents such as road traffic collisions. This rate aligns with the England average.

Figure 13: age distribution of deaths in hospital

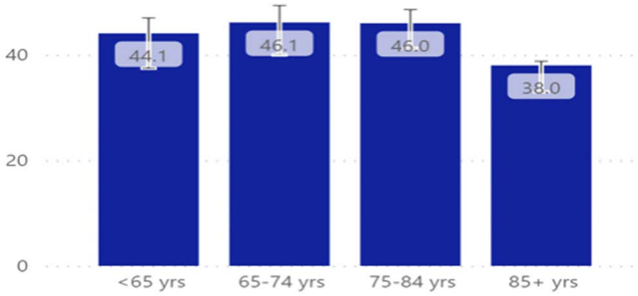


Figure 14: age distribution of deaths at home

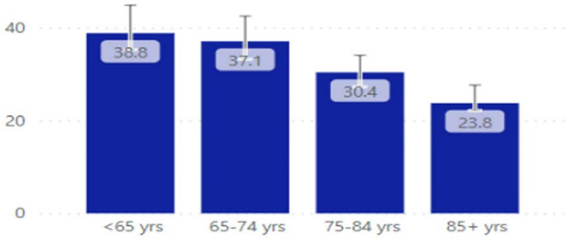


Figure 15: age distribution of deaths in care homes

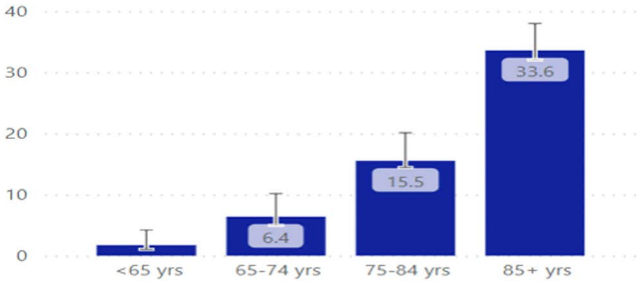
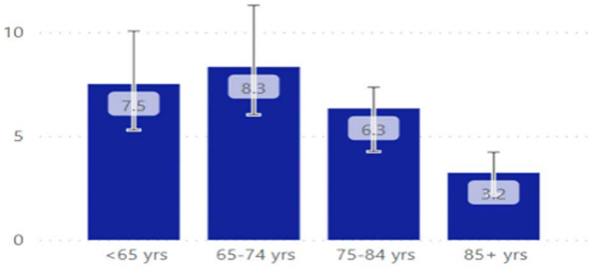
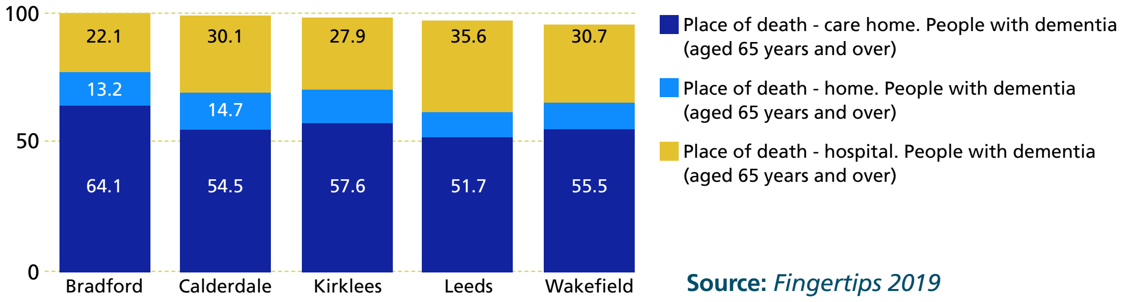


Figure 16: age distribution of deaths at hospice



The age distribution of deaths is as follows: 66.2% occurred in individuals aged over 75, with 36.9% in those over 85 and 29.3% in the 75-84 age group. Additionally, 17.1% of deaths were among those aged 65-74, while the remaining 16.8% were in individuals under 65. Although this latter group includes children and young people, their numbers are small and may not be representative. Children and young people data is presented separately in section 3.10.

Figure 17: Place of Death for people with dementia aged over 65.



Source: *Fingertips 2019*

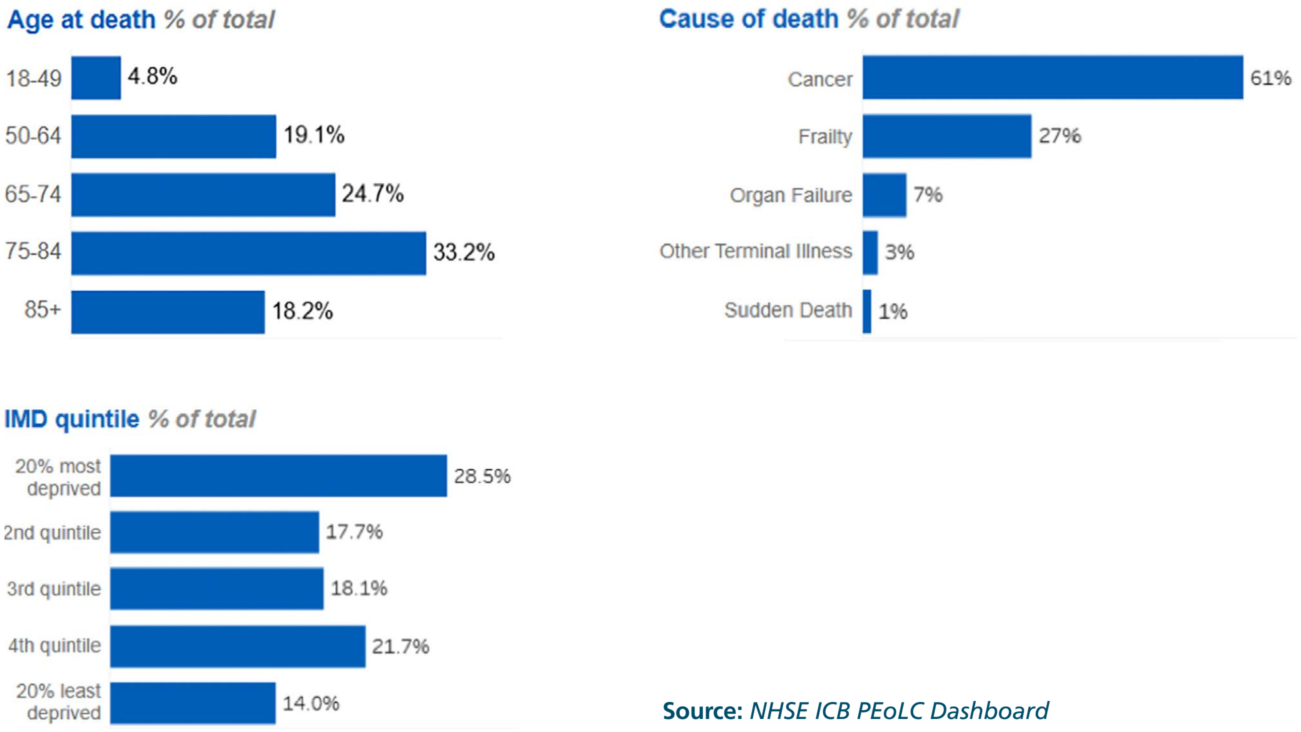
The figure above illustrates the percentage of deaths among residents aged over 65 who had dementia. Across all Places, over 50% of these deaths occur in care homes, indicating that a substantial proportion of people with dementia receive care, including end of life care, in these settings.

3.7.3 Deaths in adult hospices

This data comes from NHS England (NHSE), specifically the ICB's PEoLC dashboard. It includes activity datasets from various sources, such as NCDR, mortality records, SUS+ Emergency Care Dataset, Admitted Patient Care, Critical Care, and Outpatient datasets. Additionally, it incorporates the Palliative Care Register from the GP Quality Outcomes Framework.

Between April 2022 and September 2024, a total of 4,043 deaths were recorded in adult hospices across West Yorkshire. The following charts present the age breakdown, causes of death, and categorised by Index of Multiple Deprivation (IMD) quintiles.

Figure 18: Graphs of all-age hospice deaths by age breakdown, cause of death and percentage of index of multiple deprivation.



Source: *NHSE ICB PEoLC Dashboard*

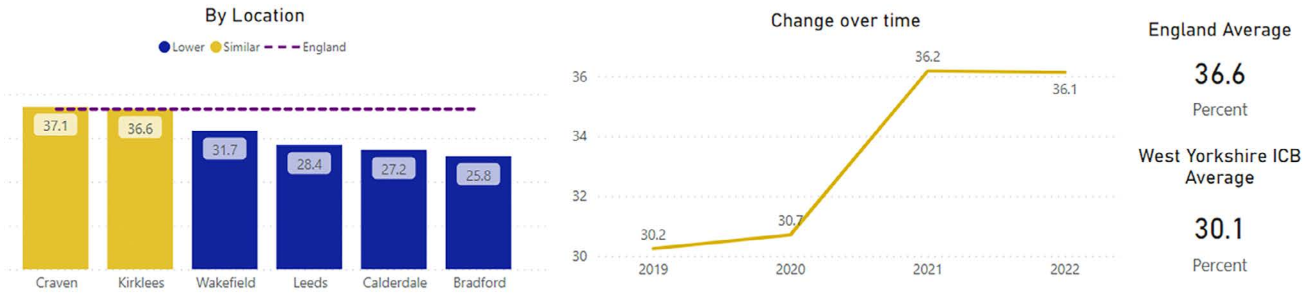
As per figure 8, hospice deaths were more prevalent in Leeds, Calderdale, and Kirklees compared to the national average in 2021. Among deaths in hospices, cancer was the leading cause, accounting for 61%, followed by frailty at 27%. While deaths occurred across all deprivation deciles, 46% were concentrated in the 40% most deprived areas of West Yorkshire.

The hospice data from NHSE does not include a breakdown by other protected characteristics or inclusion groups. It is also important to recognise that while the data reflects individuals who have died in a hospice, hospices in our region provide far more than just inpatient care. They deliver a wide range PEoLC services within communities but continue to face challenges in securing sustainable funding. Addressing this remains a regional priority. The WYICB PEoLC programme works closely with the West Yorkshire Hospice Collaborative and actively engages in financial discussions to support long-term funding solutions, ensuring alignment with the ICB's statutory duty to commission appropriate PEoLC provision.

3.7.4 Care home / nursing home data

The figures below display registered deaths that occurred in a care home where the deceased was not a permanent resident. In West Yorkshire, 30.1% of care home deaths involved temporary residents, which is below the national average. Kirklees and Craven have higher rates of temporary resident care home deaths, while Bradford, Leeds, and Calderdale have lower percentages.

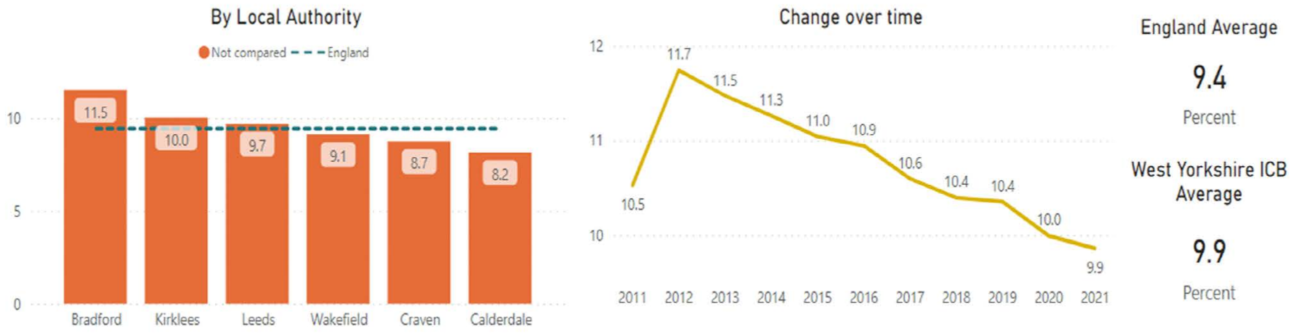
Figure 19: Temporary resident care home deaths (all ages)



Source: *Fingertips, 2024*

Care home bed availability in the region is a significant factor for palliative end of life care due to the decreasing provision and its potential impact on the growing need for community-based services. The availability of care home beds has declined from a peak of 11.7 beds per 100 people to the current rate of 9.9, reflecting a national trend. Among the Places, Bradford has the highest rate at 11.5 beds per 100 people, while Wakefield and Calderdale fall below the national average for care home bed availability.

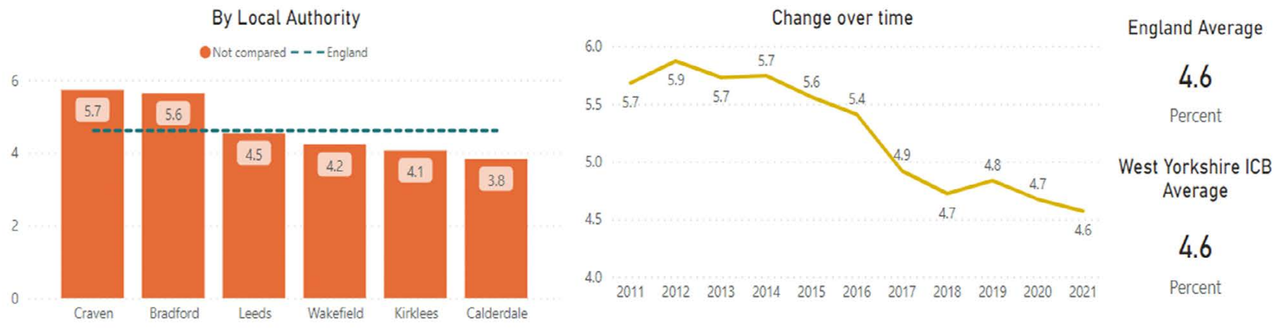
Figure 20: Care home beds per 100 people aged 75+



Source: *Fingertips, 2023*

Nursing home bed availability has also declined, reaching the current rate of 4.6 beds per 100 people, consistent with the national average. However, there are Place differences in availability. Bradford District and Craven have higher rates, while Wakefield, Kirklees, and Calderdale fall below the national average.

Figure 21: Nursing home beds per 100 people 75+



Source: *Fingertips, 2023*

3.8 Emergency hospital admissions

The table below displays the percentage of deaths involving three or more emergency admissions in the last three months of life, broken down by Place and compared to the England average for the three indicators. Calderdale report the highest number of emergency admissions in the last three months of life, exceeding the England average across all age ranges.

Figure 22: Percentage of deaths with three or more emergency admissions in the last three months of life.

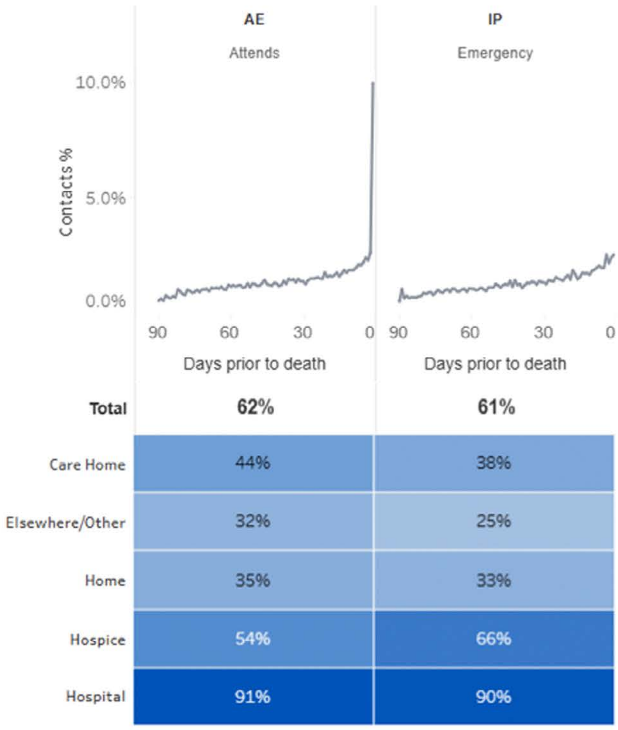
Indicator	Period	England	Bradford	Leeds	Wakefield	Calderdale	Kirklees
Percentage of deaths with three or more emergency admissions in the last three months of life (all ages)	2021	7.1	6.8	4.7	6.9	8.6	6.9
Percentage of deaths with three or more emergency admissions in the last three months of life (75+ years)	2021	6.1	5.9	3.6	6.7	7.4	6.4
Percentage of deaths with three or more emergency admissions in the last three months of life (<75 years)	2021	9.2	8.2	6.5	6.8	11.5	7.3

Source: *OHID PEoLC factsheet: Patterns of care, England 2021*

The data below, sourced from the NHSE dashboard for the 2023/2024 financial year, illustrates the breakdown of unplanned contact in the last three months of life.

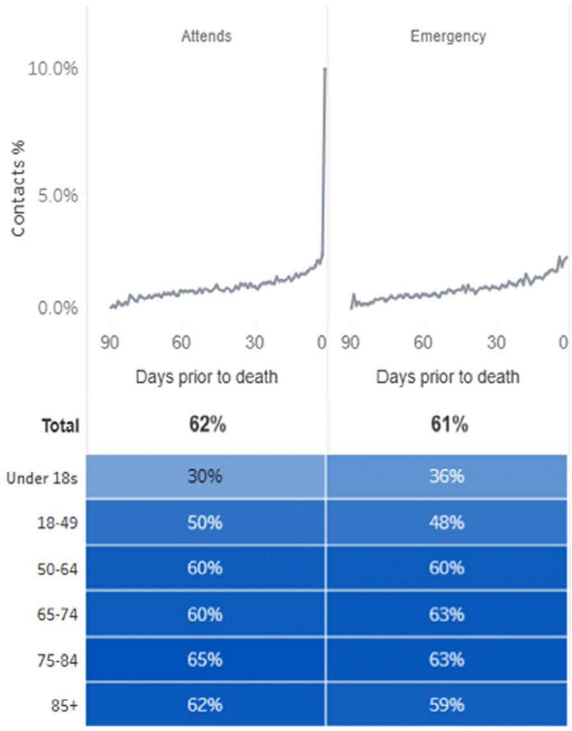
Figure 23: West Yorkshire A&E attendance and inpatient emergency admissions in the last three months of life, broken down by Place, age, ethnicity and deprivation.

Place



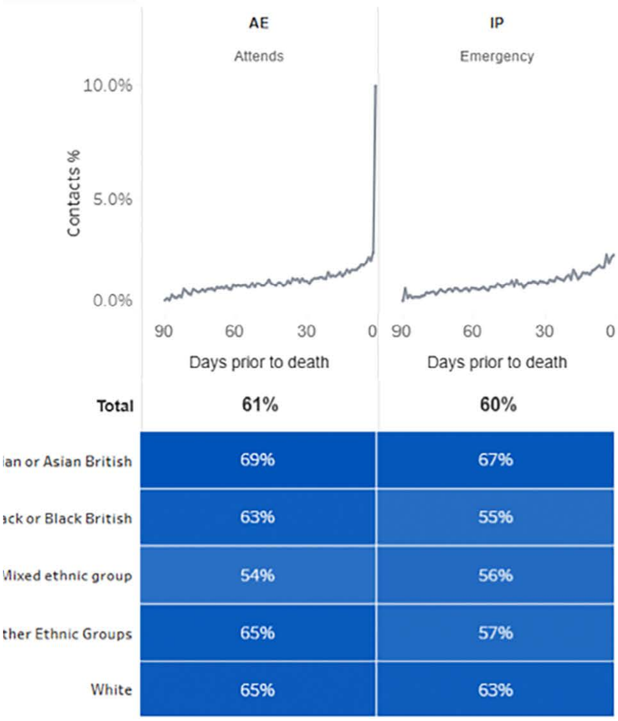
	AE Attends	IP Emergency
Total	**62%**	**61%**
Care Home	44%	38%
Elsewhere/Other	32%	25%
Home	35%	33%
Hospice	54%	66%
Hospital	91%	90%

Age



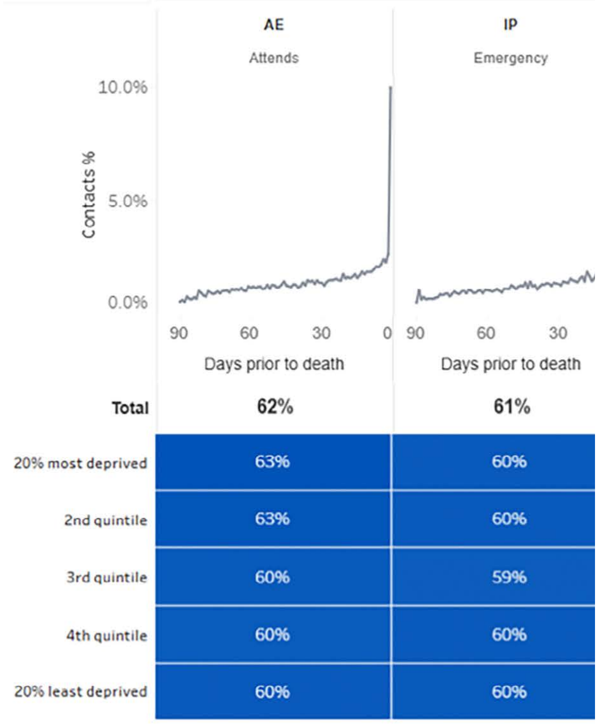
	Attends	Emergency
Total	**62%**	**61%**
Under 18s	30%	36%
18-49	50%	48%
50-64	60%	60%
65-74	60%	63%
75-84	65%	63%
85+	62%	59%

Ethnicity



	AE Attends	IP Emergency
Total	**61%**	**60%**
ian or Asian British	69%	67%
ack or Black British	63%	55%
Mixed ethnic group	54%	56%
ther Ethnic Groups	65%	57%
White	65%	63%

Deprivation



	AE Attends	IP Emergency
Total	**62%**	**61%**
20% most deprived	63%	60%
2nd quintile	63%	60%
3rd quintile	60%	59%
4th quintile	60%	60%
20% least deprived	60%	60%

Source: *NHSE ICB PEoLC Dashboard*

This data shows variations in unplanned healthcare use across ethnic groups in the last three months of life. Asian or Asian British individuals had the highest rates of A&E attendance (69%) and emergency inpatient admissions (67%), while White individuals had slightly lower A&E attendance (65%) but relatively high inpatient admissions (63%). Black or Black British individuals showed moderate A&E attendance (63%) but significantly lower inpatient admissions (55%). Mixed ethnic groups had the lowest A&E attendance (54%) and among the lowest inpatient admissions (56%), whereas Other ethnic groups had relatively high A&E attendance (65%) but lower inpatient admissions (57%).

Asian or Asian British individuals have the highest hospital utilisation rates, indicating a greater reliance on emergency services at the end of life. In contrast, Black or Black British individuals have lower emergency inpatient admissions, which may reflect differences in access to care, healthcare preferences, or systemic barriers. White individuals, however, have relatively high emergency inpatient admissions, suggesting distinct healthcare pathways compared to other groups.

The data shows a consistent trend across socioeconomic groups, with A&E attendance slightly higher (63%) among individuals in the most and second most deprived quintiles compared to 60% in the least deprived. Emergency inpatient admissions remain fairly uniform across all deprivation levels (59%-60%), indicating similar hospital care once admitted. Higher A&E attendance among more deprived individuals suggests potential barriers to accessing primary or community-based palliative care, highlighting the need for improved out-of-hospital end-of-life services to reduce unnecessary emergency visits.

3.9 Future Projections

The Projecting Older People Population Information (POPPI) platform offers valuable data on individuals aged 65 and over, supporting the analysis of population trends, key demographic characteristics, future projections, and performance comparisons. This data indicates that the most substantial growth is expected among those aged 80–89. Overall, the population of people aged 65 and over in West Yorkshire is projected to increase by 47% by 2040 as shown in the table below.

Figure 24: Projected population in 2040 compared to 2023

Population by age	2023	2040
People aged 65-69	113,200	127,400 (13%↑)
People aged 70-74	100,700	125,400 (25%↑)
People aged 75-79	89,100	108,800 (22%↑)
People aged 80-84	54,600	79,500 (46%↑)
People aged 85-89	34,900	49,000 (40%↑)
People aged 90 and over	18,100	22100 (22%↑)
Total population 65 and over	356,000	522,100 (47%↑)

Source: *www.poppi.org.uk/index.php (2024)*

The POPPI data also currently shows, 133,368 individuals aged 65 and over live alone in West Yorkshire, a number expected to increase by 29% to 171,729 by 2040. The most notable growth in the 75-and-over age group living alone is projected in Bradford (41.6%), followed by Calderdale (40%) and Wakefield (40.6%).

According to POPPI, the number of people aged 65 and over living with autism in West Yorkshire is also expected to increase from 3,829 to 4,904 by 2040, marking a 28% rise. Notably, the most significant increases within the 75-and-over age group are anticipated in Bradford (46.8%), Calderdale (45%), Kirklees (40%), and Wakefield (45.1%). These projections emphasise the importance of preparing health and care services to accommodate the growing needs of older adults with autism in our region.

With the projected growth in the older adult population, the demand for quality palliative care services is expected to rise. It is essential for our healthcare system to remain prepared and adaptable to meet the evolving health needs of our future population.

3.10 Children and young people data

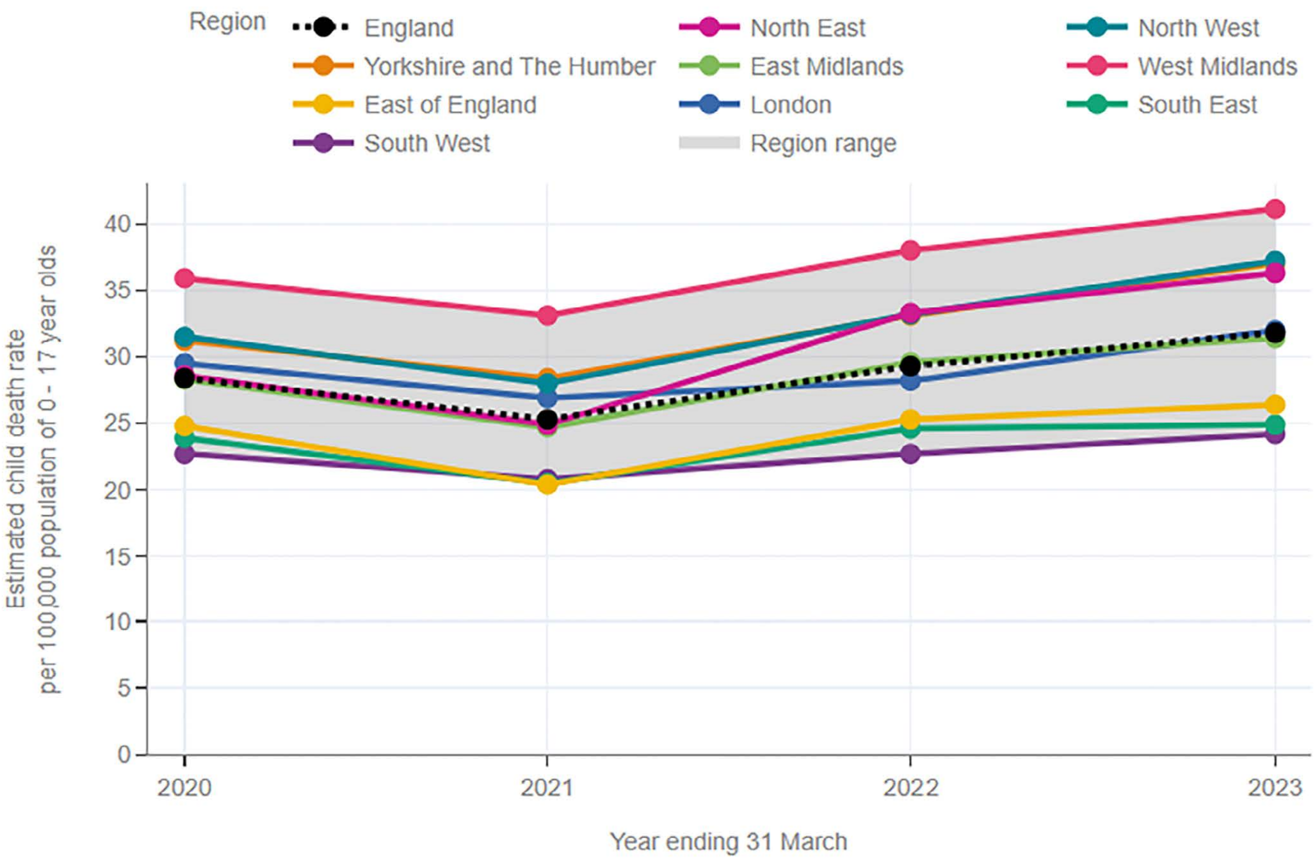
The National Child Mortality Database (NCMD) was launched on 1 April 2019 to compile data from Child Death Overview Panels (CDOPs) in England, which review all deaths of children from birth to their 18th birthday. CDOPs are legally required to collect and submit this data to NCMD, as mandated by the Child Death Review (CDR) statutory and operational guidance. This guidance instructs all CDR partners to gather information from every agency involved in the child's life and death, including health and social care services, law enforcement, and education. This process is carried out using statutory CDR forms, with the collected information submitted to NCMD. The NCMD data covers all of England, where some regional breakdowns are available, they are for Yorkshire and the Humber and will be specified below.

Available data is categorised into four groups: all ages (0-17 years), children (1-17 years), infant deaths (under 1 year), and neonatal deaths (babies under 28 days of age).

3.10.1 National data on children and young people

In the year ending 31 March 2023, there were 3,743 child deaths (ages 0-17) in England, equating to an estimated rate of 31.8 deaths per 100,000 children. This represents an 8% increase from the previous year and the highest annual total since NCMD began data collection in 2019. Infant deaths (under 1 year) rose by 4%, while deaths among children aged 1 to 17 years increased by 16%. The estimated death rate in Yorkshire and the Humber is 37 per 100,000 population of 0–17-year-olds and is above the England average.

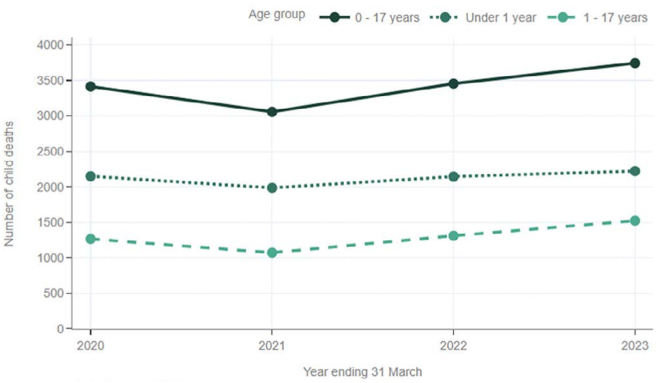
Figure 25: Estimated child death rate per 100,000 population of 0-17 year olds, by region



Source: *NCMD, ONS mid-year population estimates, ONS Census (2021) www.ncmd.info*

3.10.2 Age

Figure 26: Number of child death notifications in England, by year ending 31 March

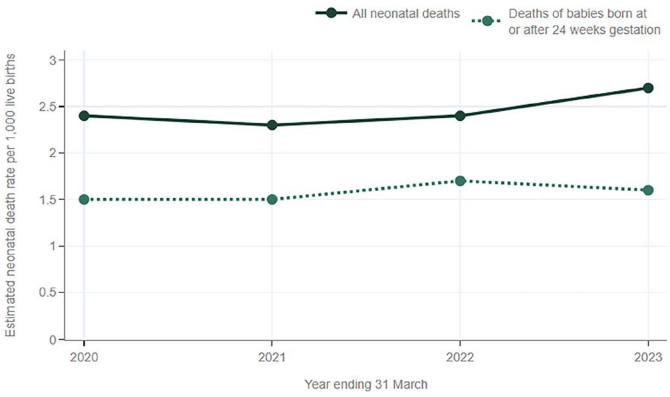


Source: *NCMD www.ncmd.info*

Neonatal deaths (babies under 28 days) accounted for 41% of all child deaths in England in the year ending 31 March, 2023.

The estimated neonatal death rate in England for year ending 31 March 2023 was 2.7 per 1,000 live births, an increase from 2.4 in the previous year. However, the estimated neonatal death rate for babies born at 24 weeks or over was 1.6 deaths per 1,000 live births of the same gestational age, a decrease from 1.7 in the previous year. The neonatal mortality rate ambition, derived from ONS data, is 1.0 deaths per 1,000 live births of babies born at 24 weeks or over, by 2025.

Figure 27: Estimated neonatal death rate per 1,000 live births in England.

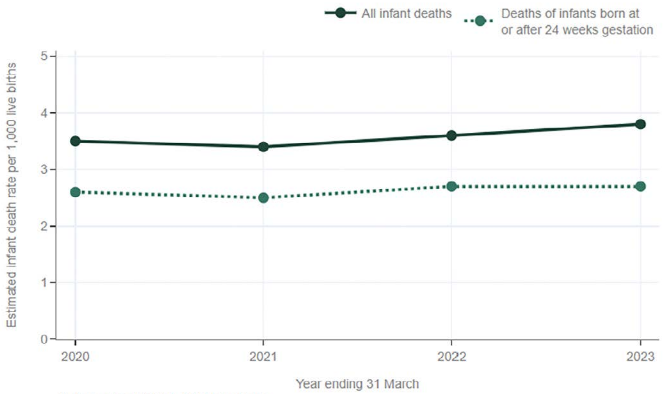


Source: *NCMD, ONS Live Births*

Please note the proportion of babies born at or after 24 weeks gestation for year ending 31 March 2023 was assumed to be the same as previous years and this estimate was used to calculate the neonatal death rate in the latest year.

Infant deaths (babies under 1 year) accounted for 59% of all child deaths in England in the year ending 31 March 2023 (this includes neonatal deaths). The infant death rate was 3.8 per 1,000 live births, an increase from 3.6 in the previous years. However, the estimated death rate for infants born at 24 weeks or over was 2.7 deaths per 1,000 live births of the same gestational age, the same rate as the previous year.

Figure 28: Estimated infant death rate per 1,000 live births in England



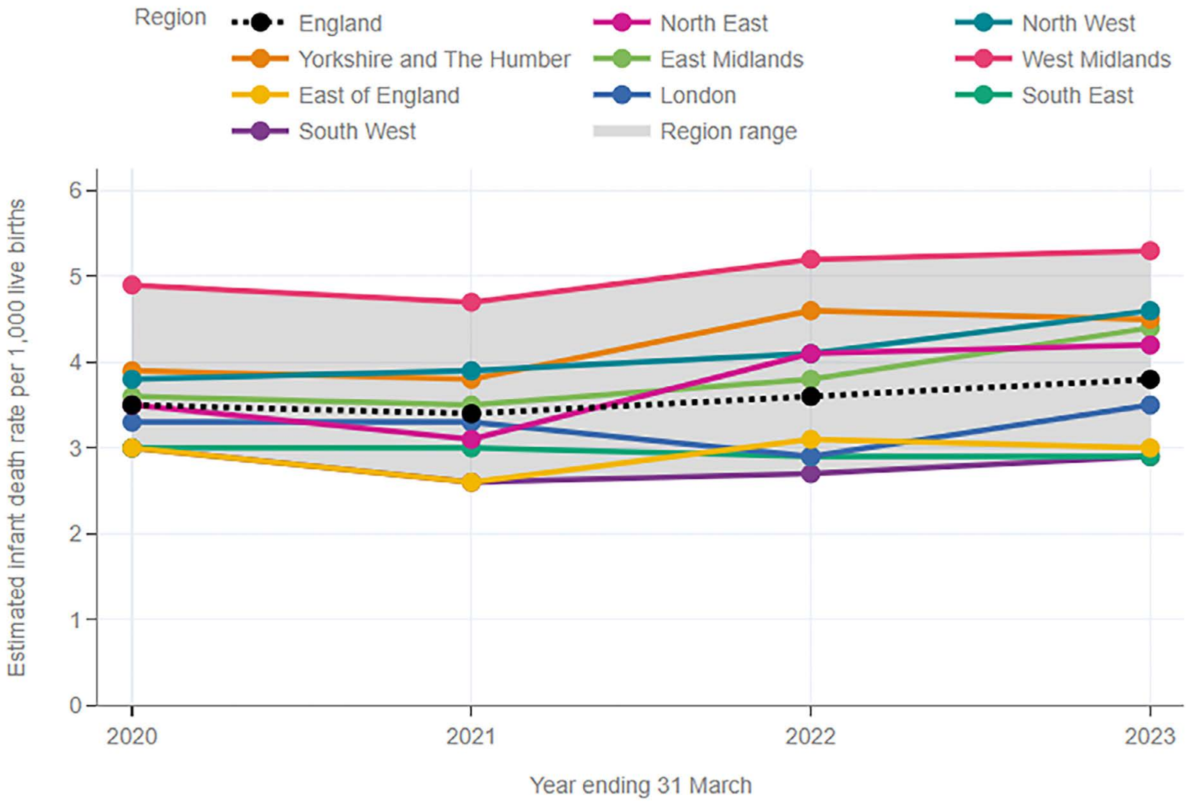
Source: *NCMD, ONS Live Births*

Please note the proportion of babies born at or after 24 weeks gestation for year ending 31 March 2023 was assumed to be the same as previous years and this estimate was used to calculate the infant death rate in the latest year.

[*www.ncmd.info*](http://www.ncmd.info)

The infant death rate in Yorkshire and the Humber is 4.5 per 1,000 live births, and exceeds the England average of 3.8 per 1,000.

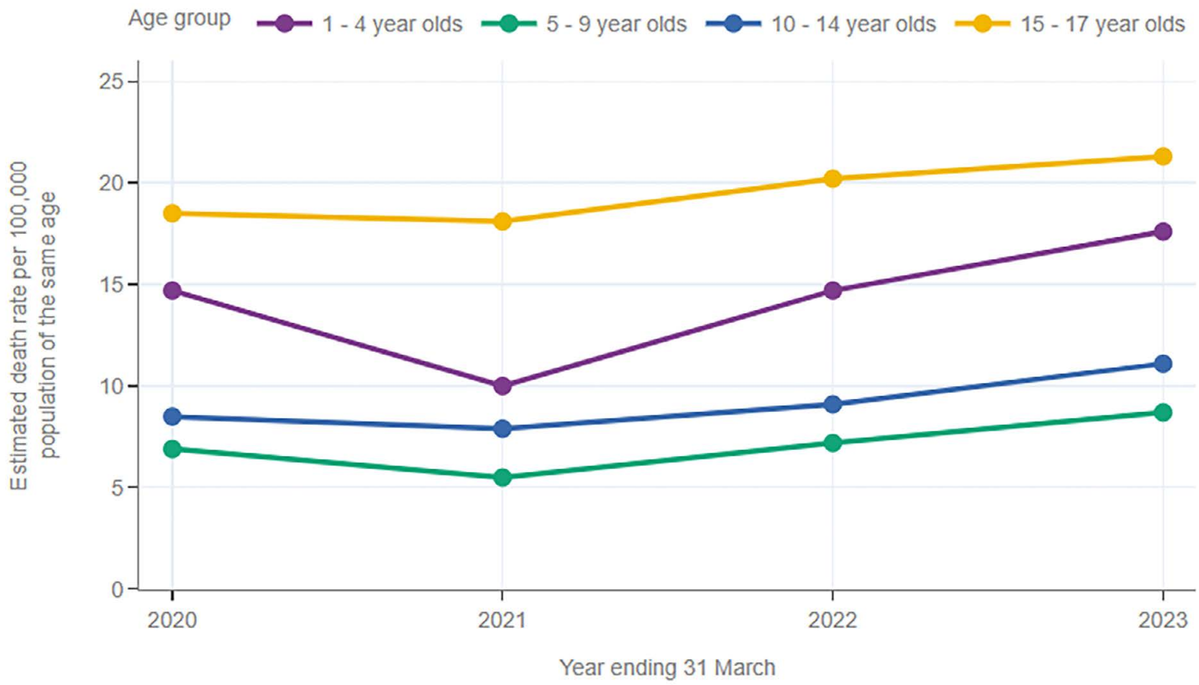
Figure 29: Estimated infant death rate per 1,000 live births, by region



Source: *NCMD, ONS Live births www.ncmd.info*

Among children aged 1-17 years, the highest death rate remained in those aged 15-17 years (21.3 per 100,000), followed by children aged 1-4 years (17.6 per 100,000). Death rates increased across all age groups compared to the previous year.

Figure 30: Estimated death rates for children aged between 1 and 17 years per 100,000 population, by age group in England

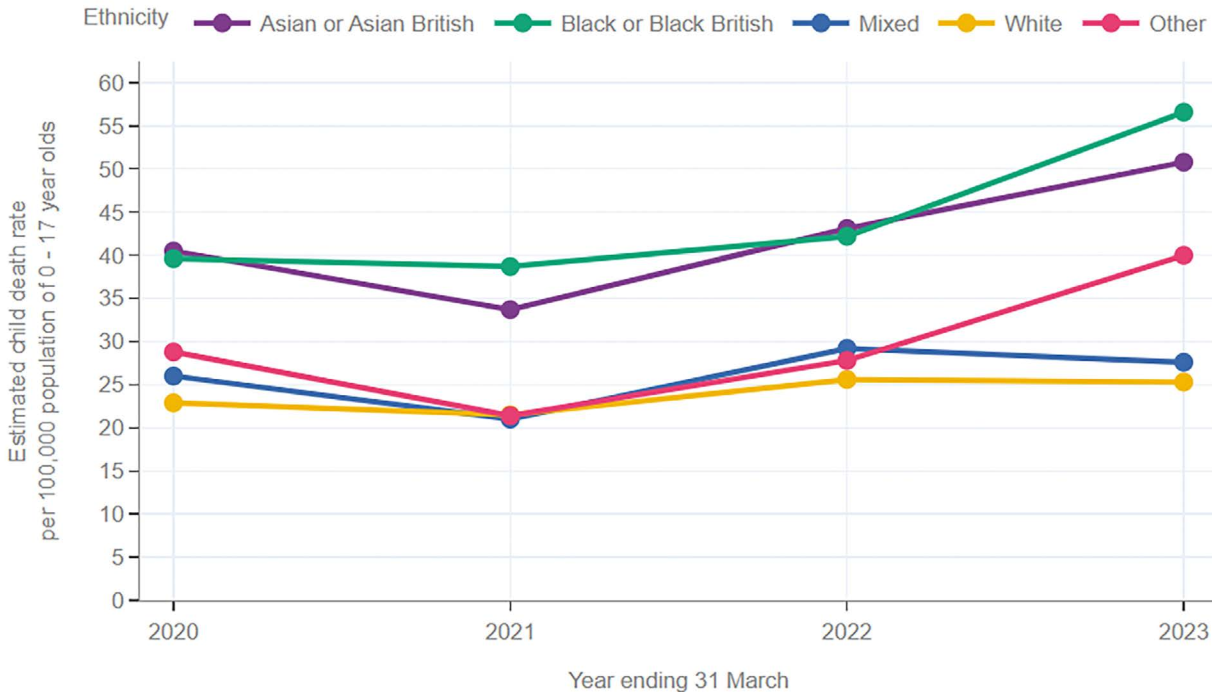


Source: *NCMD, ONS mid-year population estimates, ONS Census (2021) www.ncmd.info*

3.10.3 Ethnicity

The graph below shows in the year ending 31 March 2023, the highest child death rates were observed among those of Black or Black British ethnicity (56.6 per 100,000) and Asian or Asian British ethnicity (50.8 per 100,000). Rates for both groups continued to rise compared to previous years, while the death rate for children of White ethnicity decreased from the previous year and remained the lowest among all ethnic groups. Although this level of data is not available for children and young people in West Yorkshire, it is expected to align with the national trend.

Figure 31: Estimated child death rate per 100,000 population of 0–17-year-olds by ethnicity in England.

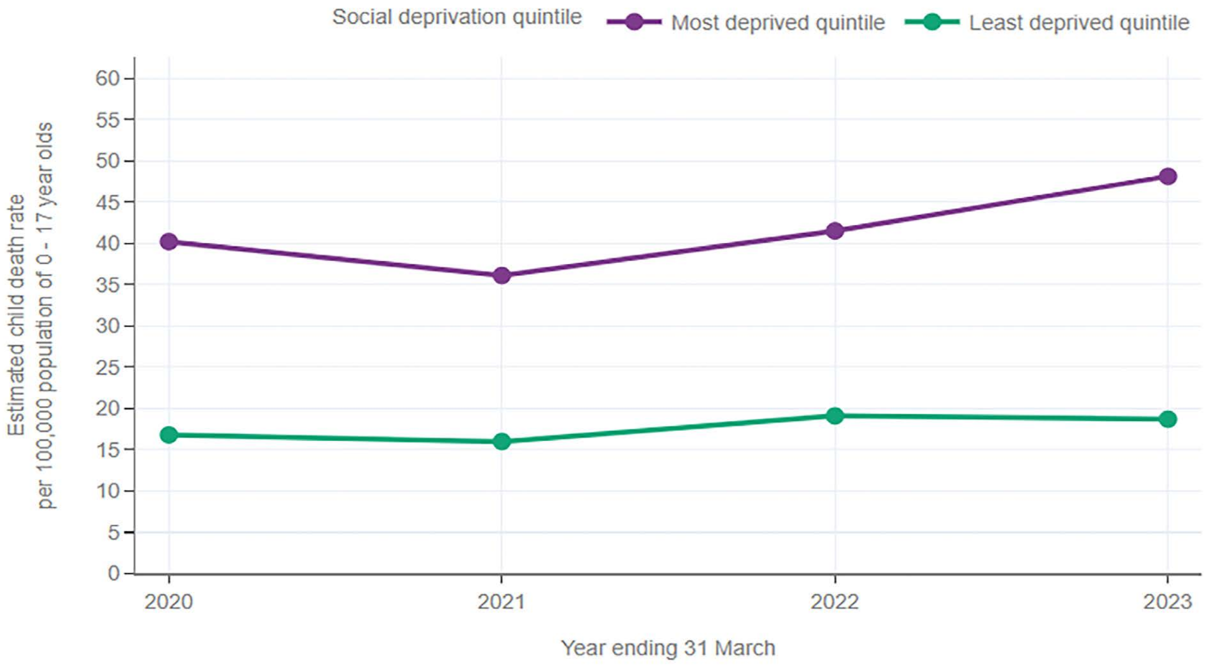


Source: *www.ncmd.info/publications/child-death-data-2023/*

3.10.4 Deprivation

In England, the death rate for children living in the most deprived neighbourhoods was 48.1 per 100,000 - more than twice the rate in the least deprived areas (18.7 per 100,000). While the death rate in the least deprived areas saw a slight decline from the previous year, it continued to rise in the most deprived areas, highlighting widening inequalities. Although this level of data is not available for children and young people in West Yorkshire, it is expected to align with the national trend.

Figure 32: Estimated child death rate per 100,000 population of 0–17-year-olds by most/least deprived quintiles in England.



Source: *NCMD, Index of Multiple Deprivation (2019) www.ncmd.info*

3.10.5 West Yorkshire level data on Children and Young People (CYP) deaths

Obtaining data on CYP deaths in West Yorkshire presents challenges, as no single dataset provides comprehensive information. Instead, data has been gathered from multiple sources to create a regional picture.

The table below presents the number of child death notifications in West Yorkshire and the estimated child death rate per 100,000 within the West Yorkshire Integrated Care Board (WYICB) footprint. In 2023, the number of death notifications for children aged 0-17 in West Yorkshire increased, reflecting a similar national trend. The estimated death rate for children aged 1-17 rose to 20.8 per 100,000, up from 12.5 in previous years, significantly exceeding the national rate of 13.6 per 100,000. A similar trend was observed in infant deaths, with the infant mortality rate in West Yorkshire reaching 5.6 per 1,000 live births - higher than the national average of 3.8 per 1,000 in 2023.

Figure 33: Data from the National Child Mortality Database (MCMD) for 2020 to 2023

No. of death notifications received of children aged 1-17 where the death occurred in the year ending 31st March				
Year	2020	2021	2022	2023
England	1,265	1,071	1,310	1,522
WY ICB	64	65	64	106

Estimated death rate per 100,000 population of children aged 1-17 in the same ICB				
Year	2020	2021	2022	2023
England	11.1	9.3	11.7	13.6
WY ICB	12.5	12.6	12.5	20.8

Death notifications received of infants (under 1) where the death occurred in the year ending 31st March				
Year	2020	2021	2022	2023
England	2,149	1,985	2,144	2,221
WY ICB	131	112	134	146

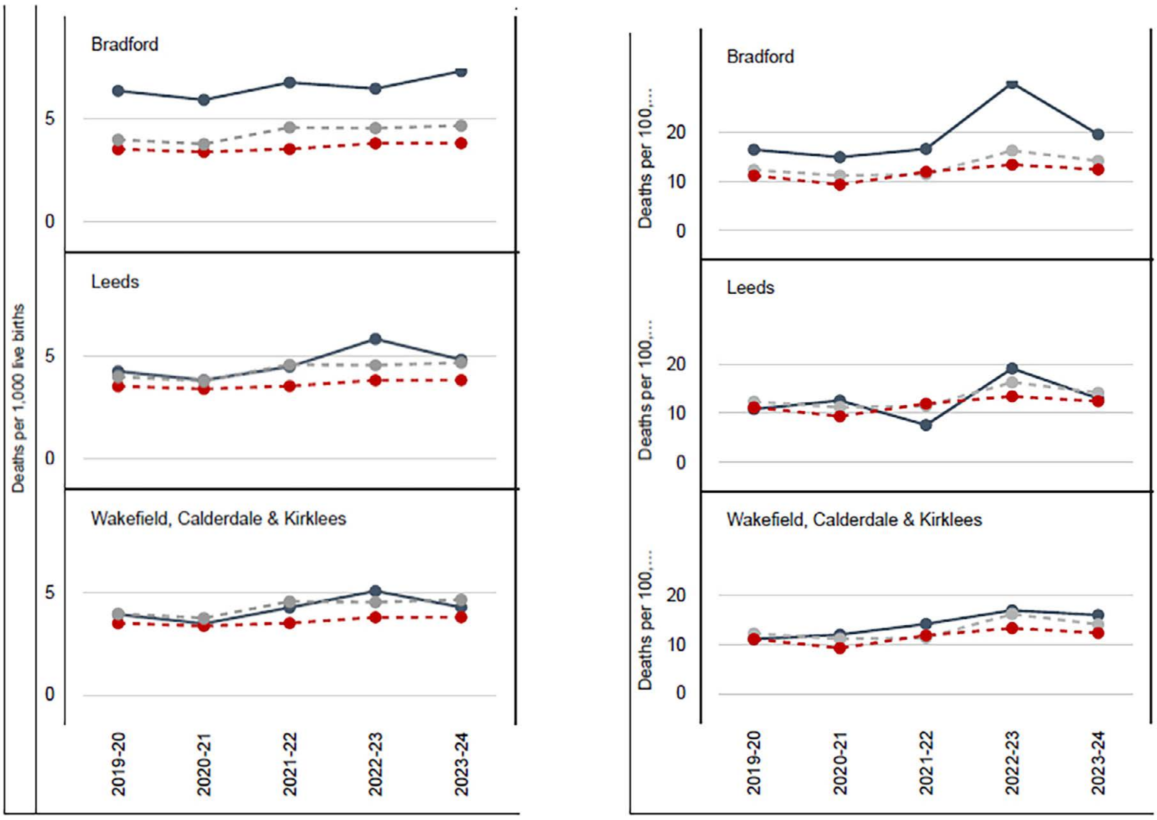
Estimated infant death rate per 1,000 live births				
Year	2020	2021	2022	2023
England	3.5	3.4	3.6	3.8
WY ICB	4.7	4.2	5.0	5.6

Number of death notifications received of children aged 0 - 17 years where the death occurred in the year ending 31 March				
Year	2020	2021	2022	2023
England	3,414	3,056	3,454	3,743
WY ICB	195	177	198	252

Estimated child death rate per 100,000 population in the same ICB (0-17 years)				
Year	2020	2021	2022	2023
England	28.4	25.3	29.3	31.8
WY ICB	36.0	32.6	36.9	46.9

The graphs below from NCMD (2024) illustrate Place trends in West Yorkshire between 2019 and 2024. For infant mortality, Bradford exhibits the highest rates with a noticeable upward trend, while Leeds follows a similar trajectory at slightly lower levels. In contrast, Wakefield, Calderdale, and Kirklees show more stability, though some variations persist. Among children aged 1–17 years, Bradford again records the highest mortality rates, peaking in 2022–23. Leeds also experiences a peak during this period, though its rates fluctuate more. While Wakefield, Calderdale, and Kirklees remain relatively stable, they display a slight upward trend. Across all areas, mortality rates occasionally surpass national and regional averages, particularly in Bradford. This may be linked to higher levels of deprivation and a diverse population, factors that contribute to health inequalities, barriers to healthcare access, and variations in health outcomes.

Figure 34: Place trends of rate of deaths from 2019-2024



Rate of infant (under 1 year) deaths per 1,000 live births by CDOP and year

● Deaths per 1,000 live births (CDOP)
● Deaths per 1,000 live births (all other regions)
● Deaths per 1,000 live births (your region)

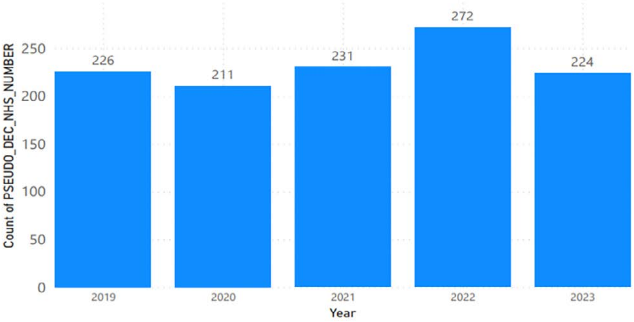
Rate of deaths per 100,000 population of children aged 1-17 years, by CDOP and year

● Deaths per 100,000 population (CDOP)
● Deaths per 100,000 population (all other regions)
● Deaths per 100,000 population (your region)

Source: *NCMD, 2024*

According to the Civil Registrations of Deaths dataset, approximately 230 CYP die each year in West Yorkshire, with the vast majority passing away in hospital. Causes of death vary significantly. This dataset records a slightly higher number of CYP deaths than the NCMD dataset.

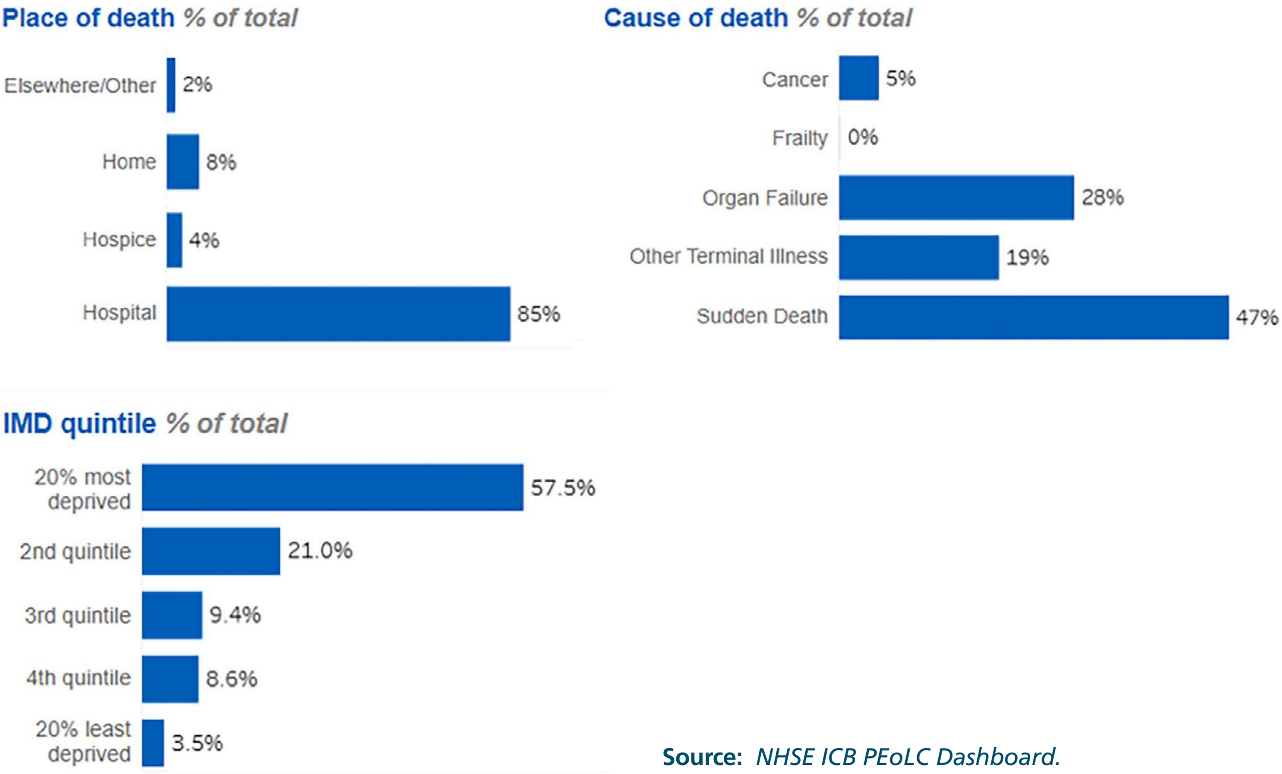
Figure 35: CYP deaths for the previous 5 years



Source: *Civil Registrations of Deaths dataset, 2024.*

The following data is sourced from NHSE, specifically the ICB's PEoLC dashboard. Between April 2022 and September 2024, there were 544 CYP deaths, with 85% (462) occurring in hospital. Additionally, 45 deaths occurred at home, 23 in a hospice, and 13 in other locations. Regarding causes, 47% of deaths were sudden, while 28% resulted from organ failure. Nearly 60% of these deaths were among CYP living in the most deprived 20% of the IMD quintile.

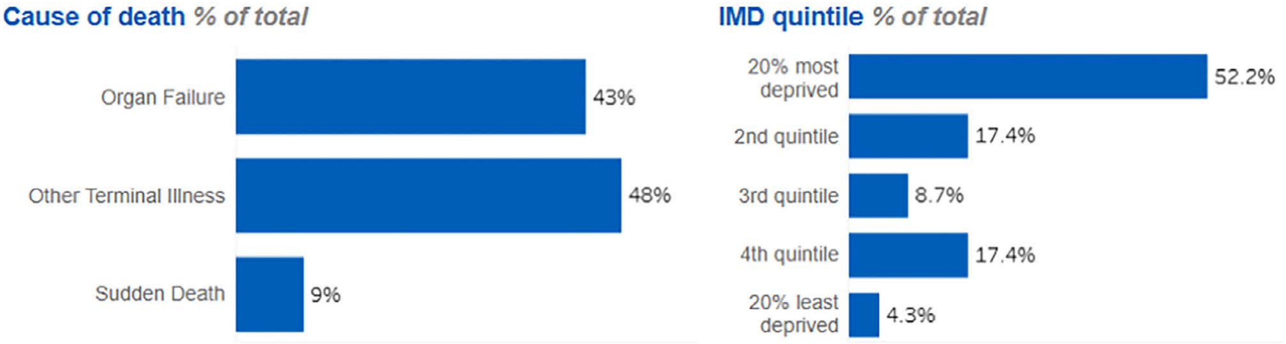
Figure 36: Graphs of CYP deaths by place breakdown, cause of death and percentage of index of multiple deprivation.



Source: *NHSE ICB PEoLC Dashboard.*

For hospice deaths among individuals under 18, organ failure and other terminal illnesses were the most common causes. Notably, 69% of these deaths were in the 40% most deprived areas of West Yorkshire.

Figure 37: CYP Deaths in a hospice



Source: *NHSE ICB PEoLC Dashboard*

Evidence from Fraser et al. highlights the difficulty in predicting which CYP will require PEoLC. Obtaining data for CYP has been challenging, as we have had to rely on various data sources, each with different methods of collation and time spans. Identifying specific numbers of CYP in the region with life-limiting conditions has proven difficult due to the use of ICD10 codes, which are hard to categorise.

Overall national data shows higher child death rates among Black and Asian ethnic minority groups, with a notable trend of more deaths occurring in deprived neighbourhoods. In West Yorkshire, nearly 60% of CYP deaths occurred in the 40% most deprived areas. Fraser's (2020) study supports this trend and indicates that the number of CYP with life-limiting conditions continues to rise.

4.0 Ambition One - Each person is seen as an individual

I, and the people important to me, have the opportunities to have honest, informed, and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

4.1 GP Quality and Outcome Framework and Advance Care Planning discussions

The Quality and Outcomes Framework (QOF) is a performance management and payment system used by the NHS to assess and incentivise the quality of care provided by General Practitioners (GPs) in the UK. It helps ensure that GPs deliver care based on evidence-based practices and that they meet certain quality standards in a variety of areas, including chronic disease management, preventive care, and end of life care. The palliative care register and the Gold Standards Framework (GSF) are closely related to the QOF, particularly when it comes to supporting patients with life-limiting conditions.

GPs can earn QOF points for identifying patients who are approaching the end of life and for ensuring they are included in the palliative care register. The GSF is part of the wider framework to help GPs deliver the best possible care for patients with life-limiting illnesses, which is in line with several QOF indicators related to end of life care. Specific QOF indicators that may relate to aspects of palliative care include controlling pain, improving communication, and delivering advanced care planning (ACP)..

We requested primary care data from each Place to determine the number of patients coded on the GSF/palliative care register, those with a recorded ACP, and how many died in their preferred place, broken down by ethnicity and IMD. However, primary care data is not publicly available and requires data-sharing agreements with individual general practices. Due to these constraints, we were unable to obtain the data within the timeframe for this HNA. It is hoped that once the data is released, it will be analysed and included as an appendix to this HNA.

4.2 ACP

Having open, honest, and well-informed conversations about dying, death, and bereavement is essential to ensuring that a person's end-of-life wishes are known and respected. To facilitate this, the workforce requires adequate training in this sensitive area. In 2023, a North East and Yorkshire (NEY) regional survey was conducted over four months to assess workforce confidence in key aspects of PEoLC. Of the 271 responses from West Yorkshire, the majority came from Leeds (101), followed by Bradford and Craven (76), Kirklees (53), Calderdale (24), and Wakefield (17). Most responses were from nursing staff (160), who make up the largest proportion of the PEoLC workforce, with additional input from allied health professionals, medical, and pharmacy staff. However, there were notable gaps in responses from psychologists, complementary therapists, mental health professionals, spiritual care providers, and social care professionals.

The survey revealed that 66% of respondents worked with adults, and 18% worked with both children and adults, with 40% having over five years of experience. Encouragingly, most staff felt confident in communicating with patients, sharing information, and accessing in-hours advice, with 81% able to recognise imminent dying. However, 25% of staff reported lower confidence in ACP discussions, highlighting a key area for improvement. Also additional training in spiritual care, symptom management, out-of-hours access, and nutrition and hydration would further strengthen the PEoLC workforce confidence in these areas.

Figure 38: NEY regional workforce survey 2023

Key Results from Confidence Questions (% of workforce who felt confident)	
Communication skills (90%)	Discussing nutrition and hydration (63%)
Culture prepared to care (87%)	Assessing and managing physical symptoms (64%)
Actively share information (83%)	Responding to spiritual and emotional needs (73%)
Know how to access in-hours advice (83%)	Advance care planning discussions (75%)
Recognising imminent dying (81%)	Responding to practical and social needs (75%)
	Know how to access out-of- hours advice (75%)

The results were shared with the WYICB PEoLC Steering Group, and the PEoLC programme is actively supporting staff to build confidence in ACP conversations. To aid this, a West Yorkshire ACP toolkit has been developed, including an easy-read version to support discussions with individuals with learning disabilities. Also in March 2024, the WYICB PEoLC programme facilitated its first regional learning conference, which focused on addressing health inequalities and provided staff with opportunities to enhance their skills and knowledge in key areas identified in this workforce survey.

The survey highlights the importance of ensuring all staff feel equipped to have ACP discussions to meet Ambition 1. With 25% of respondents lacking confidence in these conversations, there is a risk that patients may miss out on meaningful discussions about their end of life care and personal wishes.

4.2.1 Training on Advance care planning

As part of the data collection for this Health Needs Assessment (HNA), we conducted a short survey to gather insights from Places on key aspects of PEoLC. The survey was distributed through the PEoLC HNA Task and Finish Group and despite a short time frame, received strong engagement from participating Places. However, as only a limited number of respondents from each Place completed the survey, there may be gaps in the information collected.

One key focus of the survey was to assess the ACP training available for staff across West Yorkshire:

Figure 39: ACP training offered in each Place

Place	What training is available in your Place on advance care planning and/or end of life care conversations?
Bradford District and Craven	• ReSPECT competency training • Difficult conversations training with Palliative care CNS team • Last days of life training • Access to St Gemma's education sessions • Bradford District & Craven Palliative Care Network provide a workshop of three generalist palliative care sessions, one of these covers the basics of advance care planning. • Other training is more ad hoc, provided as requested in the community (for example to district nurses) and hospital (for example to junior doctors) to other generalists. • Varies between organisations within Place. For own staff Marie Curie, Sue Ryder Manorlands, Bradford Teaching Hospitals NHS Froundation Trust, and Bradford District Care NHS Foundation Trust all provide a ReSPECT communications skills workshop or equivalent. They also have access to different e-learning platforms (e.g. E-learning for Health, Marie Curie Learn and Develop). • Individual GP practices may provide their own in-house training, but this is not recorded. • Care homes educator who provides training in care homes about end of life care and advance care planning. • District wide Introduction to ReSPECT webinar people can access. • We have agreed joint competencies for training non-medical staff to complete ReSPECT forms, which includes a list of agreed online modules via e-ELCA. • Both hospices work together to provide training both for specialist palliative care staff, and generalist staff across Bradford District and Craven with a variety of topics throughout the year.
Leeds	**St Gemma's Hospice, Academic Unit of Palliative Care (AUPC):** • The AUPC at St Gemma's Hospice provides several different ACP and difficult conversations training. Both offered city wide and regionally. Training varies in offer including one off sessions, and as part of a wider programme of palliative and end of life training; these are presented in a number of different formats e.g., webinars and face to face. Offers are available to a wide range of health and social care workers. • ACP webinars for health and social care staff in West Yorkshire • ACP webinars for Leeds City Council staff • ACP seminars on larger programmes - Principles of Palliative Care / Introduction to Palliative Care / European Certificate in Essential Palliative Care • ACP and communication skills - half day training • ACP training for all new clinical staff in the hospice

Place	What training is available in your Place on advance care planning and/or end of life care conversations?
Leeds cont	• Difficult conversations webinars for all health and social care staff in West Yorkshire • Difficult conversations webinars for Leeds City Council staff • End of life conversations/ communication skills on larger programmes - Principles of Palliative Care/ Introduction to Palliative Care/ European Certificate in Essential Palliative Care • Difficult conversations and communication skills - half day training • Advanced communication skills for all health care professionals - two-day training • Communication skills training for end of life conversations - training for all clinical staff in the hospice • Advanced communication skills including having ReSPECT conversations - one day training **Leeds Palliative Care Network** • The Leeds Palliative Care Network (LPCN), hosted by St Gemma's Hospice, provides a training programme that incorporates ACP. The programme is for those who require training to be a new ReSPECT signatory and ReSPECT signatories who have not undergone this training; it is available to all Leeds community healthcare staff, primary care, and hospice staff. The programme has been offered as a webinar and has moved to a face to face offer. • Planning Ahead- half day • NB: All core providers also have significant end of life care training for all their staff. Leeds Teaching Hospitals NHS Trust (LTHT) is currently undertaking a project to ensure all their clinical support workers are trained (funded by LPCN). **Leeds Teaching Hospitals NHS Trust** Adult specialist palliative care team provides PEoLC education with ACP as a core component to over 5000 members of staff delivering PEoLC to adult patients. ACP is a component of: • Medical, nursing and AHP priority training. • Postgraduate medical/department training. In addition: LTHT host Integrated Medical Trainee Yorkshire and Humber online ACP resource. LTHT delivers ACP training within the Leeds Frailty Education Course.
Calderdale	• PEoLC training review completed. • Calderdale PEoLC stakeholder group is reviewing the action plan to ensure training as specified is completed. • Calderdale, Kirklees and Wakefield training and education steering group set up. • There is a local document about what PEoLC training is offered and where.
Kirklees	• Full ACP training • ACP, advanced communication. Care and care planning with patients and carers for dementia - introduction to services (delivered via the hospice clinical education offer).
Wakefield	• Mid Yorkshire Teaching NHS Trust mandatory training on the five priorities of care. 1051 staff completed in 2023/2024 • ReSPECT training- two year roll out training programme just completed.

Place	What training is available in your Place on advance care planning and/or end of life care conversations?
Wakefield cont	• Wakefield and Prince of Wales Hospices provide in house training to all clinical staff on ACP, basic and enhanced communication skills training, symptom management, end of life care and bereavement. • External ACP and end of life training to health and social care staff. By Wakefield Hospice at cost. • Training for prison staff on managing end of life care needs provided by Wakefield Hospice • Collaborative ACP train the trainer 3x3 day programme • Bereavement training provide externally by Wakefield and Prince of Wales Hospices. • Support for carers (frailty and dementia) training 16 hours to 60 people • EoLC Board ACP collaborative study days -3-6 per annum • All staff access to ReSPECT level 2 e-learning • IMT training on palliative care in motor neurone disease provided face to face and virtual provided to 265 staff • Symptom management training available to acute, community and hospice staff • Stopping treatment session provided to ethics study day

It is evident that there is variation across Places regarding training provision. Some responses were more detailed than others, which can be attributed to differences in the professionals completing the survey; some may not have had the same level of detail as others.

4.2.2 Advance care planning as mandatory training

When respondents were asked if the training is mandatory, Calderdale, Leeds, and Wakefield confirmed that it is, while Bradford and Kirklees indicated that it is not mandatory.

One responder described how Bradford District and Craven aims for some of their training to become mandatory. One PCN in Bradford has made 'Introduction to ReSPECT' part of their mandatory training for all staff (including receptionists etc) with a webinar, and online learning mandatory for clinicians who may undertake ReSPECT.

A Leeds responder explained the following training is mandatory.

- 'Communication skills and advance care planning' is mandatory in the hospice.
- 'Planning Ahead' training is required for those who want to become a ReSPECT signatory.

Other organisations may have other mandatory training requirements, but this information is not centrally held and was not shared as part of the HNA stakeholder survey.

4.2.3 Advance care planning training commissioned

According to the HNA stakeholder survey findings, Leeds was the only Place in West Yorkshire with commissioned ACP training through a contract. In contrast, ACP training in the rest of the region is not formally commissioned.

4.3 Provision of PEoLC and bereavement support

The HNA stakeholder survey also explored whether bereavement support was available for families and carers across West Yorkshire. Responses highlighted that hospices play a key role in providing bereavement support, though this is often limited to families already known to them. There were positive examples of practice, such as support assistants at Airedale Hospital, who proactively contact bereaved families and refer them for further support. The West Yorkshire Grief and Loss Line, which served as a single point of contact during the COVID-19 pandemic, was cited as an example of good practice but has since been decommissioned.

Additionally, children's hospices across the region were noted for providing ACP education, simulation, and communication study days, with many local areas requesting and organising these sessions with hospice staff support. Only Wakefield shared an example of working with inclusion groups for bereavement support, they are currently establishing a bereavement group for the Gypsy and Traveller community.

The information gathered in the HNA stakeholder survey reflects the status as of March 2024. However, it is acknowledged that provision may have changed since the publication of this HNA.

Figure 40: Bereavement support offered in each Place.

Place	Bereavement Support Offered
Bradford	• Bereavement visits from community nursing team for patients who die at home and were under the care of community nursing. • Specialist traumatic bereavement service to children and their families which covers sudden deaths, suicide, murder, accident. • Bereavement support via the hospices for families of patients who have been in contact with specialist palliative care services. The children's hospices provide this for children in all areas within West Yorkshire. • Airedale General Hospital end of life support assistants provide a bereavement phone call to bereaved families and are able to signpost to other services. • Commissioned support via Cruse Bereavement Support or Bradford Bereavement Service (depending on location within Place) • Adult and child bereavement service within the Marie Curie Yorkshire. This is provided by the Patient and Family Support Team for people who have accessed Marie Curie services. • A drop-in bereavement virtual group for people outside of Marie Curie. • Information and support line available which can be accessed by anyone. • Sue Ryder hospice has a similar service for patients known to them. • Both hospitals have bereavement teams which offer support around the practicalities of death certificates etc, and the medical examiners offer families time to talk when they contact them. • Schools/GPs will offer varied bereavement support, this may be dependent on pastoral support available in schools. • West Yorkshire Grief and Loss Line brought a single point of contact during the Covid pandemic, but this has been decommissioned.

Place	Bereavement Support Offered
Leeds	• Contract with Cruse Bereavement Support. • Hospices provide support to families and friends of their patients. • LTHT bereavement nurse offers a listening service, signposting advice and help with questions from relatives/friends of patients who have died in LTHT, in-patients and staff members. • Carers Leeds • Child Bereavement UK • Cruse Bereavement Support • Elliot's Footprint (children young people) • Leeds Suicide Bereavement Service • Maggie's Yorkshire • Martin House (children young people) • The Jane Tomlinson Appeal's OWLS (Overcoming Worry, Loss and Sadness) Bereavement Service for children aged 4-11 across Leeds • St Gemma's (Adults) • St Gemma's (children young people) • The Market Place • Yorkshire's Brain Tumour Charity
Calderdale	• Marigold Café - bereavement support café once a month provided by Calderdale and Huddersfield NHS Foundation Trust • Overgate hospice
Kirklees	• Bereavement support and pre-bereavement support available and counselling via hospices (The Kirkwood) • Locala- bereavement support visits by community nursing team
Wakefield	• Prince of Wales Hospice currently commissioned to provide bereavement support at Place level for adults • 6 session listening service (tier 2) • 12 session counselling service (tier 3) • Wellbeing team do pre-bereavement work • Both hospices (Prince of Wales Hospice and Wakefield) provide a 12 session counselling service • Prince of Wales Hospice spiritual lead works closely with the interfaith group in Wakefield • Working with Gypsy and travelling community to set up a bereavement group • The Prince of Wales Hospice has access to CardMedic and their website has the ability to translate/read aloud literature in other languages

4.3.1 Bereavement support - available in accessible formats

When asked whether bereavement support was tailored to different ethnic groups, cultures, faiths, and accessible formats, responses were mixed across West Yorkshire. Most Bradford and Wakefield responders, along with one from Kirklees, felt that such support was available. However, Leeds responders highlighted challenges in finding bereavement counsellors who speak languages other than English or use BSL. Some also expressed concerns about using interpreters in bereavement counselling, viewing the presence of a third person as an invasion of privacy and less effective than direct one-to-one sessions. Carers Leeds has previously provided BSL counselling, and Maggie's Yorkshire offers support for individuals bereaved by cancer in different languages, though these services are Leeds-specific. Responders from Calderdale were unsure whether bereavement support was available in accessible formats, which may reflect gaps in provision, the survey's limited timeframe, or insufficient reach in data collection.

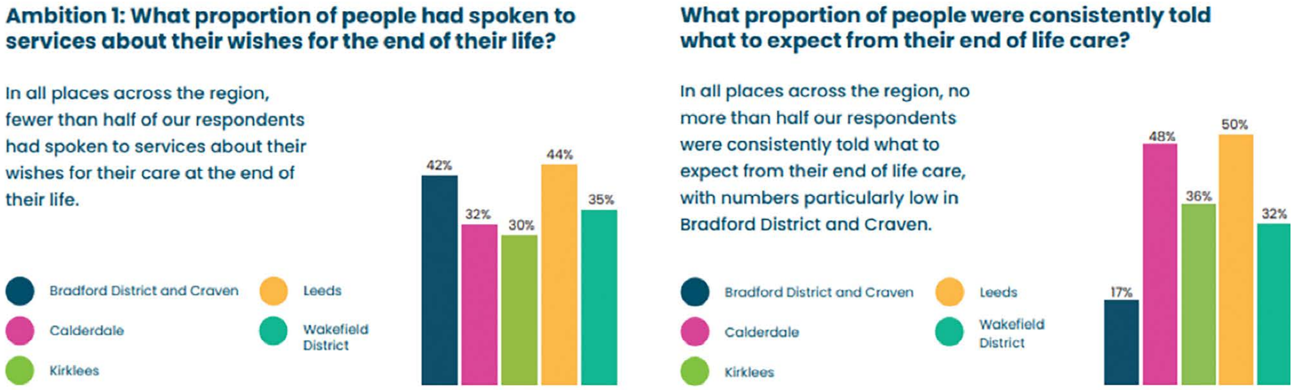
4.4 People's experiences - Healthwatch report

The Healthwatch Report (2024) identified ambition one as the region's weakest area of performance. Fewer than half of those engaged stated they had discussed their end-of-life wishes with services, and many lacked clear information on what to expect from their care. The graph below illustrates that on average, 36% of individuals across West Yorkshire had discussed their end of life care preferences with services.

There is variation across Places, with factors such as training and workforce confidence potentially influencing these discussions. Introducing mandatory ACP training could help improve these conversations and ensure more individuals receive the personalised, informed care they need.

The next graph indicates that on average, 36% of individuals across West Yorkshire reported being informed about what to expect from their care. Bradford had a notably lower figure at 17% which may be partly attributed to its diverse population, where language and cultural barriers could present challenges in facilitating these important conversations.

Figure 41: Ambition one responses from the Healthwatch report 2024.



Ambition 1: What proportion of people had spoken to services about their wishes for the end of their life?

In all places across the region, fewer than half of our respondents had spoken to services about their wishes for their care at the end of their life.

What proportion of people were consistently told what to expect from their end of life care?

In all places across the region, no more than half our respondents were consistently told what to expect from their end of life care, with numbers particularly low in Bradford District and Craven.

4.4.1 Healthwatch case studies

Listening to the voices of patients and their families to gain a deeper understanding of their lived experiences with PEoLC services in West Yorkshire is essential. Alongside their engagement report, Healthwatch developed 18 case studies that highlight people's experiences with death, dying, and bereavement support in the region. Four of these case studies focus on parents who have lost children, while the remaining 14 involve relatives of adults who have passed away. The following themes emerged from these accounts in relation to ambition one.

4.4.2 Bereavement support

- Where a hospice was involved, people were more likely to be offered bereavement support, even if the hospice wasn't the commissioned provider for bereavement support in the area.
- When people died at home, family members described not being offered any bereavement support and this would have been useful. One family member felt she was 'depleted' at this point and didn't want to have to actively seek bereavement support.

4.4.3 Honest conversation

- Quite a few relatives where an adult had died described the lack of clarity around the diagnosis, prognosis and exactly what was going to happen at the end of life.
- A daughter described how she would have liked a clearer explanation of what would happen when her mother was in the final stages of her life.
- Quite a few family members described not knowing what would happen at the final stages of a family member's life. One relative described this as using 'layman's terms' and the need for being 'clear, concise and direct.'
- Another comment from a case study where a wife described the hospice staff saying statements to her such as *"I often find this when patients get to the end of life that they don't want anything to eat"* and *"if you'd like to stay tonight, there is a bed here for you"* as hints that her husband was in his final stages. She reflected that she missed these and remembered them after he passed away. She suggested that staff should be clearer with statements such as *"we think it's likely that his death is imminent".*
- Some relatives described poor communication with them from hospital teams, in one case study a husband was moved to a care home, but the wife was not notified.
- Where family members disagreed with staff, the family members felt the staff talked down to them.
- A South Asian woman with cancer described limited communication: *"I have not been asked by the doctors or nurses anything about my feelings, they have not been able to tell me how long I will live. I have been given more appointments, but I do not know what they are for."*

- In the case studies of terminally ill children there was better communication with parents from the medical teams. They had got to know the patients over a long period of time, and the families came to trust them, the staff and parents had developed good relationships.
- In one case study, the parent had wanted the child to die in a hospice, but eventually agreed to leave the child in hospital as they would be more comfortable there.

4.4.4 Care received

Case studies from parents of children with life-limiting conditions revealed that professionals involved in the care of terminally ill children were generally supportive and attentive to both the children's and parents' needs. However, some relatives of adults shared negative experiences in care homes and hospitals, citing a lack of knowledge among care staff, as well as concerns regarding dignity and the quality of care. Several case studies highlighted instances where Advance Care Plans were created but not properly implemented, with carers needing to remind staff of their existence. This oversight had a detrimental effect on the mental well-being of the relatives. In contrast, some care home staff were commended for providing excellent emotional support not only to the residents but also to their families.

5.0 Ambition two - Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

We acknowledge that health inequalities persist, and these disparities are evident within PEoLC. This section provides a summary of data and reports that highlight the areas where these inequalities exist and outlines strategies to ensure equitable access to care for all individuals.

5.1 National Audit of Care at the End of life

The National Audit of Care at the End of life (NACEL) is a national comparative audit assessing the quality and outcomes of care provided to dying patients and their families during the final hospital admission leading to death. This includes acute hospitals, community hospitals, and mental health inpatient providers in England and Wales.

Markers 1-5, shown in the table below, represent data collected from patient notes regarding the care received during the final admission. Markers 6-7 reflect data from an online survey completed by relatives, carers, and others significant to the person who died in hospital, sharing their experiences of care and support at the end of life.

We have compiled the data for the five acute trusts in West Yorkshire into the table below to compare how each hospital performed on the key markers used by NACEL. The results show very high percentages for case notes indicating that families/carers were informed of the patient's potential for death. Airedale and Leeds performed better than the national average across all markers, while other hospital trusts displayed varying scores.

Figure 42: Scores for each Trust in West Yorkshire against the NACEL markers.

Nacel Marker	National	Calderdale and Huddersfield NHS Foundation Trust	Airedale NHS Foundation Trust	Mid Yorkshire Teaching Hospitals NHS Trust	Leeds Teaching Hospitals NHS Trust	Bradford Teaching Hospitals NHS Foundation Trust
1. Case notes recorded that the patient might die within hours or days.	87%	88%	94%	84%	94%	92%
2. Case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care.	95%	100%	97%	100%	98%	100%
3. Case notes recorded a discussion (or reason why not) with families /carers regarding the possibility the patient.	98%	100%	100%	100%	100%	100%
4. Case notes recorded extent patient wished to be involved in care decisions, or a reason why not.	87%	93%	95%	98%	98%	93%
5. Case notes recorded an individualised plan of care.	76%	70%	75%	93%	100%	72%
6. Families/carers were asked about their needs.	54%	48%	68%	47%	71%	64%
7. Families/carers felt the quality of care provided to the patient was good, excellent or outstanding.	71%	60%	74%	57%	83%	80%

5.2 Inequalities data

The table below shows several deprivation indicators (IMD, income deprivation, child poverty, older people in poverty, fuel poverty, and overcrowding). These indicators highlight that West Yorkshire is performing worse than the national average, with many areas showing higher levels of deprivation across nearly all of our Places. Specifically, the overcrowding indicator, based on room occupancy levels, shows that Bradford District and Craven, as well as Leeds, experience higher rates of overcrowding compared to the national average. Additionally, West Yorkshire has a higher proportion of older people living alone in four out of the five Places.

Figure 43: Fingertips indicators.

Indicator	Period	◀▶	England	WY&H CCGs	NHS Bradford District and Craven..	NHS Calderdale CCG	NHS Kirklees CCG	NHS Leeds CCG	NHS Wakefield CCG
Deprivation, Housing, and living environment									
Index of Multiple Deprivation (IMD) Score	2019	◀▶	21.7	-	32.8	26.4	25.2	27.3	27.3
Income deprivation, English Indices of Deprivation	2019	◀▶	12.9	-	17.9	14.9	14.3	14.3	14.7
Child Poverty, Income deprivation affecting children index (IDACI)	2019	◀▶	17.1	-	21.6	19.6	17.7	20.3	19.7
Older people in poverty, income deprivation affecting older people Index (IDAOPI)	2019	◀▶	14.2	-	19.0	14.0	14.9	15.6	14.5
Modelled estimates of the proportion of households in fuel poverty (%)	2020	◀▶	13.2	-	18.2	17.3	17.4	17.6	17.3
Households with overcrowding based on overall room occupancy levels	2011	◀▶	8.7	-	9.2	6.5	8.5	9.1	4.8
Older people living alone, Percentage of people aged 65 and over who are living alone	2011	◀▶	31.5	-	32.5	34.5	31.8	35.0	33.0

Source: *Fingertips, 2024.*

5.2.1 Learning disability

The Learning Disabilities Mortality Review (LeDeR) programme was established in 2016 in response to a key recommendation from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013). LeDeR is a service improvement initiative focused on people with learning disabilities, autism, or both. To date, the programme has completed over 9,000 reviews nationally. This well-established programme has highlighted that on average, people with learning disabilities and autistic individuals tend to die earlier than the general population and often do not receive the same level of care as those without learning disabilities or autism.

A focused review is typically conducted if:

- Areas of concern or potential lessons are identified during the review process
- The individual was from a Black, Asian, or minority ethnic background
- The individual was autistic without a learning disability
- The individual had been under mental health or criminal justice restrictions at the time of death or within the previous five years.

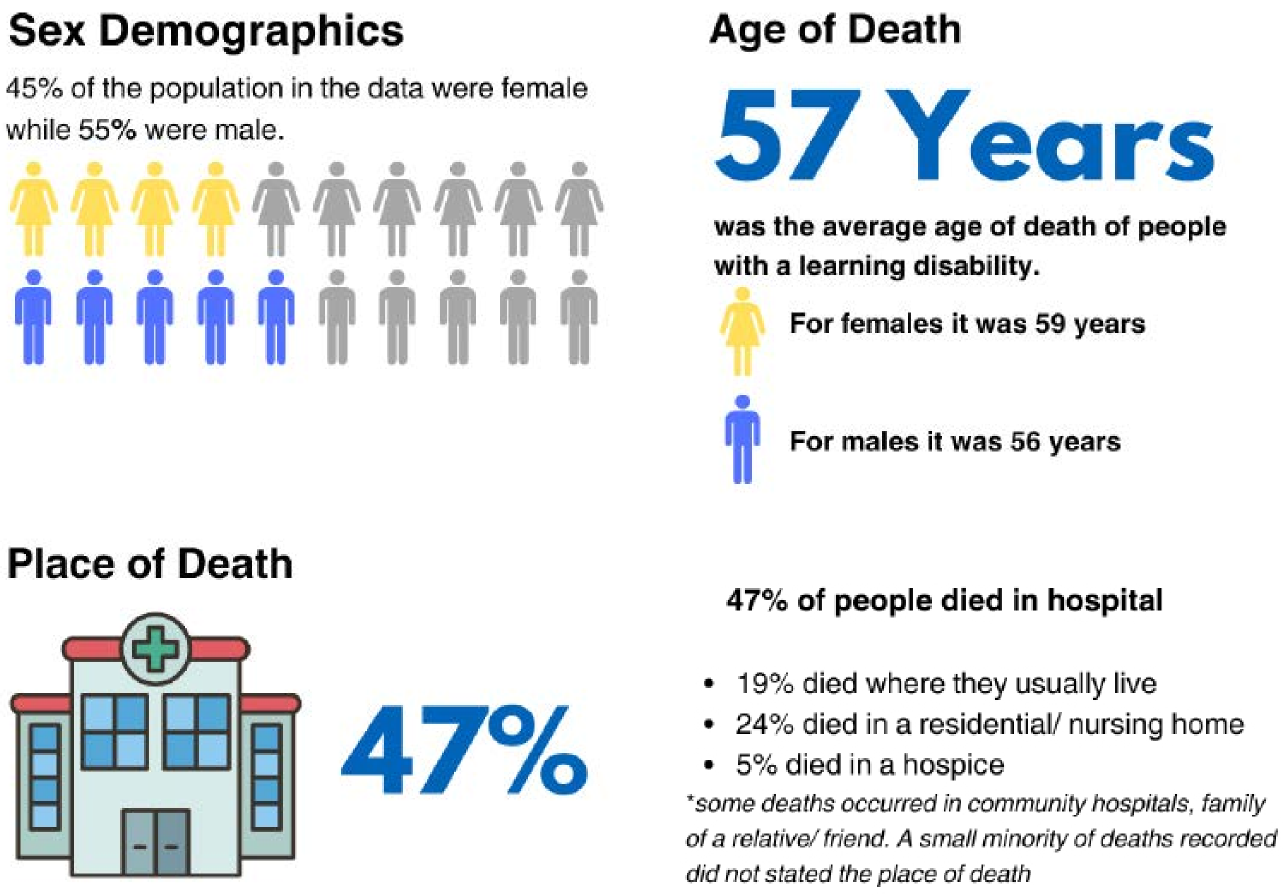
In cases where a child under 18 passes away, a statutory process led by Child Death Overview Panels (CDOP) is initiated. This multi-disciplinary review examines the events leading up to the death and its causes. This process serves as the primary review for children with learning disabilities and autistic children, with the findings then shared with the LeDeR Programme. There is no definitive record of the number of people with learning disabilities in England as no department specifically collects this data, and learning disabilities are not recorded in the UK population census. In 2023/24, West Yorkshire had 172 notifications of deaths for review. Most of these deaths occurred in Leeds, followed by Bradford District and Craven.

Figure 43: Notifications of death by Place in 2023/2024.

Place	Number of notifications 2023/2024
Bradford District and Craven	44
Calderdale	12
Kirklees	29
Leeds	55
Wakefield	32
Total	172

Below infographics are of the 150 reviews completed within the 2023/2024 reporting year for West Yorkshire.

Figure 44: Statistics from the LeDeR Report 2023/24



Sex Demographics

45% of the population in the data were female while 55% were male.

Age of Death

57 Years

was the average age of death of people with a learning disability.

For females it was 59 years

For males it was 56 years

Place of Death

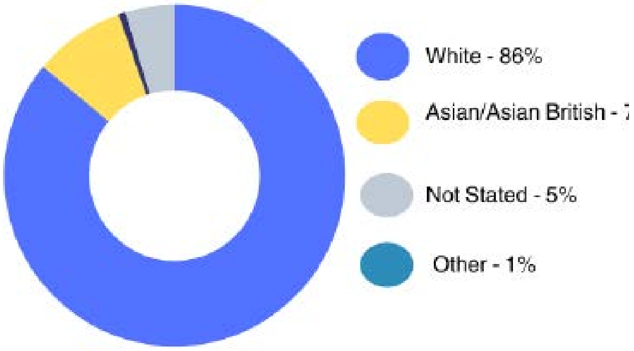
47%

47% of people died in hospital

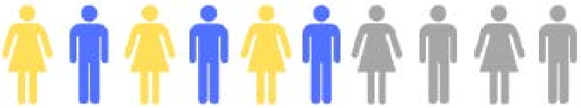
- 19% died where they usually live
- 24% died in a residential/ nursing home
- 5% died in a hospice

**some deaths occurred in community hospitals, family of a relative/ friend. A small minority of deaths recorded did not stated the place of death*

Ethnicity Demographics



Early Death



59% of people with a learning disability died before they were 65.

Source: *[West Yorkshire ICB LeDeR Annual Report 2023 - 2024]*

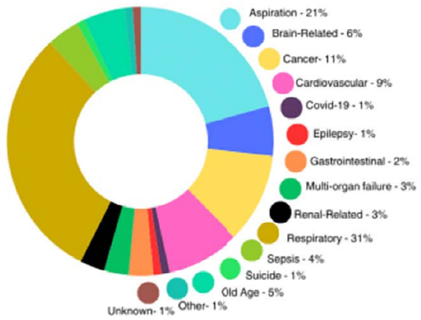
Causes of Death Demographics

31%

31% of people died from respiratory related causes.

The top five causes of death were:

- Respiratory
- Aspiration
- Cancer
- Cardiovascular
- Brain-Related



As with the general population there may be several causes of death attributed to individuals with learning disabilities. 31% of deaths reviewed were attributed to respiratory conditions. People with learning disabilities are more likely to have additional physical disabilities and limitations. Limitation on mobility and movement is a contributory factor to poor lung functioning and susceptibility to infection. The other main causes of death were aspiration (21%), cancer (11%), cardiovascular disease (9%) and brain-related cause (6%). The average age of death for people with learning disabilities is 57 years of age. The 2023/2024 LeDeR annual report also showed 47% of people had two health conditions and 33% of people had five or more health conditions. This data suggests that people with learning disabilities and autistic people in West Yorkshire are more likely to have five or more health conditions than their peer group nationally. 75% of deaths also had a DNACPR decision made prior to death.

The findings for people with learning disabilities align with the broader data on place of death presented earlier in the HNA. Deaths follow the regional trend, with the majority of individuals passing away either in hospital or at home. A relatively low number of people with learning disabilities die in hospice care, despite these settings being ideal for identifying patients in need of PEoLC earlier as highlighted in the Hospice UK report (2022). People with learning disabilities seem more likely to require acute palliative care in hospital, as indicated by the causes of death.

5.2.2 Prisons

West Yorkshire has several adult prisons including one female prison, one high-security facility, one local remand prison and one Category C prison, as well as a Young Offenders Prison. These institutions are governed and regulated by the NHS England Health in Justice team, which oversees PEoLC through the Dying Well in Custody Charter and its six ambitions aligned with those used in this HNA. Additionally all prisoner deaths are subject to investigation under the Death in Custody process

5.3 People's experiences - Healthwatch report

The Healthwatch report provides valuable insights into health inequalities and people's experiences of death, dying, and bereavement in the region. The summary infographic below based on 143 respondents, highlights key findings: 80% felt staff were caring, and 71% believed staff had the necessary skills. However, 60% had not discussed their end of life care wishes with services, and 39% were not informed about what to expect from their care. Additionally, 32% were unaware they could access help at any time, day or night, and 71% felt their relatives' care did not fully meet their needs.

Figure 45: Overall results from the Healthwatch Report.

In 40% of cases, people had spoken to services about their wishes for the end of their life.

39% were consistantly told what to expect from their end of life care.

64% said their services fit in with and respected all aspects of their life.

59% said staff always checked that care met their or their relative's needs.

62% felt care met their or their relative's specific needs.

68% knew they could ask for help at any time day or night.

71% felt sure that staff had all the skills they needed.

80% felt that staff were kind and caring.

143

Total number of responses.

Source: *Healthwatch working together in West Yorkshire, 2024.*

The next section will summarise the main findings from the Healthwatch report that are relevant to ambition two.

5.3.1 People living in poverty

Poverty is complex and influenced by societal changes, leading to diverse experiences of end of life care among those affected. The Healthwatch report highlights key considerations for understanding how end of life care intersects with the lives of people living in poverty:

- Travel expenses - particularly problematic for people living in border areas, who may be required to travel greater distances and to a wider variety of locations.
- Housing conditions are not always good and sometimes allow less space and privacy for the dying person. People may not be able to manage problems with their home such as mould.
- Work - some people may have unsocial shifts, physically and mentally exhausting jobs, unpredictable zero-hours roles and sometimes more than one job at a time. Not only does this have an impact on their ability to make appointments with services, but it also has a wider impact on their health and wellbeing.
- Dealing with a complex benefits system can be time consuming.
- Worry about money – stress of bills/debt, heating homes, reliance on food banks.
- Challenges in accessing childcare, making it harder to attend appointments.
- At risk of developing health conditions at an earlier age due to inequalities with living in deprivation.
- Some may be homeless.

Source: *Healthwatch working together in West Yorkshire, 2024.*

The findings here align with the Marie Curie report (2022), which recommends that everyone should have access to the financial support they need. PEoLC services must work closely with the broader housing and social sectors to ensure that patients receive the comprehensive health and social care support they require at the end of life.

5.3.2 People with serious mental health conditions

The term “serious mental health conditions” encompasses a wide range of diagnoses, with individuals managing their conditions in different ways. This is a highly varied group and those with severe mental illness tend to have a shorter life expectancy. PEoLC needs often overlap with mental health needs, requiring a nuanced approach. Providing quality care means acknowledging these complexities, such as:

- Some people with serious mental health conditions might have had experiences with health services in the past which have affected their level of trust.
- Dementia can impact on a person’s mental health at the end of their life.
- If the mental health condition isn’t managed, this can make decision-making about end of life care highly complicated and difficult.
- Some people living with mental health conditions can be isolated from family and friends.
- Mental health conditions can intersect with other factors, such as drug or alcohol addiction, homelessness, and poverty.

Source: *Healthwatch working together in West Yorkshire, 2024.*

5.3.3 Unpaid carers

Most of the bereaved people in the Healthwatch report had been unpaid carers. Their circumstances varied considerably, with some having worked, others not. Some had health issues of their own. In all cases, these unpaid carers had to manage the emotional effects of losing a loved one alongside the practical reality of caring for a person at the end of their life. Most of the carers were women. Key learning included the following:

- Carers not feeling knowledgeable about how to look after a dying person.
- Not fully informed of what the dying process includes.
- If the individual chose to die at home, this meant more extensive care and support had to be provided by the carer.
- Carers often don't know where to turn for support for themselves.
- Only when individuals died in a hospice were carers saying they were offered bereavement support.
- If people died in other settings, then the bereavement support was not consistent.

The Census (2021) identifies 193,885 carers in West Yorkshire.

Figure 46: Total number of carers in each Place in West Yorkshire.

Bradford	45,650
Leeds	67,490
Calderdale	17,990
Kirklees	37,730
Wakefield	31,730
Total	193,885

Source: *Census 2021*

The General Practice Patient Survey (2024) indicates that one in five patients in West Yorkshire are unpaid carers, with 23% providing over 50 hours of care per week. Among them 45% are aged over 55, and 70% have a long-term health condition, disability, or illness. Additionally, 12% experience isolation, yet only 26% feel supported in their caregiving role.

5.3.4 People from ethnic minority backgrounds

The Healthwatch report highlights that the ethnic minority population is not a homogenous group. Individuals from these communities vary in age, nationality, and religion, meaning that the cultural needs of one family may differ significantly from those of another, even within the same background. One example of this variation concerns decisions about resuscitation. Some families needed to consult a specific local religious leader, while others made the decision independently, based on their personal religious beliefs or lack thereof. A similar diversity of attitudes was noted regarding the choice to die at home. Additionally, people's experiences of racism also influenced their decision-making.

Below you'll find insights from some of Healthwatch's engagement:

Feel Good Factor (Caribbean/Black Caribbean group in Leeds)

This is a Saturday social group where Healthwatch gathered people's experiences of end of life care. A large proportion of group members either grew up in the Caribbean or are from a Black Caribbean background and are local to Chapeltown, historically a home to Leeds's Black Caribbean population. Most were women and aged 50 plus, and several had long-term physical or mental health conditions.

One of the key themes that emerged from these conversations was how past experiences with health services influenced people's attitudes toward end of life care. Many individuals shared stories about the deaths of loved ones, some dating back years or even decades. The (often negative) impact of these experiences clearly shaped their current trust in services.

A key point was that racism, even if not experienced in the health service, had led people to fear services. People repeatedly explained that health professionals had dismissed them due to racial prejudice.

There was a consensus that Black Caribbean communities prefer to die at home, though this can be challenging if families were not well prepared to provide care. Additionally, few individuals had accessed bereavement support.

Lychee Red (Chinese group Leeds)

Lychee Red is a group hosted by Health for All in Beeston aimed at the Chinese community in Leeds. Most members are of retirement age, and the group provides a very welcome social space where people can join in cultural activities, eat together and converse in their own language.

The engagement with this group found that discussing death and dying is often viewed as unlucky or taboo, partly due to a strong cultural reluctance to share personal matters, such as health issues, outside the family. Family privacy is highly valued and concerns about becoming a topic of gossip may prevent individuals from disclosing a diagnosis. There is also a strong expectation among older Chinese individuals to be supported by their families to die at home. However, for those who have died in hospitals or hospices, adult children often play a crucial role in liaising with services due to language barriers.

5.3.5 Homelessness (Leeds/Calderdale)

Engagement with people experiencing homelessness primarily involved males, many of whom had substance dependency and at least one serious mental health condition. Past negative experiences with services often led to reluctance in maintaining contact. However, positive experiences were reported with services such as St Gemma's hospice where non-judgmental, person-centred approaches were highly valued. Examples included nurses sending reminder texts, meeting individuals where they were rather than requiring a fixed address, and providing personal support such as helping someone buy a Mother's Day gift to prevent self-discharge from the hospital. The nursing team also noted that conversations about end of life care often take several months before patients feel ready to engage.

5.4 Healthwatch case studies

5.4.1 Ethnic minority experiences of PEoLC

Several individuals from ethnic minority backgrounds expressed a preference for dying at home, though some ultimately passed away in hospital, possibly due to unmet needs or a lack of discussion about their preferred place of death. Some families noted that their religious needs were documented in care plans, and a few praised children's hospices for their understanding of ethnic minority families' needs.

Among Muslim respondents, many appreciated the support from healthcare services in ensuring quick burials, often facilitated without families needing to ask. Several also valued being referred to a Muslim chaplain for spiritual support. One parent, whose daughter had a life-limiting illness, praised healthcare teams for their sensitivity to religious needs. She shared how, in her child's final moments, staff offered to play a 'Quran Cube' reciting Quranic verses, which brought great comfort to the family. However, one terminally ill Muslim patient expressed uncertainty about whether hospital staff fully understood the importance of her faith in end of life care.

5.4.2 Older patients

A family member highlighted the lack of understanding and support for dementia care, not only at diagnosis or end-of-life but also in the intervening stages, emphasising the need for better ongoing care. They recalled poor PEoLC for their father, expressing concerns that older people, despite requiring significant resources, should not be overlooked:

"Older people do take up a significant amount of funding and things, but it shouldn't be that they are brushed under the carpet because they don't matter anymore. Because they're at the end of life, they still deserve the best."

Patient Quote, Healthwatch Report 2024

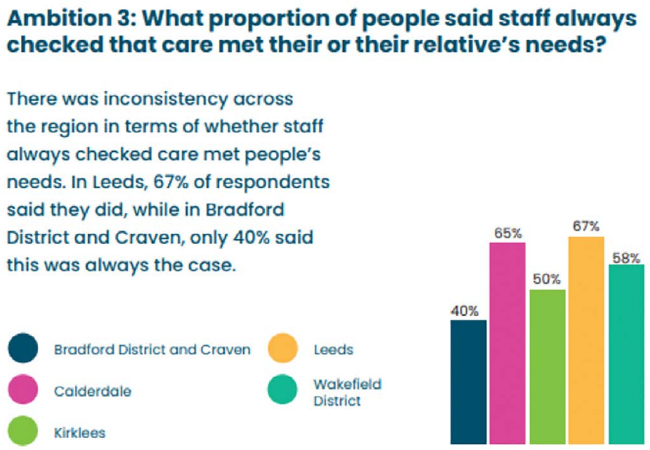
Additionally, some respondents spoke about neglect in care, feeling that elderly patients were sometimes disregarded or written off by healthcare staff. Witnessing this was particularly distressing for relatives and carers.

6.0 Ambition three - Maximising comfort and wellbeing

My care is regularly reviewed, and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

The following figures from the Healthwatch report highlight responder feedback on whether staff ensured that care met their or their relative's needs. The data shows variation at Place level, with Calderdale and Leeds scoring the highest, while Bradford District and Craven had the lowest scores.

Figure 47: Ambition three responses from the Healthwatch report 2024.



Ambition 3: What proportion of people said staff always checked that care met their or their relative's needs?

There was inconsistency across the region in terms of whether staff always checked care met people's needs. In Leeds, 67% of respondents said they did, while in Bradford District and Craven, only 40% said this was always the case.

6.1 Healthwatch case study findings

The following key themes emerged as highly relevant to the HNA:

6.1.1 Children

For children, the long-term relationships with palliative care staff, doctors, and hospices fostered a sense of collaborative decision-making with families. Relatives described a strong rapport with medical teams, who were already familiar with their child's needs. One parent, whose child had epilepsy, recalled 'nearly always' being offered a separate hospital room, which made the experience more positive.

A parent who lost two young babies shared how a hospice specialist nurse provided exceptional support to her eldest child, even arranging Manchester United tickets knowing he was a fan. This thoughtful care significantly impacted the family's experience, reinforcing that staff truly knew and cared about them.

Case studies also highlighted pain medication, oxygen, and other essential care being arranged at home, as all parties agreed this was best for the child at end of life. Parents were reassured that they could bring their child to the hospital if circumstances changed or if they preferred. One case study described carers assisting with practical tasks such as washing the child's hair, allowing parents to rest- support that was deeply appreciated.

Unlike adult hospices, children's hospices provide a different model of care, offering long-term relationships and regular respite, supporting families over an extended period. In contrast, adult hospices focus largely on end of life care meaning interactions with services are often shorter.

6.1.2 Negative experiences

Some individuals shared poor experiences in care homes. One relative described her father experiencing repeated falls, with staff unaware of the location of emergency buzzers during one incident. A patient recalled the difficulties surrounding her husband's cancer diagnosis and end of life care. His diagnosis was delayed and during an inpatient stay, he experienced several issues with his care, including being given a spout cup, which he found degrading. The diagnosis was shared only with him despite his memory impairment due to an infection, leaving his family unaware of critical details. He suffered from severe pain, lack of nutrition, breathing difficulties, and mental health struggles, including hallucinations and refusing to see relatives. His prognosis was not communicated to his family, leaving his wife unprepared and deeply impacted by witnessing his distress.

Another relative described hospital staff inserting a catheter into her father unnecessarily, stating it was done for staff convenience rather than medical need. Her father who was capable of using the toilet with assistance, removed the catheter himself, causing further distress.

Delays in essential equipment delivery were also reported. One family received a commode too late, and a hospital bed was not ordered on time, making it difficult to assist the dying person with basic needs. As a result, the patient became bed-bound, leaving family members struggling to support him.

Timely provision of equipment is crucial for smooth end of life care and PEoLC staff must actively involve carers and relatives in discussions to ensure the dying person's needs and wishes are respected.

6.1.3 Medication

One relative described their family member being over-medicated at the end of life, though no further details were provided. In contrast, another case study highlighted a patient nearing end of life without consistent pain relief, experiencing severe, ongoing pain. Their relative struggled between the care home and GP, unsure of who was responsible for pain management, often having to chase medication themselves.

Other cases described delays in accessing medication top-ups at home, causing unnecessary distress:

"We were waiting for more medication because the syringe driver wasn't sufficient. My dad was quite agitated. We called the district nurses but watching him go through that was a terrible experience."

A carer, despite support from palliative care doctors, found the resources on pain management overwhelming and difficult to understand, as too much information was given at once. Several case studies described relatives' final moments in pain or struggling to breathe, both at home and in hospice or acute settings. It was unclear whether this was a natural part of the end-of-life process or due to a lack of communication about what to expect. One positive case study described a community nurse proactively administering pain relief and recommending a syringe driver, ensuring better comfort for the patient.

Providing timely and consistent pain relief is crucial for quality end of life care, preventing unnecessary suffering. However, inconsistencies in pain management across the region cause distress for both patients and families, potentially leading to long-term emotional repercussions. Establishing clearer processes for pain medication administration is essential for supporting both patients and their carers.

6.1.4 Comfort

A relative described a patient with dementia spending their final days on a noisy ward, which she felt was inappropriate for end of life care. Some relatives also expressed concerns about unclean hospital rooms, noting unpleasant smells and lack of hygiene, which they felt compromised dignity at the end of life and was distressing to witness.

Workforce shortages and service cuts were highlighted as factors impacting the quality of end of life care, with staffing capacity affecting patient experience. One carer recalled limited food options for her husband. Hospital notes indicated he had refused to eat but she believed the available food choices were unsuitable. She was advised to bring food from home yet there was nowhere to heat it.

A lack of stimulation for patients was another concern with no music, outdoor access, or garden time in some hospitals and care homes, contributing to faster deterioration. Where these were available, relatives described a significant improvement in comfort and well-being.

One individual recalled her friend's fear of death during cancer treatment. A nurse referred her to a hospice which initially worried her as she assumed it meant she was dying. However, after attending a support group, she found friendship and comfort. This highlights widespread fears and misconceptions about hospices, with limited public awareness of their broader services.

Some patients received night sitters, though experiences varied. One person described a night sitter talking about trivial matters, seemingly unaware of the sensitivities of the dying process, which was frustrating for relatives. Positive experiences were reported when relatives were offered the chance to stay overnight with their loved ones in hospitals or hospices, with many reflecting on this as a source of comfort and support.

6.2 NACEL marker for hydration

The NACEL marker recommends that a patient's hydration status be assessed daily once the dying phase is recognised. Nationally, 79% of patients receive this assessment. Among the five trusts, four scored above the national average, while Calderdale fell just 2% below this benchmark.

Figure 48: Scores for each Trust on NACEL marker for hydration

Nacel marker	National	Calderdale and Huddersfield NHS Foundation Trust	Airedale NHS Foundation Trust	Mid Yorkshire Teaching Hospitals NHS Trust	Leeds Teaching Hospitals NHS Trust	Bradford Teaching Hospitals NHS Foundation Trust
Case notes recorded patient's hydration status assessed daily once dying phase recognised.	79%	77%	93%	86%	96%	80%

7.0 Ambition four - Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

7.1 24/7 PEoLC provision in West Yorkshire

Patients and relatives need access to specialist and/or generalised PEoLC advice 24 hours a day, 7 days a week. These services could be face to face or offered remotely. The key principles of face-to-face care 24/7 provision include the following as published in 24/7 Care and Specialist Advice for Palliative and End of life Care: Commissioner's good practice guide (2023).

Figure 49: Principles of 24/7 face-to-face care

- Available for people of all ages in all settings and during scheduled unscheduled times
- Are provided by qualified practitioners who are not necessarily specialists but:
  1. have up to date training / knowledge / confidence in providing PEoLC care.
  2. have acess to specialist palliative care advice and support.
- Responsive and timely to meet the needs of people with PEoLC.
- Coordinated with other care teams who have contact with the person.
- Linked with existing unplanned care services with escalation procedures in place where urgent care is required e.g. ambulance.
- Able to access and can update as required the health and care records, personalised care and support plans and/or advance care plan.
- Culturally aware and able to meet people's cultural needs.

- Able to provide / contribute to a seamless experience for the person, those important to them and unpaid carers.
- Able to advise on care transfers.
- Able to make informed decisions about changes to care.
- Can administer medicines including subcutaneous injections and infusions.
- Can access necessary equipment for PEoLC and have expertise to support and instruct others in using the equipment.
- Have means of travel to reach all areas within the locality.
- Have access to pharmacy services that enable medicines for symptom management in people approaching the end of their life to be dispensed at any time of day or night.
- Are sustainable regarding funding sources and available qualified workforce.
- Include arrangements for all staff to have education, training, continued professional development (CPD), supervision and support.

Source: *24/7 Care and Specialist Advice for Palliative and End of life Care: Commissioner's good practice guide (2023)*

Figure 50: Principles of 24/7 specialist care advice

- Access to a qualified healthcare professional 24/7 who:
  - has access to the person's records/ACP.
  - has the right level of competence to make informed decisions about changes to care
  - has access to more senior specialist advice.
  - has information about local systems/services.
  - works in partnership with the person, their carers and those important to them.
- Provides advice for all professionals providing PEoLC.
- Has a telephone number shared and promoted with professionals and relevant agencies.
- Clear eligibility criteria but avoids 'only those known' to the service.
- Has escalation procedures where urgent care or very specialist advice is required e.g. ambulance / transfers, on-call specialist palliative care consultants.
- Service utilises clinical staff with:
  - Knowledge and expertise in PEoLC symptom management/ local services/ how to obtain medicines / equipment and suppliers.
  - Up to date knowledge of legal frameworks such as Mental Capacity Act, Lasting Powers of Attorney, Advance Decision to Refuse Treatment, safeguarding requirements and the Children's Act
  - Knowledge and use of systems for personalised care and support plans / ACP.
  - Communication skills and training for PEoLC.
  - Clinical leadership skills and clinical supervision capability.
  - Ability to work autonomously.
- Matches call density with appropriate staffing levels.

- Sustainable funding sources and qualified workforce available 24/7
- Arrangements for all staff to have PEoLC education, training, CPD, supervision and support.
- Developed appropriate equipment, IT infrastructure, and premises including:
  - Appropriate phone system features / workforce equipment / premises for taking calls.
  - Access to information systems including SystmOne, EMIS, PPM.
  - Where appropriate, co-location with other teams to build relationships and improve integrated working
- Clearly sets out clinical governance arrangements for the service
- Uses data and insight from the service and calls received to inform future delivery models, sustainability, and impact.

Source: *24/7 Care and Specialist Advice for Palliative and End of life Care: Commissioner's good practice guide (2023)*

The tables above outline the requirements for PEoLC services to ensure 24/7 care availability. The table below presents Place-level responses regarding face-to-face specialist palliative care availability for 8 hours a day, 7 days a week. Among the five hospitals, three meet this standard, while two do not.

Figure 51: Scores for each trust on NACEL marker for comfort

Nacel maker	National	Calderdale and Huddersfield NHS Foundation Trust	Airedale NHS Foundation Trust	Mid Yorkshire Teaching Hospitals NHS Trust	Leeds Teaching Hospitals NHS Trust	Bradford Teaching Hospitals NHS Foundation Trust
Hospitals have face-to-face specialist palliative care service available 8 hours a day, 7 days a week.	60%	Yes	No	No	Yes	Yes

During the development of this HNA, surveys were distributed to Places to gather information on their 24/7 PEoLC provision. More recently in December 2024, a comprehensive mapping exercise was conducted with Places to assess all PEoLC services against NHSE's statutory and commissioning frameworks.

The mapping of all children and young people and adult PEoLC services provided in West Yorkshire was from NHS trusts and hospices, against the NHSE's commissioning framework broken down into 'core', 'specialist' and 'enhanced' provision and assessed against service descriptions from:

- NHSE Commissioning and Investment Framework for Palliative and End of life Care (2022)
- NHSE Statutory Guidance for Integrated Care Boards (2022)
- NHSE Specialist palliative and end of life care Children and young people service specification (2023)
- NHSE Specialist palliative and end of life care Adult service specification (2023)

7.1.1 24/7 PEoLC provision for children and young people (CYP)

Gap analysis of current NHS CYP PEoLC provision

- There are gaps of PEoLC 'core' provision including 24/7 community nursing, home-based care, paediatric consultant and respite provision by NHS providers. Some NHS provision exists but this doesn't usually extend to outside of core working hours.
- A WYICB pilot launched in November 2024 aims to address this by providing out-of-hours (OOH) support through Martin House and Forget Me Not Hospices for any CYP or professional, regardless of hospice affiliation. This is currently funded from the 'match-funding' arrangement which is due to end March 2025.
- 24/7 support for health professionals is also variable, e.g. community nurses, often lacking specialist palliative care training, rely heavily upon hospices and limited NHS paediatricians for managing complex cases within the community setting involving pain and symptom management.
- There is a lack of NHS 'specialist' provision of CYP PEoLC teams in all areas (apart from the two children's hospices that provide this across WY).
- Psychological and bereavement support is very limited across WY in NHS provision, this is mostly classed as 'enhanced' provision and provided by the hospices.
- There is a lack of collaborative multidisciplinary team working at a regional level due to small caseload numbers at place level.

7.1.2 24/7 PEoLC provision for adults

Figure 52: Stakeholder survey responses on 24/7 face-to-face care for adults

Summary of survey responses, comments from individuals in italics.

Indicator	Summary of the Region
Your face-to-face service have access to pharmacy services that enable medicines for symptom management in people approaching the end of their life to be dispensed at any time of day or night.	*'This has been highlighted as one of the gaps. We are working with Local Medical Committee (LMC)'.* Access to medication out of hours (OOH) appears to be an issue in three of the five places. One of the places that has stated this is met does have additional issues to accessing OOH service at Place, the other Place has access via a community palliative care team.
Your face to face services are sustainable regarding funding sources and available qualified workforce.	Three of the five places have stated issues with sustainable funding, with another place describing sustainable funding an issue in some areas within Place, and the 5th Place stating that they do have a sustainable service via a community palliative care team.
Your face to face services are available for people of all ages in all settings and during: *scheduled care times (7 days per week, often 8am to 6.30pm but will vary locally).	One area within a Place stated there is no provision for face-to-face assessment. Another Place currently only offers five day a week service however a seven day a week service is currently in development and states; *'Recruitment to expand to seven day working currently underway'.*
Unscheduled care times (7 days per week, out of scheduled care hours).	As above

Indicator	Summary of the Region
Your face to face services are provided by qualified practitioners who are not necessarily specialists but *who have up to date training to ensure they have knowledge, skills and confidence in caring for people with PEoLC needs.	Stakeholders from all Places except one stated this was available. One Place did not respond to this question.
Your face to face services are linked with existing unplanned care services that are non PEoLC specific and have escalation procedures in place where urgent care is required e.g. ambulance.	*'Fairly responsive across hospital during the week. This will change when full cohort (of staff) inducted.'* This response is linked to the seven day a week service in development for one Place.
Your face to face services are able to access and have the ability to update as required: *the person's health and care records, *the person's personalised care and support plan and/or advance care plan.	*'Not all services have access to EPaCCs. Those that use SystmOne do but patients from EMIS practices details can't be accessed. Paper versions, are used to work around this.* *'Full records available if patient has agreed to share with services including ambulance. If the ACP is on EPaCCs then its shared by:* • *Ambulance & OOH access through emergency care records.* • *NHS 111 can only see handover forms* • *Primary care, only S1 practices* • *Community teams inc. district nurses, matrons have access* • *Hospitals - some access* • *Palliative social workers / gateway to care have access to SystmOne. Other social workers have to ask for access via a nurse or GP but, no direct access. Its limited access as not shared systems* • *Care homes info added to emergency care plan* • *One in patient unit has access.* The other Places stated they do have access to SystmOne.
Your face to face services are culturally aware and staff have competencies and confidence to meet people's cultural needs.	Three of the five places have partially met this requirement. Partially met - *'ongoing training is provided around this but some don't feel they fully meet the needs of all communities.'* *'Clinical nurse specialist team working in a town centre, have a Band 4 ethnic support worker 30 hours a week to provide support to Asian families on CNS case load.'* *'One inpatient unit has employed a community engagement lead for minority groups as it is underutilised by south Asian community and other minority groups homeless etc.* *In another service population health management is being prioritised for the locality including identifying health inequalities.'*
Your face to face services are able to provide and contribute to a seamless experience for the person, those important to them and unpaid carers.	*'Equipment available in hubs across one Place. They are currently working on this as there is no access from Saturday pm to Monday am. A review is being carried out by discharge assessors each month to see what discharges are being delayed by this unavailability.* *Specialist palliative care team will advise on use.'*

Across West Yorkshire, there is no full interoperability between electronic patient records for EPaCCS or ReSPECT. Healthcare providers including primary care, community nursing, hospitals, hospices, specialist palliative care teams (SPCTs), out-of-hours GPs, Yorkshire Ambulance Service (YAS), social care, and mental health trusts, use a variety of systems beyond SystmOne and EMIS, leading to fragmentation in record-sharing.

This poses a significant challenge across the region, with the impact varying by Place depending on which systems are in use. Additionally, West Yorkshire-wide providers introduce further complexities and risks, particularly for services such as Leeds Teaching Hospitals NHS Trust (LTHT) as a tertiary provider, YAS, and GPs.

Figure 53: 24/7 specialist palliative care advice for adults

Summary of survey responses, comments from individuals in italics.

Indicator	Summary of the Region
Your service provides access to a qualified healthcare professional, available 24 hours a day, 7 days a week, who: *has access to the person's health and care records and advance care plan.	*'We have practices on EMIS so info on EPaCCs isn't available. If ACP with patients, then yes they have access. There is an OOH service.'* *'We need to be mindful of patients who may not have been registered with a GP such as homeless people.'*
Your service provides a telephone number which can be widely shared and promoted with appropriate professionals and relevant agencies.	*'Each hospice and the specalist palliative care team has its own telephone number, but each is widely distributed. '* *'The 'Goldline' SPOC- single point of contact number would allow information to be passed to specialist services. In practice there is good access for individual community nurses accessing SPCT or hospices for advice and more limited engagement from the SPOC handlers passing on concerns. When community 7/7 working re-starts this will be a priority to ensure prioritisation of OOH work (this worked well during pilot phases).'* *'For the one service that stated other there is a number but not a SPOC in the Place. This however will be a priority.'* Another Place with more than one hospice responded yes, as each hospice had a phone number.
Your service has escalation procedures in place where urgent care or very specialist advice is required e.g. *ambulance or transfer processes with appropriate workforce in place for managing i.e. on-call senior managers.	*'On call managers are available. Ambulance transfers only partially met - without a dedicated palliative care ambulance service we will continue to experience delays. When one Trust is booking a patient transfer for a palliative patient they book an end of life ambulance (for hospital and community patients) – it's a separate number – there's no agreed time scale but they will prioritise palliative patients. However, it's still not ideal as 999 calls obviously take full priority.'* Whilst other Places state this standard is met, feedback from those Places states it is challenging - for example in general, transport booking is a big challenge across a lot of services, despite some areas of really good support.
Yours service utilises clinical staff with:*knowledge of the available local services for PEoLC.	Currently under review by the End of life care Board /transformation plan to ensure a wider awareness of all services available.

Indicator	Summary of the Region
Your service utilises clinical staff with:*knowledge of medicines for PEoLC and how (prescriber and prescription) they can be obtained.	*'Know where to refer to.'*
Yours service utilises clinical staff with: *knowledge and competent use of the local personalised care and support planning systems and documents including symptom management and advance care plans.	Two Places responded to this as partially met, with one Place adding the additional narrative of EPaCCs embedded since 2014. *'More work is required on this.'*
Yours service utilises clinical staff with:*communication skills and training for PEoLC.	*'Communication skills training is provided across specialist services, including advanced communication skills training. This is not part of mandatory training but is preferable for staff undertaking ReSPECT roles. This training for non-specialist staff can be very ad-hoc.'*
Yours service utilises clinical staff with: *clinical leadership skills and clinical supervision capability.	*'There is a gap in the psychological element of clinical leadership/ supervision.'* *'Consultant vacancy at one trust but, otherwise yes.'* Two Places responded to this as partially met, this is down to staffing vacancies.
Your service matches call density with appropriate staffing levels.	*'Where we can. One trust is reviewing its model. Marie Curie night sitting service requests recently increased. Some additional funding to 31/3/24 agreed.'* *'Goldline is not specialist, there are gaps and limited resource in specialist advice.'* Two Places responded to this as partially met.

Gap analysis of current NHS adult PEoLC provision

- Inconsistent 24/7 provision in the community (core provision of commissioning framework): While Bradford/Airedale benefits from greater coverage through services like Goldline, and Kirkwood Hospice offers a central advice line across Kirklees, there is no standardised 24/7 provision across West Yorkshire. It is important to acknowledge that all hospices in the region play a vital role in providing substantial 24/7 support, not only to healthcare professionals but also to patients and families. This support also extends to partner organisations such as YAS.
- Wakefield and Kirklees has limited step-up and step-down care services (core provision of commissioning framework).
- Respite and short break services are limited across West Yorkshire, with hospices primarily providing ad-hoc respite care. To address this significant unmet need, some hospices are considering utilising Continuing Healthcare (CHC) funding to enhance their respite care offerings (core provision of commissioning framework).

- Accessing medications outside of regular 9-5 hours in the community is challenging due to current gaps in 24/7 community nursing provision for prescribing and obtaining medicines (core provision of commissioning framework).
- Emotional and psychological support, including bereavement services, is limited within NHS provision, with the majority of such support being offered by hospices. The assessment of support comes under 'core' provision of the commissioning framework.
- NHS specialist PEoLC bed-based care is limited, with the majority of specialist provision being provided by hospices. This comes under the 'specialist' section of the commissioning framework.
- Specialist multidisciplinary team (MDT) provision and membership vary across areas in West Yorkshire. To align with NICE guidelines, a minimum set of MDT components is required, as outlined in the 'specialist' section of the commissioning framework.
- There has been insufficient focus and investment in addressing health inequalities, as highlighted in early data within this HNA. St Gemma's Hospice runs a Specialist PEoLC Inclusion Service supporting individuals who are homeless or vulnerably housed, working collaboratively with partners across the city. However, this service is at risk due to a lack of available funding, despite demonstrating significant cost savings and a notable shift in care delivery from acute hospital settings to the community.

7.2 Shared records

Healthcare records for all people living with a long-term condition must encompass their needs and preferences as they approach the end of life. With the person's consent, these records should be shared with all those involved in their care. The HNA stakeholder survey tried to establish if records are routinely shared and whether effective IT systems are in place across the region. We also asked if data sharing agreements are in place with all organisations, e.g. children's services, mental health services, learning disability services, social care, third sector provision. Our findings showed most Places do have IT systems that enable record sharing, however who the data is shared with varies considerably.

Figure 54: Place findings on IT systems and data sharing

	Leeds	Bradford	Calderdale	Kirklees	Wakefield
Are IT systems in your Place effective at enabling shared records?	No	Yes	No	Yes	Yes
Do you have **data sharing agreements** set up with the following to share patient records?	Yes, but on an organisation/ patient level.	Children's Services, mental health services, learning disability services, social care, third sector.	Don't know.	Third sector, social care, learning disability services.	Mental health services, learning disability services, social care.

In terms of IT systems Calderdale representatives shared that they can't share EPaCCS to all. This is also an issue for EMIS practices. They felt there needs to be a WY-wide cloud based EPaCCs system. It is worth noting that only one person completed the HNA stakeholder survey from Calderdale so the results may not be fully representative of Calderdale Place.

Leeds Place representatives told us patient record sharing is agreed on an organisation/patient level basis via the clinical systems. There isn't a formal agreement to share patient records unless a share is added with the patient's consent for services on SystmOne or via SLIP on EMIS for the above services. There are agreements in place to share the above data into the Leeds Data Model to support data modelling.

Leeds Teaching Hospitals NHS Trust's electronic patient records (PPM+) including ReSPECT are available (read access only) to primary care, community nursing and hospices via Leeds Care Record. However not all services e.g. YAS/OOH GPs consistently have access. Elements of the primary care record are available to hospital teams via PPM+. Within this EPaCCS/ReSPECT are visible only if flagged as issues but this is not routine practice. Community nursing and hospice EPaCCS are not visible at all.

Wakefield Place representatives explained the agreements in place were brought in during the Covid19 pandemic and these continue. There is a service level agreement in place with the medical examiner between the hospices and the trust. We suspect this will be the case for all Places.

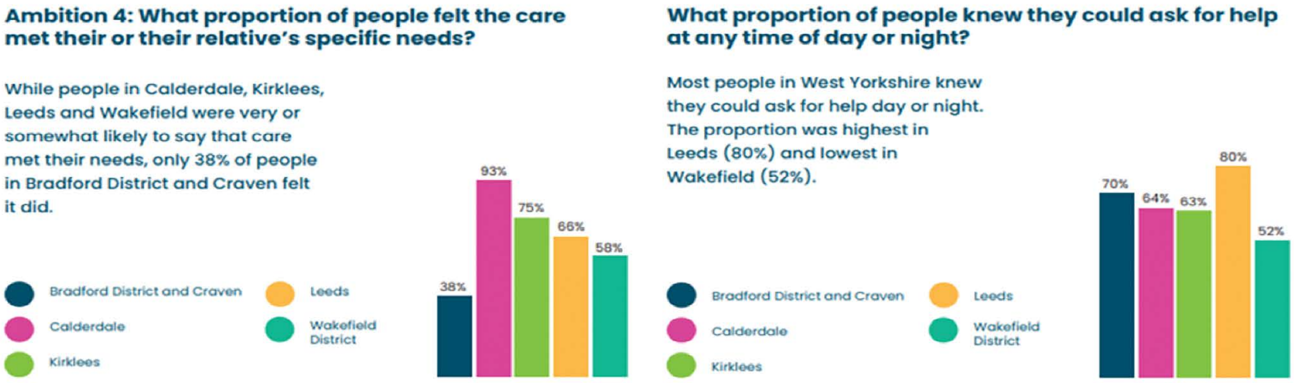
Bradford District and Calderdale representatives informed us that children's social care can access GP records via SystmOne for children known to them. They are also able to see entries from children's community nursing, school nurses and health visitors. Other organisations share safeguarding information as appropriate. Mental health services have access to SystmOne but this is not two way sharing and GPs cannot see mental health records in real time. There is some sharing between hospitals and mental health services. It is very rare that social care can see patients' medical records, so they cannot easily see the EPaCCS template. The fast-track team use SystmOne but not the healthcare professionals themselves, social workers within healthcare organisations can offer support. Some third sector organisations (especially social prescribers) can see shared SystmOne records, but this does not extend to all (e.g. Mind, The Cellar Trust providing mental health support etc).

Although there was a lack of detailed responses in the HNA stakeholder survey, it is evident additional efforts are needed to enhance data sharing across various agencies and sectors. This will ensure that staff can access up-to-date records, preventing patients and their families from repeatedly providing the same information at the end of life. Further discussions at a regional level are required to determine whether regional or Place-level approaches should be prioritised in collaboration with Places and the Yorkshire and Humber Care Record.

7.3 Patient experiences - Healthwatch case studies

Healthwatch surveyed individuals to assess whether the care provided met both their relatives' needs and their own. Calderdale received the highest rating at 93%, though responses varied across different Places. When asked if they felt able to request help at any time day or night, results again varied with Leeds having the highest score at 80%.

Figure 55: Ambition four responses from the Healthwatch report 2024



Ambition 4: What proportion of people felt the care met their or their relative's specific needs?

While people in Calderdale, Kirklees, Leeds and Wakefield were very or somewhat likely to say that care met their needs, only 38% of people in Bradford District and Craven felt it did.

What proportion of people knew they could ask for help at any time of day or night?

Most people in West Yorkshire knew they could ask for help day or night. The proportion was highest in Leeds (80%) and lowest in Wakefield (52%).

7.3.1 Children and young people

Parents of children and young people in the Healthwatch case studies felt that care was well-coordinated, with some highlighting effective collaboration between schools and other services. Many expressed satisfaction with hospice care and the coordination provided, while others described well-managed end of life care. One parent praised a paediatric doctor for their supportive approach, regularly checking in and helping them feel prepared for what lay ahead. Another parent whose child had died, recalled that they *"couldn't fault the health services"* and felt that *"they did everything."* No parents shared negative experiences regarding the coordination of care.

7.3.2 Joined up care

Where hospices were involved, patients felt they were more supported to navigate the system, as described by one patient;

"Emotionally it has been very turbulent at times, a rollercoaster. Our local hospice is now our key contact, by choice. No matter the query they help us unpick the issue and direct us to the right agency or make contact on our behalf."
Healthwatch Responder, (2024)

A patient whose parent had Alzheimer's talked about waiting for the GP to come and the frustration around this. She felt services were not joined up, didn't communicate well and even when they did, *"they weren't well informed."* Some services had internal staff who didn't communicate.

Workforce pressures could be one of the reasons behind poor communication as described by this patient;

''I spoke to the nurse, she said the Palliative Care team were due to come to our home, but they couldn't come as they were short staffed. I called them again and they said they couldn't come because we are out of area."

Healthwatch Responder, (2024)

Another patient described her mum's PEoLC experience. She explained things were OK until her consultant changed. After this they had a different consultant each time, and communication became poor between them and the information was inconsistent. The same relative explained that a referral to the hospice wasn't made and that the palliative care team was *"inaccessible and unresponsive."*

Some relatives talked about different medical staff having different opinions on treatment and not being coordinated, as demonstrated by the following statement.

"Before he started receiving end of life care, there was a doctor at the surgery. She insisted that he had a colonoscopy. But it was a different type of colonoscopy because they did it with lights. Our own doctor said she didn't agree with it, but she had to go along with it because she had ordered it. And that was the beginning of the end."
Healthwatch Responder, (2024)

Some relatives spoke about living out of area, with patients not being accepted for care due to this. Relatives described the frustration in these situations.

One patient recalled her father being admitted to hospital during the Covid19 pandemic. She found communication was limited as it was all over the phone. She stated she was also made to feel that staff were 'too busy' to discuss things with her.

One relative described a bed order for her father not coming on time. When she contacted services about it, it seemed it had something to do with the costing. She explained the frailty team were good and managed their expectations. Several relatives described the pressure and frustration of the system not being joined up.

"It had a real emotional impact, trying to actually navigate through that system is really quite tough. We didn't even have a list of telephone numbers of people to ring. We just got given one telephone number and the rest of the information I had to find myself, which was tough. And I am used to finding information, but even to navigate through that was just a nightmare. It was one of the most harrowing things that I've ever experienced, and still I'm quite traumatised by the entire thing."

Other relatives felt they could have done with more support but weren't sure exactly what and where to go for help or were overwhelmed with the information. In one case, a patient might have benefited from physiotherapy, but it wasn't offered. When a physio came, the family felt it was too late. Later in their mum's PEoLC journey, they described the nurse's hub line as *"excellent."*

The adult Healthwatch case studies show issues around coordinating care, the need for a single point of contact, and for medical teams to liaise with each other before speaking with the patient.

8.0 Ambition five - All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills, and enterprise and give me competent, confident, and compassionate care.

8.1 Executive governance

PEoLC is the responsibility of all providers within the system. The Ambitions framework recommends governance at Board level to ensure high-quality PEoLC and create environments where all staff can deliver the best of their professionalism and humanity. This includes establishing boards at the appropriate levels and ensuring regular reports on PEoLC across the system, encompassing both health and social care. Respondents to the HNA stakeholder survey highlighted the following structures:

- Bradford District and Craven: Palliative Care Network
- Leeds: End of life Population Board, led by the ICB in Leeds
- Kirklees and Calderdale: Dying well board
- Wakefield: End of life Care Board

Establishing these boards for reporting and escalation is essential, as they facilitate collaboration between agencies, ensure timely issue resolution, and promote good governance and accountability. The findings of this HNA along with any recommendations, should be integrated into these boards to support informed decision-making and service improvements.

8.2 Support and resilience

The Ambitions Framework describes the need for staff to have organisational and professional environments that ensure psychological safety, support, and resilience. This is essential for the mental health and wellbeing of front-line staff who deliver care to patients at the end of life.

We asked colleagues via the HNA stakeholder survey if staff received any pastoral support. The findings are very positive but vary for each organisation. From the self-assessment, all Places told us that staff receive peer support, clinical supervision, and pastoral support.

There is variation in the range of support available, the ways it can be accessed, and how many staff are eligible. However due to the short timeframe for data collection, further details could not be obtained to explore this further.

8.3 Healthwatch case study findings

8.3.1 Children and young people

As mentioned earlier, families of children who had spent more time with the same health and care staff felt better equipped to make joint decisions, with staff demonstrating a strong understanding of their needs. Parents praised the staff for providing support when needed, including assistance with other children. There were numerous positive stories shared with no negative experiences. Staff were particularly commended for being culturally aware and responsive to the families' needs.

8.3.2 Interaction with staff

A relative of a person living with dementia felt that more staff were needed on the dementia units in care homes. Care was minimal and the quality varied.

Other relatives reported the lack of care and attention their loved ones received in care homes. Some were left unattended and not moved in their bed, so relatives had to ask staff to assist. Other relatives were disappointed when they could see that the staff member didn't have enough experience. At least two relatives described night sitters who were very new. In one case study, relatives told the managers not to send a night sitter if the person was inexperienced. They were happy for experienced night sitters to come and really valued their expertise.

Some workers were praised by relatives and carers. This was usually when they displayed acts of kindness or took care of the person at the end of life, without having to be asked. These workers ensured the dying person was comfortable. Relatives also praised doctors and nurses where they were visible and spoke to them, helping them understand what was going to happen even if it was not the outcome they had hoped for. Open communication and visibility are key themes here.

Palliative care nurses were often described very positively as they were identified as a point of contact and support. Simple things like just listening to a family member were greatly valued.

A carer said that her husband wasn't offered person-centred care or allowed to make informed decisions for his treatment. The hospital team followed a medical model as she explained it. Her husband met a palliative care doctor by chance who explained he could refuse to have endoscopies (which the patient disliked and wouldn't impact on his terminal cancer). His carer found the PEoLC teams extremely helpful and advised her friend whose husband was also terminally ill, to use them. The friend's husband was under active treatment, couldn't access PEoLC and died eight weeks later. The carer suggested that people should be able to self-refer to the palliative care teams.

These examples show that patients benefit from shared decision making and personalised care. These approaches are standard in PEoLC but need strengthening to ensure patients are involved in decisions about their own care and treatment.

8.3.3 Primary care contact

From the Healthwatch case studies, several relatives expressed concerns about GPs visiting care home residents without providing updates to families, attributing this to time pressures. Others described difficulties in reaching a GP and when successful, found that the GP struggled to connect with the appropriate hospital team for referrals.

One carer shared a particularly distressing experience where an inexperienced GP advised taking a relative to A&E, despite the patient being at the end of life following a stroke. The journey was extremely challenging especially as the patient had previously suffered a broken hip, and A&E was unable to offer any treatment. The carer emphasised the need for GPs with PEoLC training, to visit patients requiring specialised PEoLC support.

The HNA stakeholder survey highlights that some GPs with expertise in PEoLC go above and beyond to provide personalised care, maintain continuity with patients and families, and support shared decision-making on treatment. This commitment is also reflected in the use of EPaCCS and the Gold Standards Framework (GSF) by several practices to identify patients at the end of life to ensure their needs are met within the community. However findings from the Healthwatch case studies indicate that experiences with primary care vary across the region, and this level of good practice is not consistently implemented everywhere.

8.3.4 Administering pain medication

Relatives recalled frustration about workers such as bank nurses (in care homes) not being able to administer pain medication. The relatives felt they needed to know these procedures to get the patient the medication they needed.

Families who had registered nurses come to their home found the nurses were really busy and could only administer the drugs and leave. They didn't have time to answer questions or have a chat with relatives about their concerns.

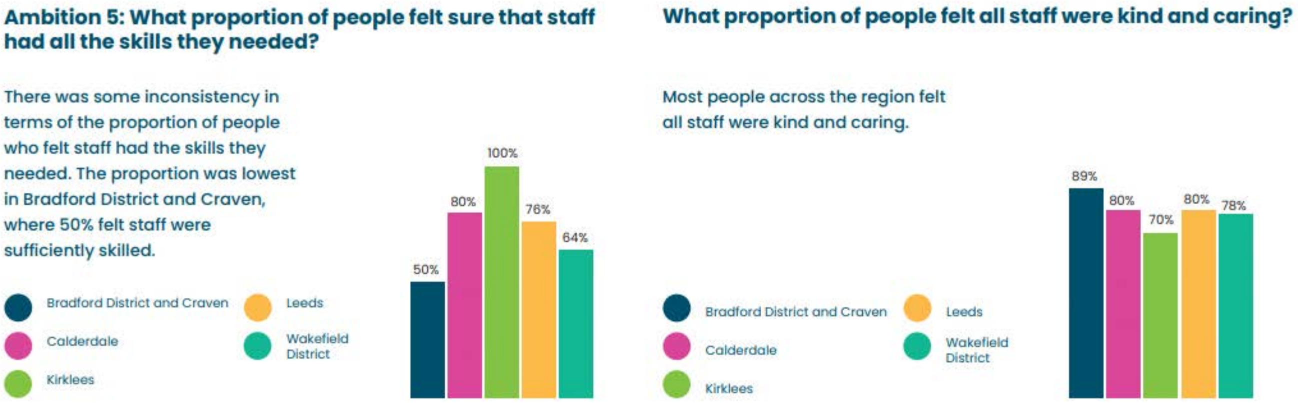
Some relatives felt overwhelmed by the number of teams involved in PEoLC.

Other relatives said that although lots of services were involved, the staff were good and they felt safe with them.

8.4 Staff skills

Figure 56 illustrates the percentage of people from the Healthwatch engagement who felt confident that staff had the necessary skills. Kirklees received the highest rating at 100%, with variation observed across other areas.

Figure 56: Ambition Five responses from the Healthwatch report 2024.



Ambition 5: What proportion of people felt sure that staff had all the skills they needed?

There was some inconsistency in terms of the proportion of people who felt staff had the skills they needed. The proportion was lowest in Bradford District and Craven, where 50% felt staff were sufficiently skilled.

What proportion of people felt all staff were kind and caring?

Most people across the region felt all staff were kind and caring.

The compassion and care shown by staff has a profound impact, particularly at the end of life. The Healthwatch report highlights staff across the region who not only treat the patient but also recognise the person behind the illness, offering invaluable practical and emotional support. Their dedication and outstanding care deserves recognition.

The report also emphasises that personalised care empowers individuals, enabling them to make their own decisions and maintain a sense of control throughout their palliative and end of life care journey.

The expert care offered by experienced PEoLC specialists is highly valued. People and families feel reassured when staff guide them and let them know what to expect, especially as the dying patient approaches the very end of life. This was most clearly evidenced in the experience of children, young people, and their families.

Sometimes people have encountered problems with staffing levels and the type of professionals assigned to roles. Some have felt that bank or agency staff were less prepared to do the highly skilled and specific role of looking after someone at the end of their life. Others have observed that staff don't have enough time to devote to individual patients. There is a challenge for our region to make further progress with training to build expertise and resilience.

The Healthwatch engagement found that 80% of respondents felt staff were kind and caring, while 71% were confident in staff's skills. Additionally, 59% stated that staff consistently checked to ensure care met the needs of both patients and relatives.

However, only 40% had discussed their end-of-life wishes with services, and just 39% felt consistently informed about what to expect from their end of life care. These lower figures highlight a key area for improvement in communication and advance care planning.

Establishing a more consistent training plan across the region would support with ensuring staff are equipped to have compassionate conversations about death and dying. This would enhance the quality of discussions with patients and their families. The Healthwatch engagement also identified variation in symptom management across different areas, particularly in administering pain medication. While additional training would be beneficial, addressing these inconsistencies requires a systematic approach to ensure equitable care for all.

9.0 Ambition six - Each community is prepared to help

> *I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing, and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*

9.1 Provision of death cafes

Death cafes exist to provide a safe, open space where people can discuss death and dying in a non-judgmental, supportive environment. The aim is to break the social taboo around death, encourage open conversations, and promote a healthy understanding of mortality. By bringing people together to share thoughts, fears, and experiences, death cafes seek to reduce the anxiety and isolation that often accompany end-of-life topics.

Participants are encouraged to reflect on their own mortality, engage in meaningful conversations, and ultimately foster a sense of acceptance and preparedness for the inevitable. The format is informal and the goal is not to provide professional grief counselling but to create community dialogue around a universally shared experience.

There are several death cafes across West Yorkshire. In Leeds these are held at various locations and led by the Leeds Dying Matters Partnership. However, reductions in third-sector bereavement funding have impacted the sustainability of the Dying Matters Partnership. Bradford and Calderdale have a limited number of death cafes available. Kirklees and Wakefield previously hosted death cafes and also organised ad-hoc events during Dying Matters Week in 2023.

While death cafes have been valuable since their inception in 2011, their sustainability is variable. Due to their reliance on volunteers or third-sector organisations, maintaining a consistent offering across all areas remains a challenge.

9.2 Dying Matters Week

Dying Matters Week is an annual awareness week aimed at encouraging people to talk openly about death, dying, and bereavement. In West Yorkshire various organisations and communities participate in Dying Matters Week by hosting events, workshops, and discussions. These include:

Death cafes: informal gatherings where people can have open conversations about death in a supportive, non-judgmental setting. These cafes are often held in locations such as community centres, libraries, or cafes across the region.

Workshops and talks: local hospices, healthcare providers, and bereavement support organisations often offer educational sessions or talks about advance care planning, writing wills, funeral planning, and how to talk to loved ones about end-of-life wishes.

Public engagement events: these may include art installations, discussions, or community events that encourage people to reflect on their own mortality and talk about their wishes. They may be organised by local councils, health organisations, or charitable groups.

Grief and bereavement support groups: some events focus specifically on supporting those who are grieving, providing opportunities to talk about the emotional aspects of loss and bereavement.

Hospices and palliative care providers: many hospices offer special sessions or resources during Dying Matters Week to promote advance care planning and provide support to those facing life-limiting illnesses.

9.3 Compassionate Communities initiatives

The Compassionate Communities initiative is a global movement that encourages communities to become more supportive and inclusive when it comes to end of life care, death, dying, and bereavement. The initiative recognises that care for those facing death, loss, or serious illness is not just the responsibility of healthcare professionals but also of the wider community, including friends, neighbours, workplaces, and local organisations.

The Compassionate Cities charter was developed by the Compassionate Communities charity. It recognises that;

"All natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities. A Compassionate City is a community that recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility."
Compassionate Cities Charter 2020

Signing the charter commits a city to encourage and facilitate care for others during life's most difficult moments, including end of life. The charter specifies 14 commitments, including discussions in schools, workplaces and places of worship, exhibitions in art galleries etc.

We asked our regional PEoLC stakeholders about the Compassionate Cities, while most colleagues had heard of it, they were uncertain about its adoption by any local authority in the region. One member noted that Bradford Council had made an initial commitment in 2014 but did not ultimately sign the charter.

Although signing the charter requires significant civic involvement, the Compassionate Communities charity also promotes smaller-scale initiatives, such as the regular activities run by Good Grief Guiseley, and other smaller scale activities organised at a local level. These types of initiatives could be developed across all our Places without the need for formal adoption of the charter.

9.4 Healthwatch case study findings

9.4.1 Aftercare support following the death of a loved one

This section refers to support in the widest sense to bereaved relatives, not just counselling as covered in the previous sections. Bereaved relatives often experience a sense of disconnection from healthcare professionals with whom they had developed close relationships during the care of their loved ones. This loss of contact can amplify feelings of grief and isolation, as these relationships provided both emotional support and a sense of continuity. Furthermore, the support they need after the loss may differ from what is typically offered, as it may involve more personalised, empathetic care rather than medical interventions.

The case studies showed that when bereaved relatives received appropriate ongoing support it made a significant difference to their mental and emotional wellbeing. This support helped mitigate the isolation and emotional burden they might otherwise face. On the other hand, when this support was lacking, relatives struggled in silence, potentially facing worsened mental health outcomes, such as depression, anxiety, or complicated grief. This disconnect left them feeling abandoned at a time when they are most vulnerable.

A powerful example was from parents who had spent much of their time taking care of their child. They now felt lost and had to find a new purpose.

"I'm still struggling because it'll be coming up to two years in December [since we lost her]. I've got other kids at home. So, you know, it's a tough one, it's supporting the kids as well as myself and I think if I didn't have my kids, I'd probably be in a lot worse state. But I'm trying to keep strong for the kids."
Healthwatch Responder, (2024)

Further evidence of this came from another case study. A relative described how she has struggled since her father has passed away.

"It's hard at the minute because all the professions are all backing away [from me] because my dad's not here and I get that, I really do understand that. But that's also hard as well."

Several parents of children described similar emotions. One example is below.

"It was like losing the whole world. My phone, my home was, constantly like, phone ringing, this appointment, that appointment, this project, that project, you know………. social workers [would say] can I come visit your daughter? She had teachers from school as well when she was off sick. They used to come home to visit. So, it was really a busy life. And then once she was gone everything was quiet. So, it was a, a big change of life. It wasn't just losing my daughter; it was losing everything."
Healthwatch Responder, (2024)

Parents who have dedicated much of their time and energy to caring for a child, particularly one with a serious illness, often experience a profound sense of loss not just of their child, but also of their role and purpose. The daily routines, the responsibilities, and the connection with healthcare teams all become integral parts of their lives. Once the child passes away, these parents are left with a void, not just emotionally, but also in terms of identity and purpose. They may feel as though they've lost their reason for being, and that can be incredibly difficult to navigate. When these parents are not offered proper support after the death, the struggle can be especially overwhelming. They may feel adrift, unsure of how to move forward or what their life looks like now without their caregiving role. This feeling of "lostness" can impact their mental health, leading to depression, anxiety, and even physical health problems.

For some relatives, losing a loved one means losing valued relationships with healthcare workers, leaving a void. Providing people with targeted support whether through grief counselling, peer support groups, or even assistance in finding new meaningful activities or roles, can help them rebuild a sense of purpose and move through their grief in a healthier way. It's crucial for healthcare providers to recognise this shift in role and to offer resources that can help them navigate the aftermath of losing someone. This type of support doesn't just address the grief itself, but the broader identity shift and sense of purposelessness that often accompany it. Better support during this transition would help people adjust back into the community. But this needs to be on the terms of the bereaved relatives.

'But I don't want to move on. I want her to be moving with me. So that's what I'm trying to do now.'
Healthwatch Responder, (2024)

One couple described losing two babies in a short period of time. Staff were helpful and kind, but for aftercare they really valued a support group with other parents who had lost two children with the same condition. Despite only small numbers in the group, the couple found it extremely helpful to talk through their emotions. They felt less isolated and lonely.

9.4.2 Workplace

A relative explained that she didn't feel her employer was very supportive and after her father's death, she was expected to go back to work. She didn't feel there was enough support.

Several relatives talked about not being offered any support after the death of a loved one. This was not about bereavement counselling. It was about lack of support after the funeral, people in the community not knowing what to say to them and being uncomfortable talking about death.

One carer explained that she took time off work to attend her husband's appointments, to understand more about his illness. She described the experience of PEoLC as lonely and suggested a buddy system or the *"ability to contact someone who has experience of the journey - possibly a specific support group linked with local carers charity [would be helpful]."* Healthwatch Responder, (2024)

Another said her workplace allowed her to work flexibly but it meant working late into the evening, and if something happened to her dying relative in the evening it would have a ripple effect on her.

Greater efforts are needed across the region to enhance support for bereaved individuals. Implementing the 13 steps of the Compassionate Cities Charter could provide a structured approach to strengthening this support and fostering a more compassionate community.

9.4.3 Mental health

Many relatives and carers said the experience of PEoLC has left a long-lasting impact on them including their mental health. Some talked about the mental toll of coordinating things and having to support the immediate family.

One carer was emotionally depleted after the death of a loved one but would have really valued a conversation in around six weeks, to check in and gather feedback. She felt she would have been in a much better position to have given feedback.

9.4.4 Community

For some patients and relatives, the end of life involved being supported by the community. This certainly came across from people who were from a Muslim background, where they knew they would be supported by their community and wider relatives. For other ethnic minority groups there was limited evidence of this from the Healthwatch engagement.

One carer (white British) explained that most people avoid talking about death and don't know what to say, and so the support in the community or wider family is not always there and it shouldn't be assumed it is.

A few other people also described the fear their loved one had during the end of life and felt there needs to be more support and discussion around this. This was also said in different ethnic minority groups. Some relatives felt people were uncomfortable talking about death and end of life care and that this needed to change.

Integrating death cafes and the 13 steps of the Compassionate Cities Charter could help bereaved relatives and communities engage in open discussions about death. For meaningful impact, this approach should be broad and inclusive, reaching across schools, places of worship, workplaces, and other community settings.

10.0 Discussion

It is important to understand the context in which this HNA was developed. This was a time-limited piece of work, meaning some data may be incomplete and certain topics or areas may not have been explored in depth. Requests for data on 24/7 PEoLC provision and the HNA stakeholder survey were sent to Places with a quick turnaround, limiting the ability to conduct a rigorous review and validation process. Additionally, delays in accessing primary care data meant that not all relevant information could be included in this HNA. However, this does not mean the missing data will be lost. As more unified data becomes available, it will be added as supplementary information to the HNA and will directly inform future transformation work based on the findings of this assessment.

At the start of this HNA, there was no central repository for data. Despite this, the HNA has successfully gathered a broad range of information within a short timeframe- a significant achievement that reflects a strong commitment to improving PEoLC across the region. Providing a regional overview of PEoLC marks a key milestone. This data will be invaluable in shaping future decision-making and service planning, ensuring a more informed and coordinated approach to care.

The HNA findings will be used to guide the development of equitable PEoLC services across West Yorkshire, ensuring compliance with statutory duties. We recommend this HNA as a starting point for PEoLC services across the region to work together to create a programme of work on transformation to enable quality improvement.

The key findings from the HNA are summarised below.

10.1 Baseline data

There is a need to articulate data consistently across West Yorkshire and establish a baseline by collecting relevant information on health outcomes, access to care, and quality of life. This should include standardised metrics to measure disparities and track progress over time.

10.2 Service coordination

The HNA and Healthwatch engagement report highlighted that services are often disjointed, leaving families to take on a key coordinating role, which adds to their distress and emotional burden.

To address this we must work towards a seamless, integrated system where services collaborate effectively, ensuring clear communication channels and reducing the need for families to act as intermediaries. By fostering better coordination and accessibility, we can improve the overall experience for patients and their loved ones.

However, it is important to acknowledge that PEoLC services are facing challenges, including budget constraints and workforce pressures, as reflected in the Healthwatch report. One way to support families is by ensuring clear, accessible information about available PEoLC services, empowering them to navigate the system more easily and access the support they need.

10.3 Training

NHSE (2022) Palliative and end of life care: Statutory guidance for integrated care boards (ICBs) states there must be sufficient workforce in place across all settings, with the knowledge to deliver the care required. Regard should be given to supporting general clinicians to build knowledge, skills, and confidence to deliver high quality, personalised PEoLC, supported by specialist palliative care clinicians and services where appropriate. Significant disparities exist in the availability of specialist PEoLC training and awareness of how to access it across different places. Bridging these gaps is essential to delivering consistent and high-quality care.

We will work to ensure our workforce has access to adequate training and development for palliative and end of life care. We aim to do this by developing a training framework that will standardise training across West Yorkshire. It will be aligned to NHSE Career Pathway, Core Capabilities in Practice and Education Framework, incorporating a Qualification in Specialism Standard, for Palliative and End of life Care, and will be available to all our workforce involved in caring for patients with PEOLC needs regardless of where they work.

10.4 Advance care planning

To enhance patient outcomes in PEoLC through ACPs, we propose the following approaches:

- **Early conversations:** initiate discussions about care preferences and goals as early as possible. Encourage patients and their families to express their wishes, values, and priorities. These conversations should occur well before the advanced stages of illness.
- **Collaboration with partners:** strengthen partnerships with other healthcare providers, community organisations, and social services. By working together, we can create a seamless continuum of care. Specifically, we recommend integrating ACP into Long-Term Conditions (LTC) clinics. This ensures that patients receive personalised, patient-centred care aligned with their preferences.
- **Multi-morbidity strategies:** to enhance patient care for those with multiple chronic conditions, integrating ACP into interdisciplinary team and multimorbidity strategy planning is crucial. By making ACP the norm, similar to other shared decision-making plans (such as birth plans), we can ensure that patients receive personalised, holistic care that aligns with their preferences and values. This approach promotes patient-centred care and improves overall wellbeing.

10.5 24/7 Access to PEoLC care

NICE (2021) states that people approaching the end of their life, and their carers should have access to support 24 hours a day, 7 days a week. The goal is to ensure equitable access to services, guidance, and resources, regardless of the time of day, to provide the highest quality care.

We want to ensure that people, their carers, and healthcare professionals in West Yorkshire have seamless access to the support they need at all times. There are different elements to equitable and quality 24/7 provision which need to be considered, and these are listed below.

1. **24/7 support for adults and children needing end of life care:**
   Commission and provide services, including advice lines and healthcare professionals, which are available at all hours, as part of the commitment to providing continuous care.
2. **Access to healthcare records and ACPs:**
   Enable healthcare professionals to have real-time access to critical patient records and advance care plans to ensure informed decision-making and appropriate care.
3. **Provision of essential equipment:**
   Ensure timely availability of necessary equipment like specialist beds, oxygen, and other end of life care devices.
4. **Access to pharmacy services and out of hours medicines:**
   Prioritise access to pharmacy services, ensuring that medications for symptom management are available, even during out-of-hours periods.
5. **Information for patients and carers:**
   Provide clear and accessible information to patients and carers about available services and how to contact them.
   Ensure that patients and carers understand how the services can support them and what to expect from the care provided.
   Facilitate access to the available services, ensuring patients and carers know how to reach them and when they will be available.

10.5.1 Key features to consider for 24/7 implementation:

- **Equity in access:** ensure that all individuals in West Yorkshire, regardless of their location, background, ethnicity, or financial resources, can access these services.
- **Seamless coordination**: services should be coordinated effectively, so that transitions between different care providers or between different times of day (e.g. day to night) are smooth and without gaps.
- **Ongoing monitoring**: regular review and feedback mechanisms to ensure that services continue to meet the needs of patients, carers, and healthcare professionals, with the flexibility to adjust as needed.

Implementing these strategies aims to enhance the quality of care for people at the end of life while ensuring that carers and healthcare providers receive the support they need. This approach aligns with the vision of providing equitable, seamless, and 24/7 access to care, ensuring that everyone receives the right support at the right time.

10.6 Health inequalities

People living in West Yorkshire are more than twice as likely to live in a poorer area of England than the average England resident. Our HNA has specifically addressed inequalities related to protected characteristics and vulnerable populations impacted by health disparities. These groups include individuals living in poverty, those with learning disabilities, individuals coping with serious mental illness, unpaid caregivers, people in contact with the justice system, ethnic minority communities, and homeless individuals.

The average age of death in inclusion health groups is significantly lower than the general population and those in the most deprived decile. We know people experiencing homelessness and/or with drug and alcohol dependence may have a less predictable life course. We need to work with people with lived experience, system leaders, VCSE groups and existing services to understand the needs of our population experiencing health inequalities and from inclusion health groups.

We will use our local experts to build on their skills and knowledge to develop pathways and services that are accessible and appropriate for all our population, and allow people to die in a place of their choice, with their loved ones, and with their end of life wishes in place.

Specific populations:

- Data from our HNA indicates that individuals from IMD1 (the most deprived communities) and those from ethnically diverse communities experience higher rates of A&E attendance during the last three months of life. Notably, IMD1 areas also have a higher proportion of ethnically diverse communities.
- Inclusion health: individuals from these cohorts often have the poorest experiences with PEoLC. As a result, tackling health inequalities must remain a core priority in the planning and delivery of PEoLC across our system. We need to address the unique needs of marginalised groups which include but are not exclusive (due to variation in need at each Place)
- LGBTQ+ community: provide culturally competent care, address discrimination, and offer support tailored to LGBTQ+ individuals.
- People experiencing homelessness: collaborate with shelters, outreach programmes, and healthcare providers to improve access to end-of-life services.
- Learning disabilities: proactively identify individuals with learning disabilities and involve them and their carers in care planning.

10.7 Bereavement services

The palliative and end of life care statutory guidance for integrated care boards (ICBs) (2022) emphasises the importance of ensuring that bereavement services in PEoLC are readily available and accessible. The issue of variation in service provision across the region highlights the need for a more consistent and equitable approach to bereavement support.

Understanding the current disparities in bereavement service provision across the region is critical. Some areas may have more robust services, while others, for example Leeds, may be experiencing cuts. There is a clear need to ensure that all areas within West Yorkshire have equitable access to bereavement services, regardless of the local area's financial challenges or resource constraints. This includes ensuring that all regions, particularly those facing service reductions, can still provide comprehensive support for families and carers.

Bereavement support should be integral to PEoLC services. Specialist palliative care teams and hospices often provide not only physical care but emotional, psychological, and spiritual support for the family, which a lot of the time extends into bereavement support. Strengthening communication and integration between palliative care teams, social services, community organisations, and local voluntary sectors will ensure that bereavement support is not siloed but part of a more holistic care approach. Partnerships with local hospices, charities, and support networks is vital to ensuring equitable bereavement services are delivered. Community led initiatives and peer support networks are also vital to help in the delivery of bereavement support to communities across West Yorkshire. Further mapping needs to be done to fully understand the gaps in bereavement services across West Yorkshire.

11.0 Key recommendations

- **Ensure equity and access for all:** tackle health inequalities by utilising local expertise to create accessible and inclusive pathways and services tailored to the needs of marginalised groups. Preserve exemplary practices, such as Leeds St. Gemma's PEoLC inclusion service, which stands out as an effective model providing critical PEoLC support to health inclusion groups.
- **Strengthen partnership working:** develop collaborative relationships across the system to create equitable and financially sustainable palliative and end of life care services for the future. This includes our VCSE and hospice sectors, which play a vital role in delivering PEoLC.
- **Strategic use of data:** promote the consistent collection and application of data across West Yorkshire to guide decision-making and enhance service planning.
- **Service coordination:** improve integrated system working where services collaborate seamlessly, alleviating the burden on families and improving the overall care experience.
- **Workforce education and training:** offer comprehensive training and professional development opportunities to equip the workforce with the skills needed to deliver high-quality PEoLC.
- **Advance care planning (ACP):** enhance personalised PEoLC, particularly for individuals with multimorbidity, by promoting ACP. This ensures that professionals are aware of and can respect individuals' preferences and wishes for their end of life care. This includes ensuring the workforce is equipped with the skills to confidently and effectively initiate ACP discussions.
- **24/7 access to care:** ensure equitable, round-the-clock access to responsive and timely PEoLC for all patients and their families.
- **Improve public awareness and education:** promote greater awareness of death, dying, and the role of palliative care in West Yorkshire, while providing clear information on how individuals can access these vital services when required.
- **Enhance community and family support:** strengthen community and family engagement by developing care models that allow people to receive care closer to home, including improved access to bereavement support.

12.0 References

1. 24/7 Care and Specialist Advice for Palliative and End of life Care: Commissioner's good practice guide (2023).
2. Allsop MJ, Ziegler LE, Mulvey MR, Russell S, Taylor R, Bennett MI. 2018. Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliative Medicine. 32(8), pp. 1322-1333*
3. Birtwistle J, Millares-Martin P, Evans CJ, Foy R, Relton S, Richards S, Sleeman KE, Twiddy M, Bennett MI, Allsop MJ. 2022. Mapping and characterising electronic palliative care coordination systems and their intended impact: A national survey of end of life care commissioners. PLoS One. 17(10).
4. Boland AC, Kane CM, Ward J, Hosker C, Wilkinson AE, Miller SD, Gillon S. P260 Improving end of life care for people with COPD; outcomes of a newly established integrated palliative COPD MDT.
5. Caroline Jane Nicholson, Sarah Combes, Freda Mold, Helen King, and Richard Green. (2022). *Addressing inequity in palliative care provision for older people living with multimorbidity. Perspectives of community-dwelling older people on their palliative care needs:* A scoping review. *Palliative Medicine. P1-23*.
6. Chapman E.J., Edwards Z., Malia C., Boland J., Maddocks M., Fettes L., Mulvey M.R., Bennett M.I. Practice review: Evidence-based and effective management of pain in patients with advanced cancer. *Palliative Medicine; 34(4):444-453. Apr 2020.*
7. Clarke G, Hussain JA, Allsop MJ, Bennett MI. 2022. Ethnicity and palliative care - we need better data: five key considerations. *BMJ Supportive and Palliative Care.*
8. Clarke, G., Crooks, J., Bennett, M.I. et al. Experiences of pain and pain management in advanced disease and serious illness for people from South Asian communities in Leeds and Bradford: a qualitative interview study. *BMC Palliat Care 22, 90 (2023).*
9. Confidential Inquiry into premature deaths of people with a learning disability (CIPOLD) www.bris.ac.uk/cipold/
10. Davies H, Safdar NZ, Kwan JY, Jain K, Sciberras P, Hurlow A, Tam SK, Coughlin P, Mees BM, Scott DJ. End of life Care for Unplanned Vascular Admissions. Annals of Vascular Surgery. 2024 Feb 1;99:280-9.
11. Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, Maddocks M, Murtagh FEM. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med. 2019 Apr 23;16(4):e1002782. doi: 10.1371/journal.pmed.1002782. Erratum in: PLoS Med. 2019 Jul 18;16(7):e1002878. PMID: 31013279; PMCID: PMC6478269.
12. Department of Health. End of life Care Strategy – Promoting high quality care for all adults at the end of life (2008). Department of Health. Available at: End of life Care Strategy (publishing.service.gov.uk)

13. Department of Health. (2016). *Choice in end of life care: government response.* Available at: www.gov.uk/government/publications/choice-in-end-of-life-care-government-response

14. Department of Health. (2019). *End of life Care Strategy Fourth Annual Report 'How people die remains in the memory of those who live on.* Available at: assets.publishing.service.gov.uk/media/5a7b6bf3ed915d429748ef29/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf

15. Department of Health and Social Care (2023). Chief Medical Officer's annual report 2023: health in an ageing society. Available at: Chief Medical Officer's annual report 2023: health in an ageing society - GOV.UK (www.gov.uk)

16. Dixon et al. 2015. Equity in the Provision of Palliative Care in the UK: Review of Evidence

17. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. The Lancet.

18. El Mokhallalati Y, Chapman E, Relton SD, Bennett MI, Ziegler L. 2023. Characteristics of good home-based end of life care: analysis of 5-year data from a nationwide mortality follow-back survey in England. British Journal of General Practice. 73(731), pp. e443-e450

19. Elliot, Hermione (2011) Moving beyond the medical model. Journal of holistic healthcare. Volume 8 Issue 1 May 2011.

20. Kavanaugh, M.S., Stamatopoulos, *V. Young Carers, The Overlooked Caregiving Population: Introduction to a Special Issue.* Child Adolesc Soc Work J 38, 487-489 Epub 2021 Oct 2021

21. Fraser LK, Murtagh FE, Aldridge J, et al *Health of mothers of children with a life-limiting condition: a comparative cohort study* Archives of Disease in Childhood 2021;106:987-993. Epub 2022 Jan 10.

22. Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. *Estimating the current and future prevalence of life-limiting conditions in children in England. Palliat* Med. 2021 Oct;35(9):1641-1651. doi: 10.1177/0269216320975308. Epub 2020 Dec 15. PMID: 33323043; PMCID: PMC8532217.

23. Fu Y, Mason A, Boland AC, Linklater G, Dimitrova V, Doñate-Martínez A, Bennett MI. Palliative Care Needs and Integration of Palliative Care Support in COPD: A Qualitative Study. Chest. 2021 Jun;159(6):2222-2232. doi: 10.1016/j.chest.2020.12.055. Epub 2021 Jan 9. PMID: 33434498.

24. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet. 2014 Mar 8;383(9920):889-95. doi: 10.1016/S0140-6736(13)62026-7. Epub 2013 Dec 11. PMID: 24332307.

25. Hibbert N, Malia CP-7 Widening access to palliative care for homeless and vulnerably housed people in Leeds *BMJ Supportive & Palliative Care 2021;11:A11-A12.*

26. Hospice UK (2021). Equality in hospice and end of life care: challenges and change. London.

27. Hurlow A, Pattison C, Cracknell A, et al46 Using a quality improvement approach to improve treatment escalation plans and reduce cardiac arrests at a large acute nhs trust. *BMJ Supportive & Palliative Care 2018;8:A27.*

28. Hurlow A, Wyld L, Breen A. An evaluation of advance care planning during the COVID-19 pandemic: a retrospective review of patient involvement in decision making using routinely collected data from digital ReSPECT Clinical Medicine. 2021 Jul;21(4): e395.

29. Iwaniszak C, Rees E, Meal R, Winfield A, Pattison C, Hodge K, Kite S. 165 Improving care of patients with terminal agitation (ta) at end of life at Leeds Teaching Hospitals nhs trust. BMJ Supportive & Palliative Care. 2018 Mar 1;8:A70.

30. Jacob F, Hurlow A, Deddick-Dyson S, Fowler-Roughton G, Ferguson A, Gillon S, Kite S, Rees E. 52 Needs assessment of end of life care in the emergency department. BMJ Supportive & Palliative Care. 2023 Mar 1;13(Suppl 3): A27-8.

31. James R, Flemming K, Hodson M, Oxley T. Palliative care for homeless and vulnerably housed people: scoping review and thematic synthesis. BMJ Supportive & Palliative Care. 2023 Dec 1;13(4):401-13.

32. Kings Fund (2022). *What are health inequalities?* Available at: What are health inequalities? | The King's Fund (kingsfund.org.uk)

33. NHS England 1(2024). NHS England's statement on information on health inequalities. Available at: NHS England » NHS England's statement on information on health inequalities (duty under section 13SA of the National Health Service Act 2006).

34. NHS England 2 (2024). Inclusion health groups. Available at: www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/inclusion-health-groups/

35. NICE (2019) NG61End of life care for infants, children and young people with life-limiting conditions: planning and management. Available at: Overview | End of life care for infants, children and young people with life-limiting conditions: planning and management | Guidance | NICE

36. Marie Curie (2015). Changing the conversation: Care and support for people with a terminal illness now and in the future. Available at: Marie Curie: Changing the conversation

37. Marie Curie (2022) Poverty at the end of life in the UK. Available at: www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf

38. National Palliative and End of life Care Partnership. Ambitions for Palliative and End of life Care: A national framework for local action 2021-2026. (May, 2021) Available at: ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf (england.nhs.uk)

39. Moss, R. Small, N. Islam, S. Hussain, J (2021). How do people from the south Asian community view, use and understand advance care plans? How ready are they to use these advance care plans alongside other palliative care support? Available at: CRM-EndOfLife Oct2021.pdf (borninbradford.nhs.uk)

40. Oxley T, Herbert M, Copley A, et alP-89 Introduction of ReSPECT to facilitate emergency care planning in the oncology department at bradford teaching hospitals foundation trust. BMJ Supportive & Palliative Care 2022;12:A42.

41. Rietjens J et al. (2017). *Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. The Lancet.* Available at: www.thelancet.com/journals/lanonc/article/PIIS1470-2045%2817%2930582-X/fulltext

42. Reilly DE, Raymond K, O'Donnell C. *"It was emotional"* - A group for people with learning disabilities to talk about end of life. British Journal of Learning Disabilities. 2020;48(3):199-205. doi:10.1111/bld.12317

43. Robinson O., Pini S., Boland E., Swinson D., Hurlow A., Hartup S., Mayland C., Flemming K., Richards S., Mulvey,M.R. Exploration of pain assessment and management processes in oncology outpatient services with healthcare professionals: a qualitative study. BMJ Open Dec 2023

44. Pask S, Davies JM, Mohamed A, Leniz J, Chambers RL, McFarlane P, Bone AE, Barclay S, Higginson IJ, Sleeman KE & Murtagh FEM (King's College London, Cicely Saunders Institute; Hull York Medical School at the University of Hull; and University of Cambridge, UK). Better End of life 2022. Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Research report. London (UK): Marie Curie. (November 2022) www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2022/j409-beol-report-2022.pdf

45. The Choice in End of life care Programme Board. *What's important to me. A Review of Choice in End of life care.* (February 2008). Available at: Executive summary (publishing.service.gov.uk)

46. Evelyne D Trottier, MD, Samina Ali, MD, Marie-Joëlle Doré-Bergeron, MD, Laurel Chauvin-Kimoff, MD. *Best practices in pain assessment and management for children.* Paediatrics & Child Health, Volume 27, Issue 7, December 2022, Pages 429–437,Available at: https://academic.oup.com/pch/article/27/7/429/6885178

47. Tyas A, Boland A, Gillon SS43 Has introduction of severity criteria improved palliative care provision for patients with idiopathic pulmonary fibrosis?Thorax 2019;74:A28-A29

48. Universal Principles for Advance care planning (ACP) First published March 2022

49. www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf

50. West Yorkshire Joint Forward Plan Delivering our Integrated Care Strategy. (March, 2024) www.wypartnership.co.uk/application/files/5617/2243/9319/Joint_Foward_Plan_2024.pdf

51. World Health Organization. WHO definition of palliative care www.who.int/cancer/palliative/definition/en/ (2011).

13.0 Appendix list

Appendix 1 - Literature review

There is sporadic and limited evidence/research on PEoLC from West Yorkshire residents. We have summarised recent research and reports that we could find that are linked to this area of work. Some of the research contains data from some local West Yorkshire residents. We have reviewed the literature available to us and themed it.

Older people

Professor Chris Whitty in his report 'Health in an aging society' explains that in the UK people are living a lot longer and that we need to focus on how to maximise their independence and minimise the time people spend in ill health. His report suggests those living in the most deprived ten percent of areas will spend 26.4 years in poor health compared to those in least deprived areas, where they spend 15.6 years in poor health. We know that there are increasing numbers of people with multimorbidity, especially amongst the frail elderly population. He discussed frailty and how this overlaps with multimorbidity, but that it is not the same. He suggests that frailty is used to identify the group of older people who have the highest risk of adverse outcomes such as disability, falls, hospital admissions and the need for long term care. He suggests that there are inequalities in frailty with higher rates in areas of deprivation.

Nicholson et al (2022) found that older people living with multimorbidity are projected to become the main receivers of PEoLC in the future, however there is limited evidence of their specific needs. They explain that multimorbidity is increasing worldwide and thus there is a greater use of healthcare services alongside lower quality and quantity of life, and this rises with age. Nicholson et al found that the most common palliative care needs included pain, loss of function, unhappiness, remaining socially connected, future planning and patient centred care including meaning and purpose to life.

The Marie Curie Better End of life Report (2022) found that out-of-hours emergency department attendances 'increase' in frequency as death approaches and is more common among people living in the most socioeconomically deprived areas. Although all areas have access to telephone lines for general NHS services out-of-hours (e.g. NHS 111 in England and Wales), not all areas have a designated telephone line for out-of-hours palliative care support. Access to medicines out of-hours can be complicated and time consuming. They found gaps between what is theoretically in place and what is actually experienced by patients and informal carers. Equipment is hard to access; that care packages are often delayed or unavailable. Much out-of-hours care relies on stretched community nursing services.

Pain management

Chapman et al (2020) completed a pragmatic overview of the evidence supporting interventions in pain management in advanced cancer, preliminary results are demonstrated but further research is required. A strong opioid remains the drug of choice for treating moderate or severe pain. Bisphosphonates and radiotherapy are also effective for cancer-related bone pain. They suggest optimal management requires a tailored approach, support for self-management and review of treatment outcomes.

Pain is a subjective experience that can be adapted by emotions, developmental factors, culture, current context, and previous pain experiences. Pain assessment and management are essential components of paediatric care. Historically, children's pain has been under-recognised and under-treated, and while progress in both assessment and treatment has been made in recent years, a knowledge-to-practice gap remains. Pain is under-evaluated in many settings, with the youngest children and individuals who are cognitively impaired being the most negatively impacted. Multiple reasons for suboptimal treatment of pain are reported, including the difficulty of assessing pain in children, lack of time and resources, and educational, cultural, and legal factors (Trottier et al 2022)

Langford (2024) undertook research activities in West Yorkshire with breast cancer survivors. Chronic pain reported in this study highlights an important unmet clinical need, whereby breast cancer survivors are not receiving adequate pain management, resulting in reduced health-related quality of life associated with a high prevalence of moderate to severe pain.

West Yorkshire based research by Robinson et al (2023) made recommendations for integrating standardised pain assessment into routine clinical practice for all cancer patients, therefore reducing inequalities in cancer care pain management. Trottier et al (2022) recommends education on the use of developmentally appropriate pain assessment tools is an essential first step to providing optimal pain management in paediatrics.

We appreciate pain management is one of the many symptoms addressed in PEoLC. It has been categorised here, as it came out as a theme from the research.

Primary care

Patients who received good continuity of primary care and palliative care support experienced a better overall quality of end of life care than those who did not, as perceived by relatives in a study by El Mokhallalati (2023). Narratives from relatives showed those who died from cancer or outside of hospital were more likely to receive good end of life care. Being older, female, from areas with least socioeconomic deprivation, and White were associated with better overall end of life care as perceived by relatives.

It is important to acknowledge the limited scope of research and studies involving Palliative and End of life care (PEoLC) within this primary care context. The term 'Hospice at Home' has been consciously omitted from our report, as such provisions are more accurately described under the umbrella of primary or community care, given the diverse range of organisations providing care within the community environment.

Hospice

Hospices have an important role within the health and care system and in their local communities. Hospices like other third sector organisations are uniquely vulnerable to an adverse financial climate.

The All-Parliamentary Group 'Hospice and End of life Care' report (2024) finds that some senior decision makers lack understanding of the role of hospices.

The statement regarding the lack of comprehension of the functions of hospices is indeed accurate. This has been confirmed through local-level discussions with various systems, individual hospices, and even within collaborative settings. A significant observation that emerged from these conversations is the stark difference between children's hospices and those for adults. It's important to note that the misunderstanding about the operations of children's hospices is even more pronounced than that for adult hospices. This highlights the need for increased awareness and understanding about the unique needs and services provided by children's hospices, for example, the provision of short breaks which provides respite to parents throughout a child's life.

The report also shares evidence from an adult hospice that identifies a lack of understanding of the role hospices play in managing symptoms and preventing emergency hospital admissions or ambulance call outs. Another hospice argued the need for hands-on care for people at the end of life is not understood or reflected in funding for end of life care services. The report strongly advocates that decision makers understand the wide variety of care provided by hospices, not just at the end of life, and not merely about the number of people who have died in a hospice.

Allsop et al (2018) identify patient and organisational factors that influence the duration of hospice-based palliative care in the United Kingdom prior to death. They suggest that the actual time of palliative care before death for patients with life-limiting illness is much shorter than is supported by research evidence and in health care policy. Despite increasing rhetoric around early referral, patients with advanced disease are receiving referrals to hospice specialist palliative care very late in their illness trajectory. Age and diagnosis persist as determinants of duration of hospice specialist palliative care before death. They found increasing age persisting as a significant predictor of fewer days of hospice care, as did being male, having a missing ethnicity classification and having a non-cancer diagnosis.

Despite a consistent approach to national policy spanning decades a recent extensive literature search demonstrated persistent inequalities in hospice care provision. The Hospice report in the UK (2022) summarises this well and has found this to be particularly prevalent for people without cancer, the oldest old, racialised communities and those living in rural or deprived areas, who all remain under-represented among those receiving hospice care. They found that, while a substantial body of evidence now exists on inequalities linked to general health in the late stages of life, there are still huge gaps in the evidence base, including appropriate end of life care for the LGBTQ+ community, people experiencing homelessness and those living with specific conditions. They also recommend actively searching for people with learning disabilities within their local areas, rather than waiting for them or their carers to come forward.

End of life doula

The closest analogy is the birth Doula, or birth educator/ birthing companion. The role of a doula for the dying is to offer companionship and support the dying person in whatever way is needed. They can offer support to the family, give information, leave room for conversation, facilitate sharing, discuss practical requirements, create an environment that is conducive, liaise with professionals, are an advocate for the dying person, and with respect and sensitivity to the religious and spiritual beliefs of the family. Elliot (2011) suggests drawing on new non-medical approaches utilising the role of doulas, mentors or trained volunteers.

Since 2022, a pilot by End of life Doula UK (EoLDUK) has been commissioned by NHS Leeds ICB to provide doula services within Leeds and the surrounding areas based on a set funding amount. The pilot reflects a novel approach to offering end of life care under NHS funding, by using doula services to offer flexible person-centred support. The commission and evaluation have adopted a pilot approach. It is important to acknowledge that this was this was a pilot, the role of doulas alongside existing services remains unclear and they are not currently a core component of PEoLC.

Socio economic status

Low socio-economic status is associated with increased risk of death in hospital rather than in the community and more emergency hospital admissions in the final months of life (Davies et al 2019).

Evidence from Davies et al’s systematic reviews indicates consistently that use of specialist PEoLC is lower in lower socio-economic groups (whether measured by area deprivation, income, or education), This suggests a mismatch between PEoLC need and provision. There is some evidence that use of non-specialist PEoLC is also lower in these groups. A local WY children’s hospice also commented that they see the impact of having a child with a life shortening condition is that it often impacts financially diversely on the family – specifically where a parent has to give up / reduce hours of work to look after the child.

Further to this, the Marie Curie ‘Dying in Poverty’ report (2022) shows that more than 90,000 people each year die in poverty. When people are given a terminal diagnosis and are in the final stages of life, their chances of falling below the poverty line increase. The risk is increased for those at a working age, where one in four who die in working age, is below the poverty line. The inequalities increase for ethnic minority groups, where two in five working age people from ethnic minority groups die below the poverty line. They add women are more likely to fall below the poverty line than men at the end of life. These people are having to make impossible choices, whether to heat their home, or eat. They worry about bills and incurring debts when they die. The report adds this may only get worse due to the cost-of-living crisis and that the UK is facing a ‘cost of dying’ crisis. The report recommends that this is addressed by ensuring everybody is able to access more of the financial support they need with the cost of housing, energy, childcare and disability at the end of life.

Learning disability

Reilly et al (2020) in their study undertook questionnaires and face to face sessions with people with learning disabilities about death and end of life. People in the group wanted help to talk to their own parents about what might happen when their parents die. People did not have enough information about the cost of funerals. The research group was important as it helped the participants to learn, and they wanted support to plan for the end of their lives and their parents' lives. The research group tried to provide information and support on these topics. The learning from this research can be applied to residents within West Yorkshire.

Heslop et al (2013) found that for many people with a learning disability who were dying, end of life care was not coordinated and the support for the person/ family could have been improved. It also identified that people with a learning disability were less likely to have access to specialist palliative care services. Their research shone a light on the health inequalities that exist for people with learning disabilities particularly at the end of life. This led to the Confidential Inquiry into premature deaths of people with a learning disability (CIPOLD).

Carers

We know that carers often say they do not get the support they need. The Marie Curie report Changing the conversation: *Care and support for people with a terminal illness now and in the future* (2015) found carers said that seven out of ten people with a terminal illness in the UK do not get the care and support they need. Indeed, the demands placed on parents, particularly those caring for children with palliative care needs, are immense. They are expected to provide round-the-clock life-sustaining support, manage their work commitments, care for other children, and handle financial responsibilities. In such circumstances, basic needs such as eating and sleeping often take a backseat.

Fraser et al (2022) also supports this theory, their study revealed that mothers of children with palliative care needs face a risk of premature death that is more than 50% higher compared to mothers of children without long-term health conditions. Furthermore, these mothers are at an even higher risk of developing cardiovascular diseases. These findings highlight the need for comprehensive support systems for these parents, not only to assist them in their caregiving roles but also to help them maintain their own health and well-being. This could include access to respite care, psychological support, and resources to manage the financial implications of long-term care. By addressing these needs, we can help ensure that these parents are better equipped to care for their children while also taking care of themselves.

Similarly, the role of young carers, who, alongside their parents, provide crucial support to siblings with life-limiting conditions; this role becomes even more critical during the transition from child to adult services, a period when families lose access to certain support services from children's hospices, such as respite and short breaks, yet continue to care for their child who has now become an adult (Kavanaugh 2021)

Children and young people

It can be difficult to calculate which children may benefit from palliative care. Using the number of children who have died can underestimate the ongoing need according to Fraser et al (2020). In the UK and other countries, the terminology life-limiting and life-threatening conditions have been used to describe the population of children who may benefit from input from paediatric palliative care services.

Fraser et al's study aimed to estimate the current prevalence of children with a life-limiting condition in England and to model future prevalence of this population up to 2030 to inform planning of paediatric palliative care services.

The prevalence of children with a life-limiting or life-threatening condition in England has risen over the last 17 years and is predicted to increase. The observed prevalence of children with a life-limiting condition varies by ethnicity, social economic status and geography. Prevalence is highest among the most deprived groups and in children of Pakistani origin. West Yorkshire has a high population in both demographics.

Ethnicity

Clarke et al (2023) found that people from South Asian communities with advanced disease or serious illness may have unmet pain needs, and those with lower English language proficiency found it harder to understand technical medical information about their condition and treatment. There are a number of issues for healthcare professionals to address including improving interpersonal communication. Providing clear and accessible pain medication information is key. Healthcare professionals need a greater awareness of: people's fears and concerns about pain medication; their potential use of alternative pain management strategies, and cultural issues such as resilience, privacy, dignity and gender roles.

Mayland et al (2021) undertook a systematic review of bereavement care for ethnic minority populations. There was no research literature outlining the role of family, friends and existing networks, and a real absence of evidence about outcomes and levels of satisfaction for those from an ethnic minority background who receive bereavement care. They highlight the need to understand more about the role of family, friends, and existing support systems, alongside outcomes and satisfaction which will begin to develop the evidence base underpinning the current provision. They discuss the need for direct user representation through proactive engagement and co-design approaches which may begin to determine the most appropriate models and format of bereavement care for ethnic minority communities. In order to shape the design and delivery of services in West Yorkshire, we must consider the diverse characteristics of the region we serve. It's crucial to ensure that the system's needs are met in a way that accurately reflects this diversity.

Two pieces of research by Moss et al (2023, 2021) built on the observation that people from a South Asian background are less likely to access end of life care or have an Advance Care Plan. They sought to understand why this was and how this could be addressed in order to reduce health inequalities. Both studies based their findings on feedback from people "who were familiar with palliative and end of life care services and with the views of South Asian communities (current patients, carers and relatives were not included)". They observed that "the South Asian community only have a vague awareness of end of life care options".

Moss et al (2021) suggests that there needs to be more fundamental work to understand the community and how they view the end-of-life period. It is only by improving understanding that initiatives can be planned and delivered in a way that maximises the chances of successful uptake. In this community, discussions about end of life often focus on what happens after death and not on the care that is available before death and on the options as to what is included in that care.

It is unhelpful that advance care planning tends to be about what should not be done e.g., do not resuscitate or do not admit to hospital. It omits discussion on what should be done to increase the quality of life of a person who is dying.

This section describes research and themes relating to the south Asian population. . Our HNA was not able to identify enough evidence to describe research and themes relating to other ethnic groups.

Data

Clarke et all (2022) suggest that complete and valid ethnicity data is essential for monitoring racial and ethnic disparities, but consideration needs to be given to collecting data well and using it responsibly. They suggest palliative care could provide leadership in this field. They describe five key areas for the development of ethnicity data:

1. Improvement of ethnic group categories.
2. Sensitive, proportionate approach to data collection
3. Timely data collection.
4. Support for staff collecting ethnicity data.
5. Responsible and contextualised use of ethnicity data.

A national cross-sectional online survey of end of life care commissioning leads for Clinical Commissioning Groups (CCGs) in England was completed by Birtwistle et al (2022). They enquired about the current implementation status of Electronic Palliative Care Coordination Systems (EPaCCS), their role in information sharing and intended impact. They requested routine patient-level data relating to EPaCCS. Of the 63% of CCGs who responded, only 67.1% had operational EPaCCS, with most systems (67%) not supporting information sharing with care homes and social care providers. One of the common challenges to the implementation was limited healthcare professional engagements. Only one third of patients have an EPaCCS record at death with limited recording of patient preferences.

Homelessness

James et al (2023) highlights gaps in knowledge and services with people experiencing different types of homelessness. They advocate that service providers should offer need-based and nonjudgmental care and co-produce services for this vulnerable group.

Hibbert and Malia (2021) supports the above and described an award-winning local project where increased numbers of homeless patients have been supported by PEoLC services in Leeds. Referrals continue to rise with positive word of mouth. Patients are achieving end of life care in their preferred place. Health care professionals and homeless workers have been empowered to manage the complex needs of this group, supporting people to die with dignity and choice. We need to utilise this learning and share across the region.

Integrated working / quality improvement

Evidence from the following publications show the potential benefit of integrated working and quality improvement also the need for earlier recognition of PEoLC need and appropriate referral in selected populations. Rashid et al (2023) and Fu et al (2021) both found that multi-disciplinary meetings had benefits for integrated working, and this could lead to a reduction in acute healthcare usage.

Research by Kite et al (2018), Hurlow et al (2018) and Iwaniszak et al (2018) supports the positive impact of collaborative quality improvement approaches to improving PEoLC outcomes.

Tyas et al (2019) found introducing idiopathic pulmonary fibrosis disease markers of severity, following the intervention from a specialist palliative care consultant, along with having a respiratory consultant with a specialist interest in palliative care, has improved access to palliative care and symptom control for these patients. They also found that patients known to specialist palliative care are also more likely to die out of hospital.

Davies et al (2024) found PEoLC was insufficient and of low quality despite a high mortality in unplanned vascular admissions. They suggest clinical guidelines and pathways are needed to ensure these patients are considered for end of life care and those with diabetic foot sepsis or ruptured abdominal aortic aneurysms are offered it by default.

Jacob et al (2023) found palliative care patients in emergency departments are at risk of dying there or shortly after. They suggest future work is needed to highlight the priorities identified such as streamlining the Rapid Discharge Plan (RDP), appropriate training, and renovation of emergency departments environment. An in-reach service may help to identify a higher proportion of patients with palliative care needs.

Hurlow et al (2018) suggest appropriate planning should take place for the majority of patients recognised to be dying. This was enhanced by use of the rapid discharge pathway. Lack of recognition is a barrier to planning; particularly in those with multi-morbidity and frailty.

Recommended summary plan for emergency care and treatment (ReSPECT)

ReSPECT is increasingly replacing the standalone approach to CPR discussions which were recorded on DNACPR forms. ReSPECT has been introduced in all places across West Yorkshire.

Hurlow et al (2021) found increased advance care planning discussion during a crisis can be achieved alongside increased patient participation in decision making. A tool such as ReSPECT that supports recommendations for, as well as limitations on, treatment may have enabled the expansion of ACP.

Oxley et al (2022) studied the introduction of ReSPECT to facilitate emergency care planning in the oncology department at Bradford Teaching Hospitals Foundation Trust. This quality improvements programme demonstrated a positive impact on the percentage of patients who had a ReSPECT form completed by time of death/discharge. However, this change was not sustained, and further input is required to achieve this. Once this is accomplished it would be beneficial to share with other specialities within the Trust to facilitate improvement at an organisational level.