Staffordshire and Stoke-on-Trent Integrated Care System

All Age Palliative and End of Life Care Strategy

Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Strategy

2025-2028

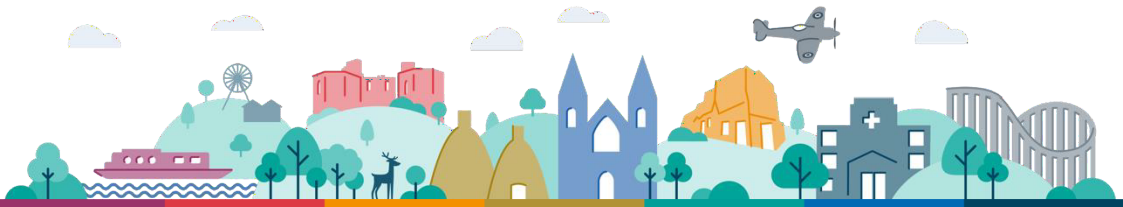
Foreword

We are proud to introduce the All Age Palliative and End of Life Care Strategy 2025–2028 for the Staffordshire and Stoke-on-Trent Integrated Care System (ICS). This strategy represents a significant milestone in our collective commitment to improving palliative and end of life care for our communities over the next 3 years.

Building on the National Palliative and End of Life Care Partnership's Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026, this strategy outlines our shared vision across the ICS to enable compassionate, high-quality, personalised palliative and end of life care for patients of all ages.

The document captures the evolving health and care landscape, including new approaches and innovations, as well as the implications of national policy and local developments. It recognises the unprecedented challenges posed by the COVID-19 pandemic, which has both highlighted and intensified the need to support vulnerable individuals and communities. Looking ahead, it also considers the ongoing pressures within the NHS and our shared responsibility to maximise resources while ensuring equity and excellence in care.

In developing this strategy, we have engaged extensively with partners across the health and care system, as well as with individuals and communities who bring invaluable lived experience. Their insights and perspectives have shaped the strategy's priorities and provided assurance that it reflects the needs and aspirations of Staffordshire and Stoke-on-Trent's diverse population. We extend our thanks to all who contributed to this effort; your voices have been essential in helping us design a strategy that is ambitious, inclusive, and grounded in real-world experience.



Delivering this strategy will require genuine and sustained collaboration. The ICS is committed to fostering stronger partnerships between health, care, local government, voluntary, and community organisations - as well as with the people we serve.

The ambitions set out in this strategy are bold, but we are confident they are achievable with the shared dedication of our system partners. By working together, we can create a future where palliative and end of life care patients have improved wellbeing at the end of life, supported with dignity, compassion, and the highest standards of care.

Thank you for your commitment and collaboration as we move forward together.

David Pearson MBE
Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) Non-Executive Chair.

Neil Carr OBE
Chair, Staffordshire & Stoke-on-Trent Integrated Care System (ICS) Community Transformation Portfolio Board, Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) Partner Member – Physical Health, and Chief Executive, Midlands Partnership University NHS Foundation Trust.

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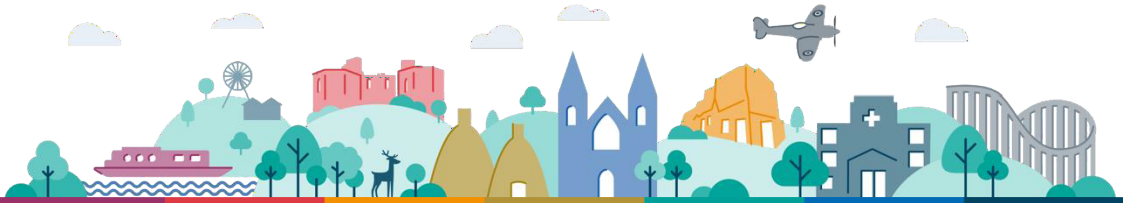


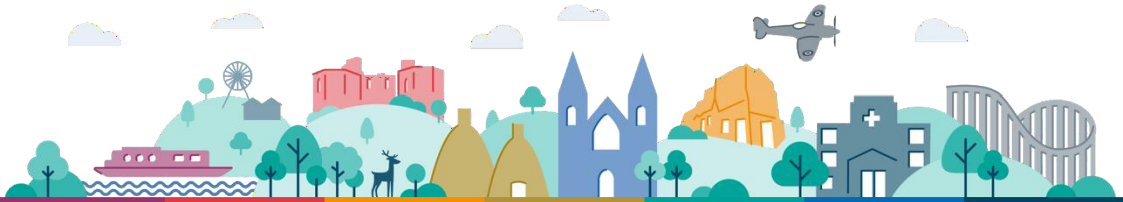
Introduction

This strategy sets out the vision, mission and goals that we want to achieve together as an Integrated Care System (ICS) over the next 3 years to improve palliative and end of life care (PEoLC) for our residents of Staffordshire and Stoke-on-Trent (SSOT).

The inevitability of dying is inextricably connected to each and every one of us. Whilst death should not be seen as a failure, poor care at the end of life should. Death does not discriminate based on our individual characteristics, and nor should the care that we deliver at the end of life. Personalised care, reflective of the priorities, preferences and wishes of individuals, can improve wellbeing at the end of life and enable people to die with dignity.

The Ambitions for Palliative and End of Life Care (2021–2026) established a national framework with six core ambitions to shape local action. This strategy builds on that foundation, ensuring our work remains aligned with national priorities while addressing the unique needs of our local population.

In developing our strategy we have sought to understand more deeply our local population and the specific needs of the individuals, families, carers and communities within it. Reflecting our commitment to cross-organisational working, we have considered the rich and valuable feedback from professionals and providers across Staffordshire and Stoke on Trent regarding what our priorities should be to improve the care that we deliver. At the heart of this strategy are the views of the population that we serve; we work with them, and we work for them to support them to die well, and to live well until they die.



Definitions

Palliative care

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

End of life care

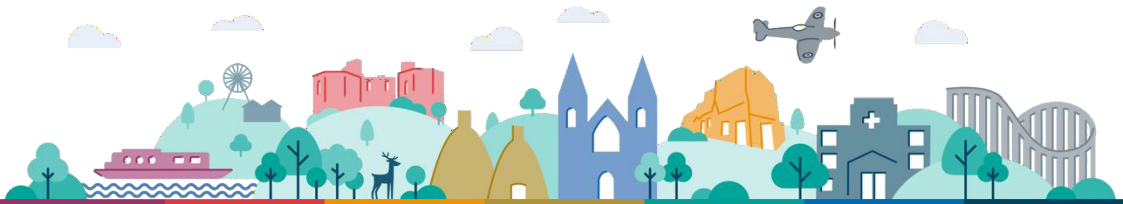
In England, the term 'end of life care' refers to the last year of life.

Children and young people (CYP)

A child is defined as a person aged up to their 19th birthday. A young person is generally considered to be a person aged 18 to 25, or 30. It is recommended by Together for Short Lives that plans need to be in place, and the young person prepared for their transition from as early as age 14.

Together for Short Lives define palliative care for CYP as:

"Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social, and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support."



Vision, Mission and Goals

Our healthcare system continues to face mounting challenges stemming from a growing population, demographic shifts, and persistent health inequalities. Our challenge is to meet this demand within the constraints of significantly limited financial resources and an overstretched workforce.

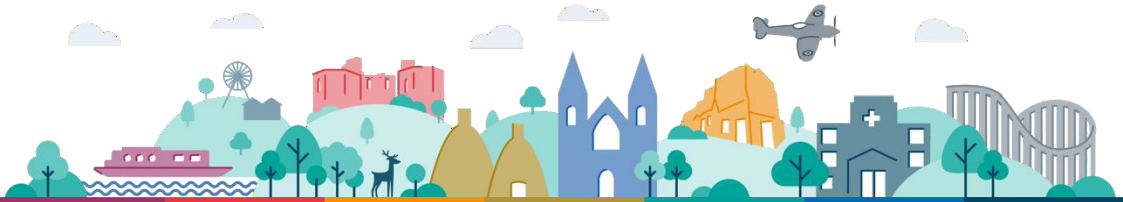
In this context, PEoLC plays a critical role, not only as an essential service but as an enabler that supports broader NHS priorities to improve patient outcomes, enhance patient experience, and promote equity across all sectors.

Our strategy aims to deliver compassionate, high-quality, and equitable palliative and end of life care for all residents, regardless of background or circumstance. We are committed to addressing these challenges by strengthening our partnerships, optimising resources, and promoting a collaborative approach across healthcare, social services, and community organisations.

Guided by our shared mission and values, we seek to ensure that all residents can access the care they need, particularly at the most vulnerable times of life.

Context and challenges

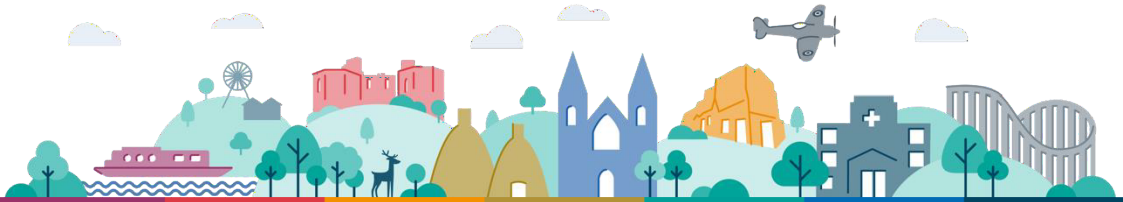
The demand for PEoLC services continues to grow as our region faces an ageing population and increased rates of chronic illness. Health inequalities further exacerbate these demands, as communities experiencing social and economic deprivation often have higher rates of morbidity and limited access to healthcare services. Additionally, the COVID-19 pandemic has intensified existing disparities, disrupted core healthcare services, and highlighted the need for greater resilience in our healthcare system. Furthermore, our system is experiencing significant financial challenges due to increasing costs of care and medications.



Amid these pressures, the resources available to provide effective PEoLC remain limited. Financial constraints and a shortage of appropriately trained healthcare professionals across all the environments affected by PEoLC present significant barriers to meeting the needs of all residents throughout a 24-hour period. In response, the NHS has established a set of priorities for 2024/25 to recover core services, improve productivity, and enhance patient outcomes. This includes reducing health inequalities, improving emergency care response, reducing elective procedure delays, increasing access to primary care, and supporting mental health. Our PEoLC strategy aligns with national guidance and enables the achievement of the local and national objectives accommodated in the national priorities and PEoLC ambitions framework. We will continue to review delivery plans associated with the strategy against emerging national and local guidance, including the NHS 10-year Health Plan.

ICB financial recovery principle

The Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) has generated a set of principles in response to the significant financial challenges which exist for 2024/25. Most importantly, the ICB will not take measures which adversely impact upon the safety of services provided and that the decisions we make do not adversely impact the access, experience or outcomes of any disadvantaged individuals, inclusion groups or communities.



Vision

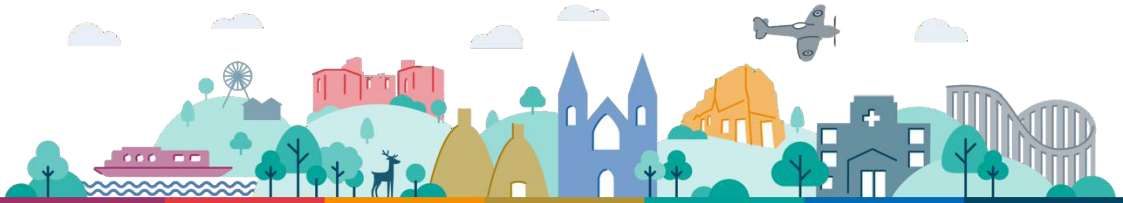
Work together to ensure the best possible outcomes for patients, residents and communities, within a culture of respect, trust and support.

Mission

Enable effective delivery across organisational boundaries to improve outcomes and reduce inequalities in population health and healthcare. Creating innovative, safe, and high-quality care for citizens and our communities, that we are all proud of.

Purpose

Lead collaboratively and strategically to achieve safe care, wellbeing and experiences, for all of our residents and communities.



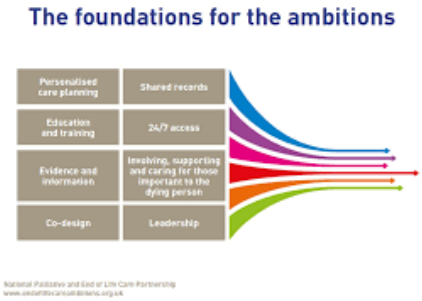
National Context

The current national context for palliative and end of life care delivery in England is shaped by several key policy frameworks and strategic objectives.

As previously referenced, the primary framework guiding this sector is the Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026. The ambitions emphasise personalised, holistic care with a focus on enabling individuals to live well until the end of life. This ambitions framework (figure 1) sets out the national vision underpinned by eight foundations (figure 2) to improve end of life care through collaboration and action between system partners at integrated care system (ICS) level throughout England, providing a structured approach to improving palliative and end of life care for people of all ages.

Figure 1: The six ambitions for palliative and end of life care

Figure 2: Foundations for the ambitions



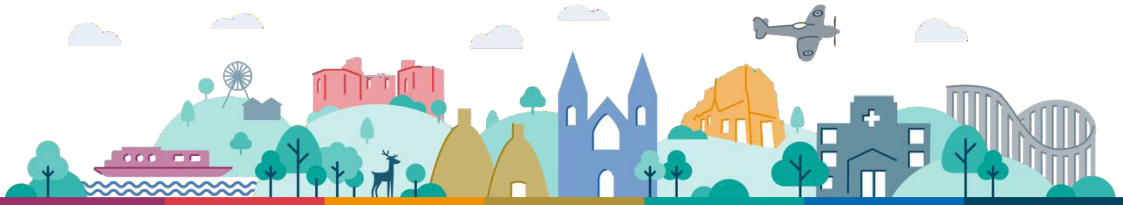
To support these ambitions, Palliative and End of Life Care statutory guidance for ICBs was published in 2022. The guidance emphasises early identification of patients nearing the end of life and the importance of personalised care planning.

Integrated care boards (ICBs) play a critical role in commissioning PEoLC services that meet these standards, working across health, social care, and voluntary sectors to ensure 24/7 access to necessary resources. This integrated approach aligns with broader NHS goals, including addressing health inequalities and ensuring that care is responsive to both medical and social needs, especially as the demand for services increases due to demographic trends and an ageing population.

In the recent publication of Lord Darzi's report Independent Investigation of the National Health Service in England it stated, "Dignity, compassion and respect are important at the end of life" and according to a poll commissioned by the charity Compassion in Dying (2024), 83% of adults would prioritise quality of life over living longer in the last years of life.

Additionally, a recent update from the Office for Health Improvement and Disparities outlines ongoing efforts to enhance PEoLC, including improving data on care home provisions and planning to address workforce shortages. This emphasis on training, support for caregivers, and community -based approaches are essential in ensuring that high quality care is accessible and sustainable across England.

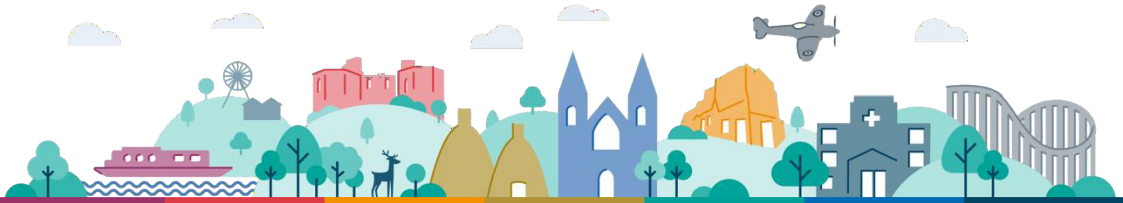
While England has improved the identification of patients approaching the end of life, a recent Marie Curie report highlights that gaps still exist, particularly for underserved communities and those requiring 24/7 services. Enhancements in digital infrastructure, shared care records, and community collaboration are helping mitigate some of these gaps, but further systemic support is necessary for optimal PEoLC delivery.



Palliative care is now a statutory requirement of the Health and Care Act 2022, stipulating that ICBs have a duty to commission palliative care services within ICSs. The statutory requirements for ICBs mean that they are responsible for the commissioning of high quality safe services that are tailored to the needs of the individual. The Health and Care Act 2022 states a legal duty on ICBs to commission palliative care services under s3(1) of the NHS Act 2006.

The National Institute for Health and Care Excellence (NICE) quality standards set out priority areas for quality improvement in health, public health and social care, for adult and children's end of life care, and for the last few days of life. The quality standards are as follows:

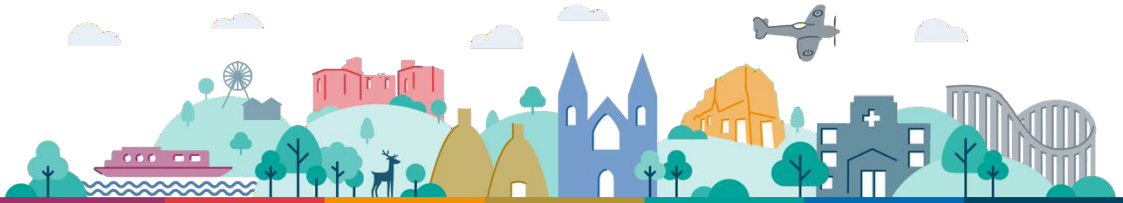
- NICE quality standard 13: related to end of life care in adults, this requires services to be commissioned from, and coordinated across, all relevant agencies, encompassing the whole end of life pathway. Also stating that an integrated approach to provision of services is fundamental in delivering high quality care to all people approaching the end of life, their families and carers.
- NICE quality standard 160: contains 6 quality statements to aid high quality care and improvements in priority areas supporting end of life care for Children and Young People (CYP) from birth to 18, largely related to CYP diagnosed with life-limiting conditions and expected to result an early death for the person. It also covers support for family members and carers.



Local Context

The principles of palliative care are set out in the ICP Strategy for Staffordshire and Stoke-on-Trent, which we need to consider in how we continue to support our population:

- care should be individualised: each person should have a personalised plan that is reviewed regularly
- access to services should be fair to all: everyone should have access to end of life care, regardless of age, background, needs, or where they live
- comfort and wellbeing: care should maximise comfort and wellbeing, including psychological and practical support
- care should be coordinated: individual needs should be documented on a shared plan that is visible to the whole system
- staff need to be prepared: relevant staff should have mandatory training in end of life care
- communities need to be prepared: by developing communication programmes around death and dying.

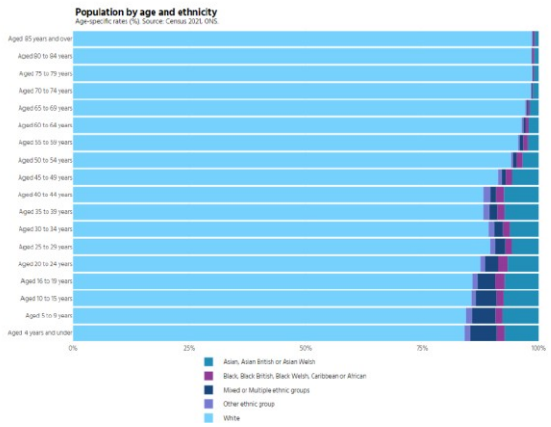


Local Context *continued*

Staffordshire and Stoke-on-Trent (SSOT) is a mix of rural and urban areas, with extremes of wealth and deprivation. We have a diverse and ageing population, with many people needing support for multiple and complex needs. We also have one of the largest gaps in life expectancy and healthy life expectancy in the West Midlands, with people in our most deprived areas living with poor health for 12 years longer than those living in less deprived communities.

In 2022, the approximate population of the ICB geography was circa 1,146,300 people, of whom over 77% lived in Staffordshire and 23% in Stoke-on-Trent. Stoke-on-Trent has a younger population, Staffordshire an older one.

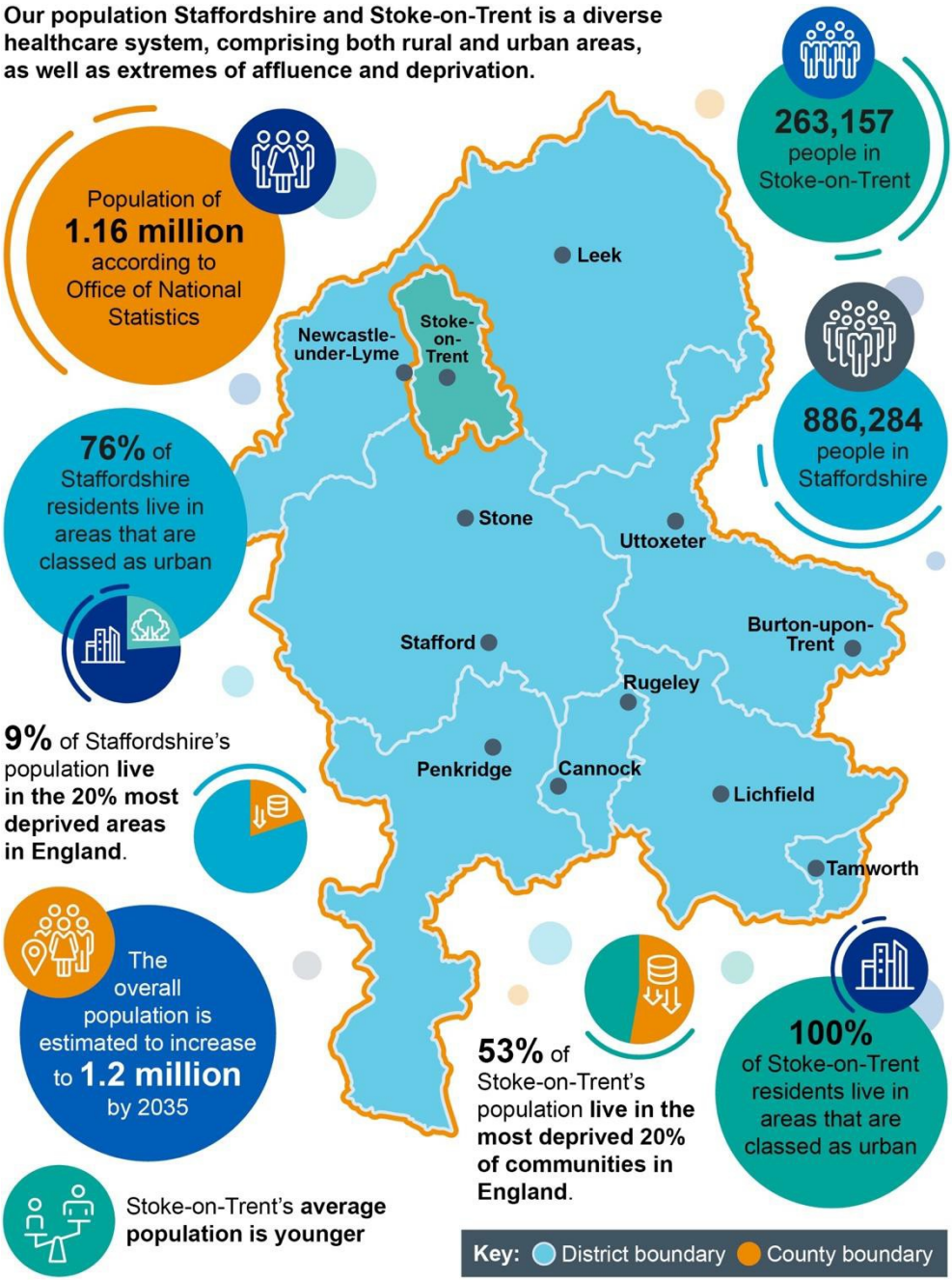
Ethnicity profile in Staffordshire and Stoke-on-Trent



- Older age groups within the ICB tend to be less ethnically diverse than younger age groups

Local Context - area map

Our population Staffordshire and Stoke-on-Trent is a diverse healthcare system, comprising both rural and urban areas, as well as extremes of affluence and deprivation.

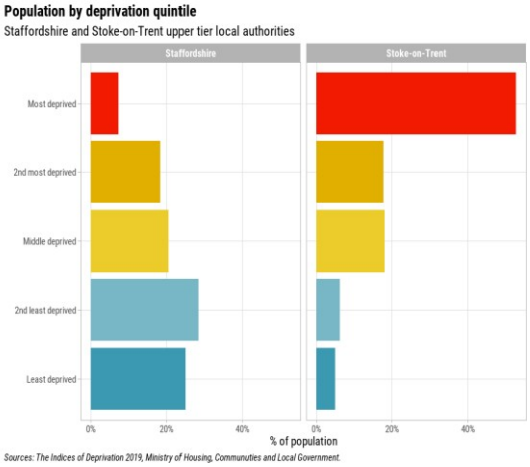


Stoke-on-Trent is the 13th most deprived local authority area in England, with just over half the city's residents living in areas considered to be among the country's most deprived 20%.

Some communities experience social exclusion, and report they struggle to access housing, secure employment, or health and care services. These problems are usually linked to other difficulties such as poverty, violence or complex trauma, and need special care.

Deprivation in Staffordshire and Stoke-on-Trent

- The Index of Multiple Deprivation (IMD) is the national measure of relative deprivation for England. The IMD is typically classed into five quintiles, with 1 being the most deprived and 5 being the most deprived
- People who are in quintile 1 are also described as being in the most deprived 20% in England
- More than half (53%) of the population in Stoke-on-Trent live in the most deprived 20% areas in England
- Less than one tenth (7.4%) of the population in Staffordshire live in the most deprived live in the most deprived 20% areas in England
- People who are more deprived tend to have poorer health outcomes and increased deprivation is associated with premature mortality



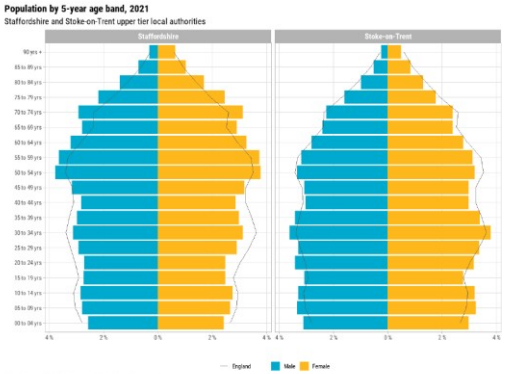
In SSOT, avoidable premature death from cardiovascular disease (CVD) in people under 75 years old is almost double the England average, as is premature death for those with a severe mental illness (SMI).

We have high death rates from respiratory diseases in people aged under 75, but low rates of review of asthma and chronic obstructive pulmonary disease (COPD). In line with the national picture, the 5 leading causes of death in our area are cancer, COVID, dementia and Alzheimer's disease, ischaemic heart disease and chronic lower respiratory disease.

Our ageing population continues to impact on finite health and social care resources and is strongly linked to the increased demand for long-term care, chronic disease management, and end of life care. It is a significant challenge to ensure services remain sustainable while we adapt them to meet the complex needs of older adults.

Current age profile in Staffordshire and Stoke-on-Trent

- The overall all population within SSoT, according to the latest 2021 Census, is 1.13 million
- About 258,000 people live in Stoke-on-Trent and 876,00 people live in Staffordshire
- Staffordshire has a slightly older population compared to England, whilst Stoke-on-Trent has younger population compared to England
- Both local authorities have a similar proportion of its population who are of working-age (57% in Staffordshire and 58% in Stoke-on-Trent)
- Staffordshire has a higher proportion of its population who are of retirement age (22% in Staffordshire are aged 65 and over compared to 17% in Stoke-on-Trent)
- Stoke-on-Trent has a higher proportion of its population who are children and children and young people (25% are aged under 15 in Stoke-on-Trent compared to 21% in Staffordshire)
- Differences in age-structures between the two local authorities will impact the levels of health and social care need, with older people typically experiencing poorer health due to increasing age



It is well documented that health and wellbeing outcomes are impacted by a whole range of factors related to the circumstances in which we are born, grow, live, work and age. These are commonly known as the 'wider determinants' of health. We recognise that there are many factors that impact on the wider determinants of health including socioeconomic factors, physical environment, health behaviours and health care.

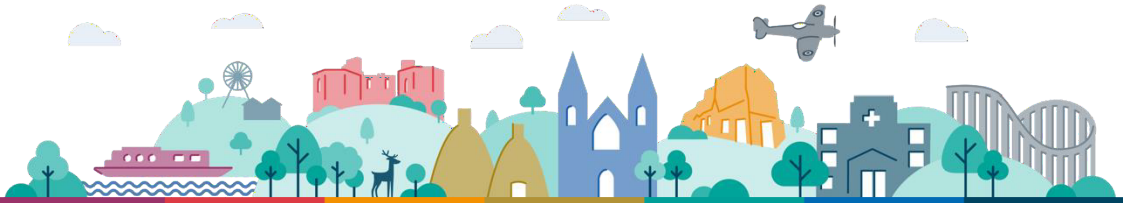
Local strategies aim to support the enhancement of effective integrated care approaches across our care system. This should enable the delivery of personalised care that provides the right support for patients, leading to a reduction in avoidable emergency admissions and which supports people to die in their place of choice.

Staffordshire and Stoke-on-Trent Palliative and End of Life Care Programme Board commissioned a Needs Assessment for Palliative and End of Life Care (PEoLC) which was published in 2024.The needs assessment provides key data regarding palliative and end of life health and care needs in SSOT and is intended to be utilised to inform and guide strategy, decision making and service development.

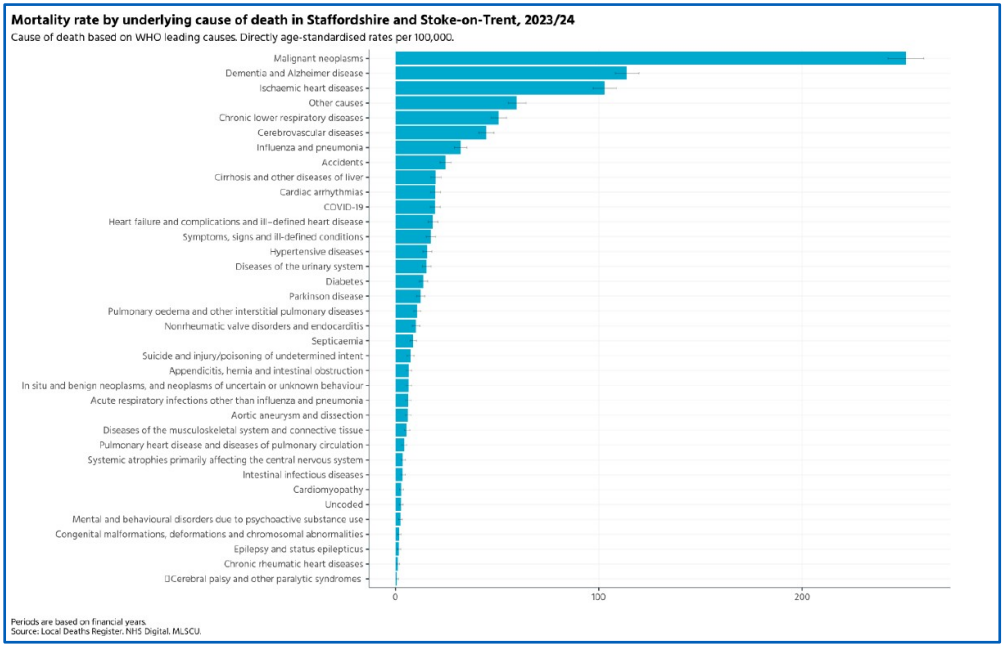
The full report is available in the appendices.

Sample of key findings:

- People generally state that they would prefer to die at home but in England in 2022, 43.4% of all deaths occurred in hospital, compared to 28.7% at home
- In Staffordshire and Stoke-on-Trent during the same period, 47.1% of deaths occurred in hospital, significantly higher than the England average and conversely 26.9% of deaths occurred at home
- Over the past decade we have unfortunately seen increases in the number of people experiencing three or more emergency hospital admissions at the end of life which can be disruptive and has a negative impact on a person's quality of life.
- Younger patients (<65) are more likely to have 3+ emergency admissions in their last 3 months compared to older patients (75-84, 85+)



- There are higher rates of female patients on the palliative care register. It has repeatedly been shown that women are more likely to receive palliative care than men
- There are higher rates of white patients on the palliative care register. It has repeatedly been shown that ethnic minorities are less likely to receive palliative care
- In line with the national picture, the 5 leading causes of death in SSOT are cancer, COVID, dementia and Alzheimer's disease, ischaemic heart disease and chronic lower respiratory disease
- In Stoke-on-Trent there are high rates of death from all causes considered preventable, and high and sharply rising rates of male suicide and death from drug misuse, although the numbers are small compared to the major causes of death.

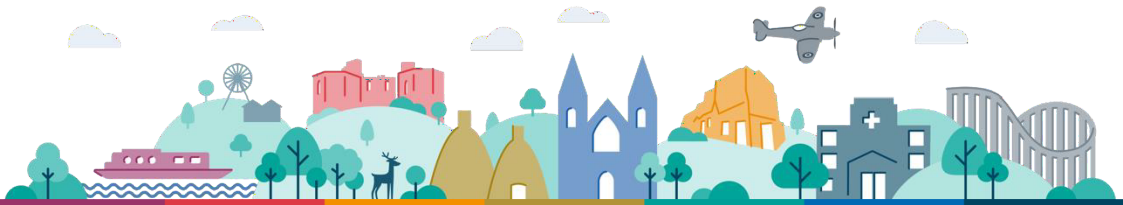


The infant mortality rate in the West Midlands has been consistently higher than the national rate for England and Wales. The disparity between regions is widening, with babies born in the most deprived areas being almost three times as likely to die in their first year of life than those born in the least deprived areas. Many of these babies are likely to be born with a low or very low birthweight. The infant mortality rate for our population is the highest in the country and almost twice as high as the average for England.

- The child mortality rate in England and Wales for the year ending 31 March 2023, was 31.8 deaths per 100,000 children. This was an 8% increase from the previous year.
- The infant mortality rate in England for 2020-22 was 3.8 deaths per 1,000 live births.
- In 2020-22, the infant mortality rate in Staffordshire was 5.1 deaths per 1,000 live births. This is the 25th highest rate in the country.
- In 2021-23, the infant mortality rate in Stoke-on-Trent was 7.6 deaths per 1,000 live births. This is the highest rate in the Midlands.

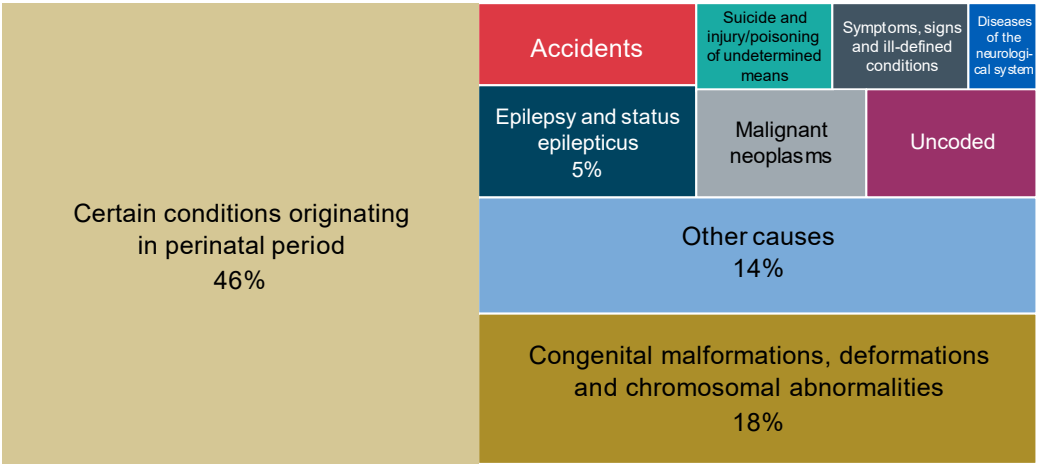
Prevalence of CYP with life limiting conditions

- Nationally (2001-2017) we have witnessed a 162.69% increase in CYP with a Life Limiting Condition (LLC).
- The largest area of growth with CYP diagnosed with a life limiting condition in the West Midlands is congenital with incidences increasing in the Pakistani and Asian communities.
- In the West Midlands, the 16-19 age group diagnosed with a LLC has increased from 16.4 per 10,000 to 49.5 per 10,000 (2001-2017), strongly indicating that CYP are living longer with much greater clinical complexity requiring transition into adult services.
- More locally the Stoke-on-Trent City Council Local Authority area had the highest prevalence of CYP with a LLC (79.9 per 10,000 2017) in the West Midlands.



Leading causes of death for children in Staffordshire and Stoke-on-Trent, 2023-24

Percentage of deaths by leading cause amongst persons ages 0 to 19.



- The latest data for the 2023/24 period shows that amongst the 0 -19 age group:
- Conditions in the perinatal period is the most common cause of death accounting for nearly half of all deaths in this age group followed by congenital malformations, deformations and chromosomal abnormalities – Meaning the majority of deaths in this age group are birth related

Periods are based on financial years. Source: Local Deaths Register. NHS Digital. MLCSU.

Underpinning our local ICS plans are the national statutory levers supporting our ambitions, and drive to improve care for CYP with life limiting conditions and at end of life for all ages.

Integrated care boards (ICBs) now have a responsibility to ensure that people with palliative and end of life care needs can access high quality, personalised care and support.

Personalised Care -Implementing the comprehensive model published in 2019 promotes the improvement of end of life care by introducing proactive and personalised care and support planning.

The NHS England Palliative and End of Life Care (PEoLC) team developed a national delivery plan for 2022–2025 to improve access, quality, and sustainability of palliative and end of life care, and in parallel the previously referenced Ambitions for Palliative and End of Life Care national framework was developed by a partnership of national organisations, setting out a vision to improve end of life care through collaborative action system partner at a local level. National palliative and end of life care aims and objectives align to the Ambitions for Palliative and End of Life Care national framework.

Evidence for Change

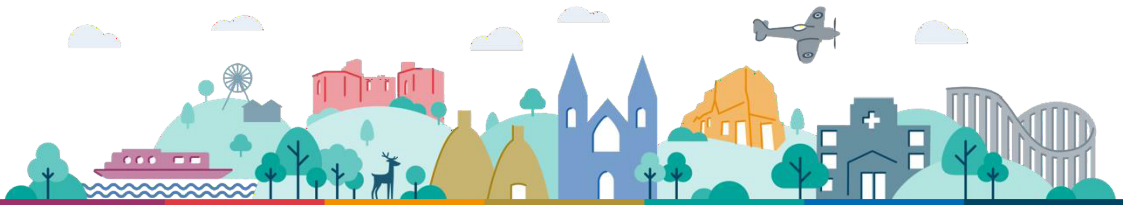
Professional and provider engagement

Two online engagement sessions were held in August and September 2024. Seventy professionals attended in total, encompassing representation from a wide range of providers of children's, adults and young adults' services, including from the community, acute trusts, hospices, local authorities and third sector providers.

There were two themes identified to aid discussion:

- *Against the National Ambitions Framework, where are we in Staffordshire and Stoke-on-Trent? What are we doing well? Where are the gaps and opportunities?*
- *How do we all work together to improve achievement against the national ambitions?*

Several themes emerged from the workshops, which alongside the public feedback have been used to inform the strategic objectives.



1) Positive practice

Feedback was given on passionate staff working well together, with a real desire to provide good care. The education offer is comprehensive, and development of the team for CYP has been positive. There has been a move towards standardising practice, and there was appreciation for this strategy encompassing all ages.

2) Changes to be made

There was a call to challenge if the current system was fit for purpose, and for there to be a radical change towards a single point of access for information and support.

3) Directory of services

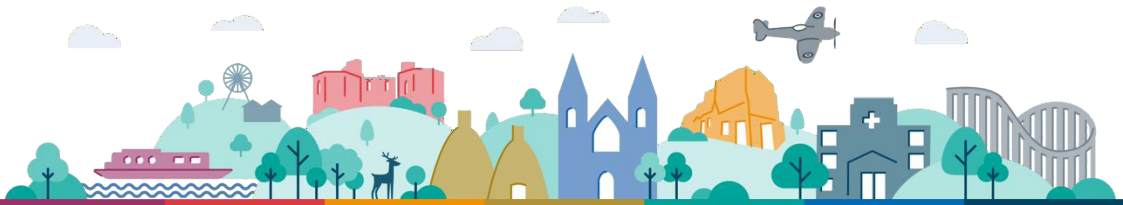
There was an ask for an up-to-date directory of services, and a website to access the latest information.

4) Communication

There was a call for better communication for all (including reduced jargon, and consideration to the literacy age of the population and language needs). Furthermore, an appeal to empower the public to talk about death and dying and normalising these discussions.

5) Digital

Providers want to see systems 'talking to one another' better.



6) Coordination of care

It was highlighted that there can sometimes be duplication of care, or conversely things being missed due to unclear roles and responsibilities. There was also an appeal for better coordination between health and social care and for a problem-solving approach to solving issues.

"The palliative care plan needs to meet the changing needs of the patient - what is agreed at the early stages of the journey may not be appropriate (and) not reflect the patient's wishes as time progresses." – engagement feedback.

7) Listen to patients

There was an ask for personalised care, using real patient experiences to guide us.

8) Learning from colleagues

Providers wanted to see more collaboration, perhaps in the way of a forum, and more shared learning.

9) Role of the patient

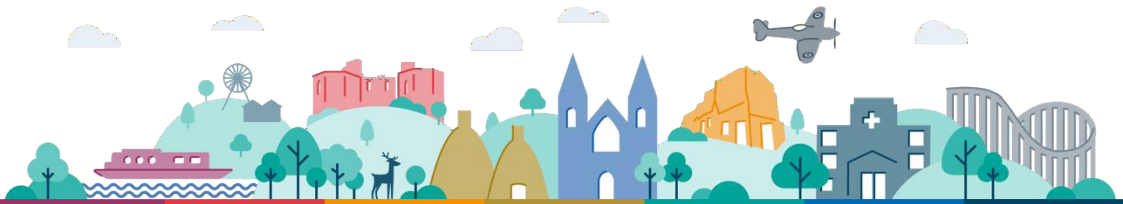
It was felt that patients should be empowered to be involved in their care, and a call to reduce health inequalities.

10) Equipment

The need for timely access to equipment was highlighted.

11) Support groups

Empowering communities to support one another, along with voluntary care organisations was discussed.



12) Medication

Providers found that access to medication out of hours could be challenging.

13) Finance/Staffing

It was highlighted that finding social care staff could be difficult, as could working in a financially pressured system.

Public Engagement

A survey was available to the public for 3 weeks and was socialised with key stakeholder organisations and patient groups, and promoted via ICB and ICS corporate communication channels. There were 248 responses, with a good response rate from all age groups.

77% of respondents had experience of PEoLC either from themselves or someone close to them, and of those, 70% had had this experience in SSOT.

Chart 1 demonstrates the perceived quality of the care received.

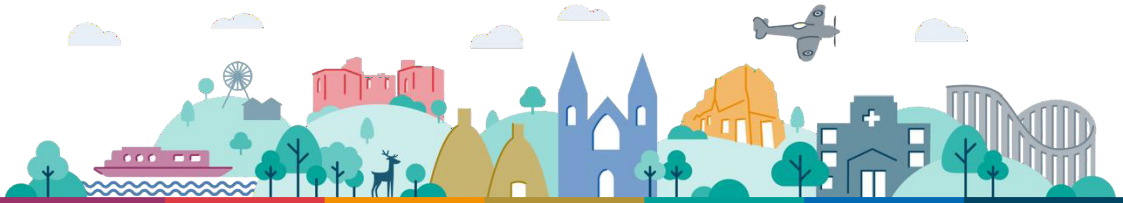
Chart 1. How would you rate the care that was received?

Example engagement feedback

"Despite an 89-year-old diagnosed with heart failure…and COPD, no discussion of palliative care took place. No support was offered either in hospital or the community despite lots of resources being available. It seems it is reserved for cancer patients only in the community."

"I would hope the referral pathway and access for care available is straightforward and clear for families to navigate. I can imagine it would be stressful to navigate a complicated system at a time of distress."

"The goals of [the] palliative care should align with mine, and I should be given options of where I want to receive care, particularly my end of life care."



We asked the public what they valued the most about the care that they have received, which is summarised below:

We also asked what could have been done better. Some themes that emerged were:

1) Provision of care

People found the pathways to getting funding for care at the end of life lengthy, stressful and hard to navigate.

2) Supporting patient wishes

Some people felt that the support wasn't in place to allow death in the preferred place, or to fulfil the wishes set out in the ReSPECT form. Some felt a large burden of hospital appointments and wanted to avoid attendances in the emergency department.

3) Coordination of care

The public found that care wasn't always coordinated well, and there often wasn't any continuity. They wanted more timely responses to their needs, personalised care, and more staff and provision of care to achieve this.

4) Earlier intervention

The public felt that they would like the end of life phase to be recognised earlier (especially for non-cancer patients), and for information on prognosis to be communicated better. They wanted more information to be available about death and what to expect.

5) Care provision out-of-hours

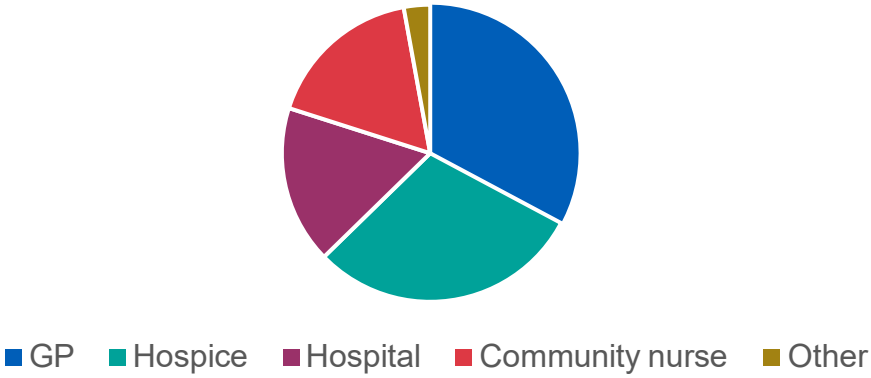
People wanted to be able to have access to the right equipment at the right time, an improved supply of medication, and less onus on carers to collect paperwork and authorisation forms.

6) Accessing support

People found it difficult to access all of the information that they needed, including services available for families and carers and also on other things that they need like financial support.

We asked the public where they would go to access palliative care should the need arise. Chart 2 demonstrates the majority indicating that they would access this via their general practitioner (GP) or a hospice.

Chart 2. Who do you think you would contact to access palliative care should the need?



We also asked how the public would like palliative care services to help them, their family, or their friends in the future, the results of which are depicted below:

Respect wishes Comfortable

Straightforward Easy to access help Minimal suffering

Available Support for Family Support and advice

Outline process Preferred place of death Pain free Hospice

Services Knowledge on what support available Emotional support

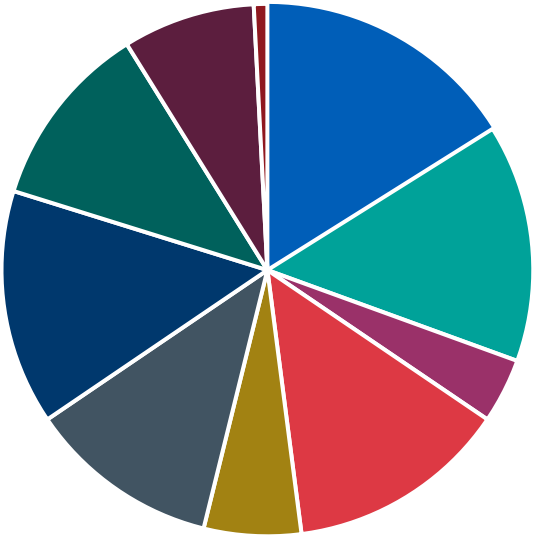
Link person Good death Access to information Quickly

Right support at the right time Quality of life

Patient choice Easy to navigate Sufficient care

We asked what things would be most important to people at the end of life, which is represented below in chart 3.

Chart 3. When thinking about the end of life, the following is important to me:

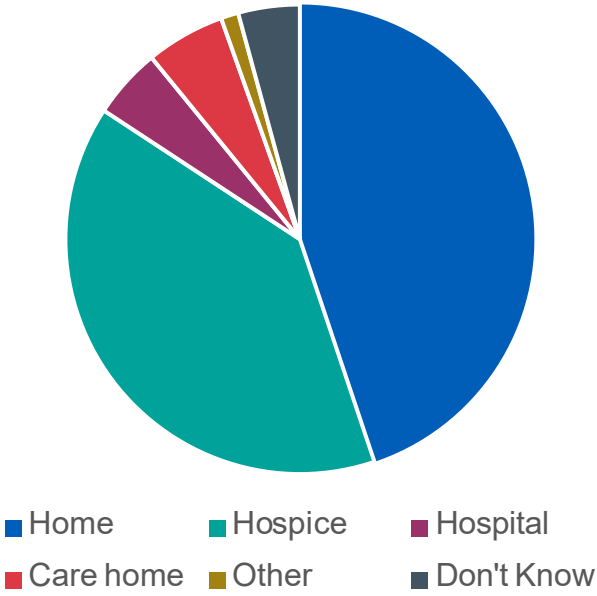


- Feeling comfortable, including being pain free
- Having affairs in order (e.g. family and pets are cared for, money matters are taken care of)
- Living for as long as possible
- Dying in the place that I have chosen
- Having spiritual needs met
- Not being alone
- Having wishes being respected
- Having support for my emotional needs
- Bereavement support
- Other

In terms of the timing of information being given regarding end of life care, the vast majority (71%) of respondents wanted information to be freely available whenever they should want it, with only 2% indicating that they would want it in the last few weeks of life. 88% of respondents felt that we talk about dying too little as a community, and nobody thought that we talk about it too much.

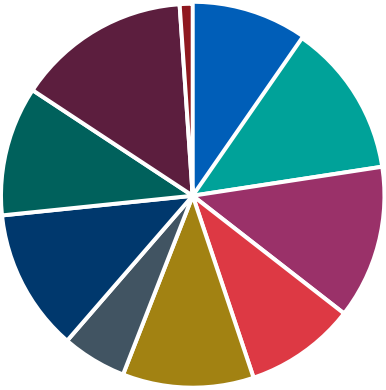
A clear majority of people wanted to be cared for either at home or in a hospice at the end of life:

Chart 4. Where would you want to be cared for at the end of your life?



We also explored public perception around what hospices do. There was generally a good spread of respondents in each category:

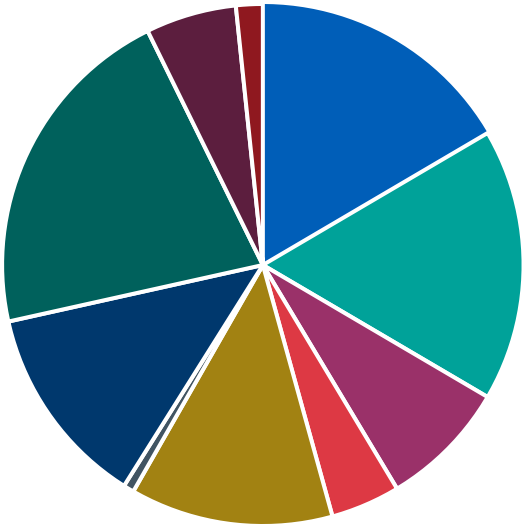
Chart 5. What do you think that hospices do?



- They are a place to go to die
- They provide medical care
- They provide personal care (e.g. help with washing and dressing)
- They provide spiritual care
- They provide other therapies e.g. massage
- They provide rehabilitation (to reach physical goals) and exercise programmes
- They provide counselling
- They have support groups
- They provide support for families/carers before and after death
- Other

Lastly, we explored perceived barriers to the public accessing PEoLC:

Chart 6. What could stop you from wanting to discuss your wishes when faced with a condition that might shorten your life?



- I wouldn't know who to speak to
- I wouldn't know what the choices for care are
- I'd be too scared or anxious
- I would rather not think about it
- I wouldn't want to cause upset to family or friends
- Spiritual beliefs
- I wouldn't know when to have this discussion
- I'd be worried there wouldn't be access to the care or support that I need
- I wouldn't trust healthcare staff to help me
- Other

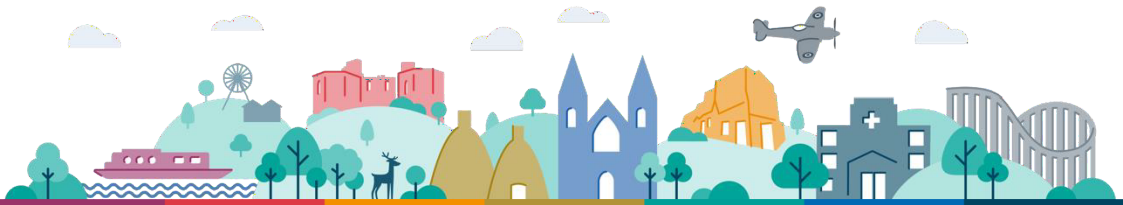
Example engagement feedback two

"I believe we need to talk about death much more than we do."

"Based on your experience, is there anything we could have done better? Better coordination of services and professionals all working together."

"An earlier commencement of palliative care would have been beneficial."

"My view is that services do not communicate adequately with each other."



Literature Review

Leading on from this important public engagement question, we went on to explore the literature regarding the barriers to accessing palliative and end of life care at the right time.

The key themes that emerged from the literature are as follows.

1) Breakdown in communication

This might be between patient and provider, or between providers. PEoLC discussions can be uncomfortable, at odds with the training of healthcare professionals to prolong life, and there can be a fear of 'getting it wrong'.

2)Misconception of 'palliative care'

There is a perceived stigma around the term 'palliative care', and it is often thought of as an approach that is only adopted at the very end of life.

3) Unpredictable disease trajectory

Clinicians can find it difficult to accurately predict which patients are approaching end of life, and there is an argument for providing palliative care from the time of diagnosis of a life-limiting condition.

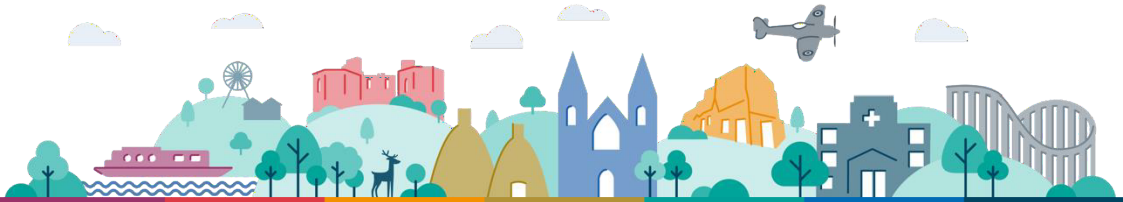
4) Timing

If offered too early, some patients might find PEoLC discussions distressing. Clinicians feel that PEoLC discussion should start early but be introduced gradually over time.

5) Lack of time and resource

Increasing workload, time pressure, staff and resource can also provide barriers.

This literature review is insightful, particularly when interpreted alongside the public engagement where the main barriers to PEoLC were not knowing who to speak to, what the options for care are, and being worried that there wouldn't be access to the care or support needed. The full report can be found in the appendices.



Objectives

To generate our strategic priorities, we aligned feedback received through public and provider engagement events, our public survey, along with the latest data that we have about our local population. We are committed to working together as a system to implement and deliver on the 6 objectives identified below:

Objective One
The development of a web-based repository, accessible to both the public and professionals, encompassing:

- a directory of services
- details of available educational resources to improve knowledge and skills
- other resources for the public and professionals for PEoLC

Why?

There was a clear ask from professionals and providers for a directory of services, and also from the public who fed back that they are finding it difficult to navigate the system and access the information they needed. A barrier identified to accessing PEoLC was not knowing what was available, or who to speak to. The repository could also inform patients and carers about other support available (e.g. financial) and also support everyone involved in gaining the skills and knowledge required to meet the needs of the population.

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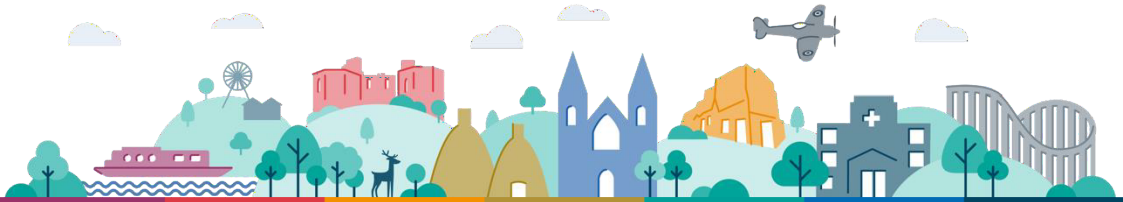


Objective Two

Supporting patients to die in their preferred place of death, including:

- early identification of people who need PEoLC
- proactive care planning
- reducing unnecessary emergency department attendances
- normalising discussions around end of life care

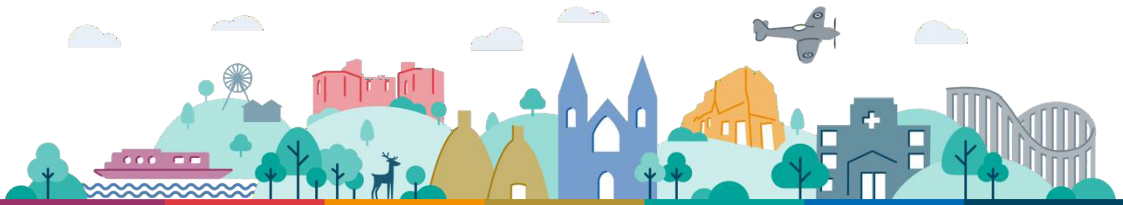
Why?

The majority of our population want to die at home or in a hospice. At present, a higher than expected number die in hospital. Our engagement tells us that we don't talk about dying enough, we need to do it earlier, and we need to normalise these discussions.

Engagement feedback

"Sometimes expecting carers to pick up drug authorisation charts/ medication charts and paperwork when they are the sole carers and have no one to sit with their loved one whilst they do such tasks can place immense psychological burden and distress on them."

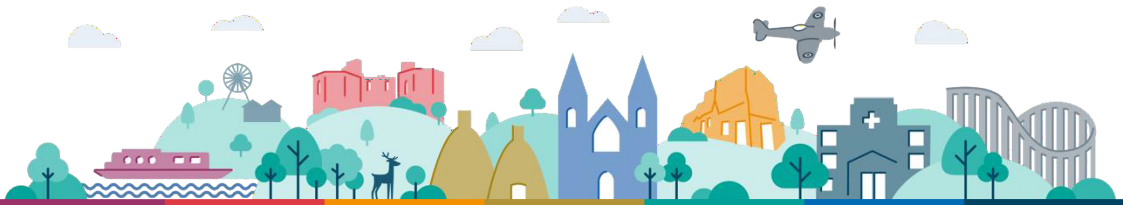
"The pain and symptoms of life-limiting conditions cannot always wait until regular "opening hours" of services, so care should be accessible 24/7."



Objective Three
Developing a forum for professionals and providers to collaborate, share learning and good practice, improve communication and reduce silo working.

Why?

There was a clear call for increased collaborative working from professional and provider feedback, alongside sharing of good practice regionally and nationally. The public also felt that care wasn't always coordinated well, and unclear roles and responsibilities of the people caring for them.



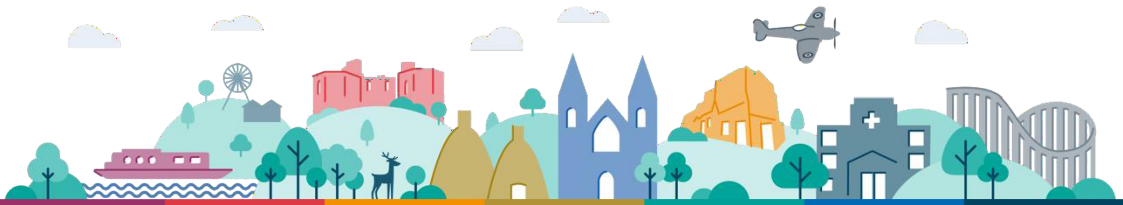
Objective Four

Prioritising out-of-hours access to:

- medication
- authorisation forms without the onus of family members and carers collecting paperwork
- specialist palliative care support both to the public and healthcare professionals, working together with care providers in primary, community and social care alongside VCSE to deliver high quality care

Why?

Professionals felt that they couldn't easily access required medications out-of-hours, and the public also felt that the onus was often on them to collect it alongside paperwork. The public wanted a single point of access to advice and support out-of-hours.

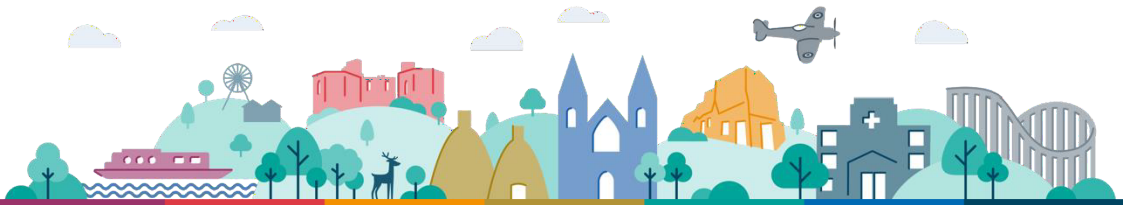


Objective Five
Development of Electronic Palliative Care Coordination Systems (EPaCCS) to:

- improve communication between different healthcare professionals
- record patient wishes in a format available to all care providers
- Overcome ‘systems not talking to each other’

Why?

The public want their wishes to be respected. Professionals find that different digital systems are a barrier to communication across health and social care. EPaCCS is a means of capturing important information about a patients care and wishes at the end of life, which can be accessible to multiple health and social care workers.

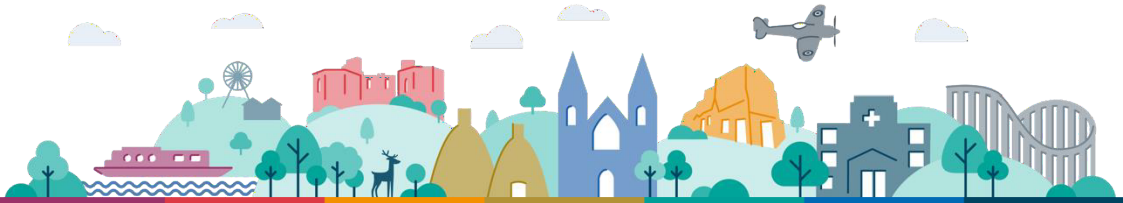


Objective Six

Continue to develop resilient and compassionate communities in Staffordshire and Stoke-on-Trent by working with local authorities and voluntary, community, and social enterprise groups to develop local initiative.

Why?

The public have told us that they would like spiritual and emotional support, as well as physical support, as do their families and carers. There is already some fantastic work at a locality level in some areas, which we could better understand and learn from in other areas. Professionals want to see us empower communities to support one another.



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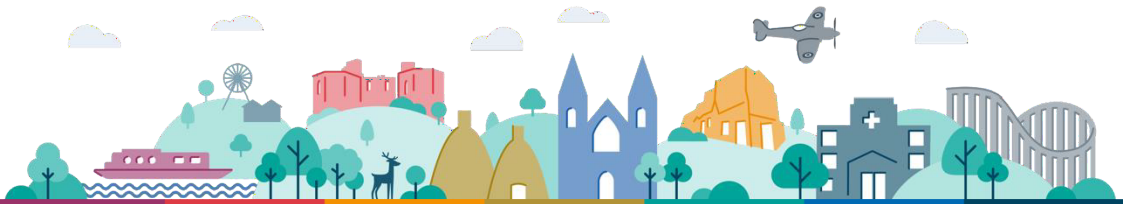
In addition, the views, opinions and experiences of the residents of Staffordshire and Stoke-on-Trent have been invaluable and have been at the forefront of the strategy development to ensure it represents the people we serve.



Appendices

Appendix 1 Assessment

PEoLC Needs January 2024

Appendix 2

PEoLC data

Appendix 3

PEoLC literature review