NHS
South Yorkshire
Integrated Care Board

South Yorkshire Integrated Care Board

All Age

Palliative and End of Life Care

Strategy

2023/24 to 2025/26

'I hope this survey brings about change as the population is getting older and plans need to be made for the future'.

Version control	
Version 4	The feedback version. Completed 20 November 2023. Updated following initial feedback back from the PEOLC Strategic and transformation Board. Appendix in development.
Version 3	Interim version shared with Sheffield and Rotherham place-based PEOLC group (due to the timing of the meeting) whilst awaiting version 4. This version is the same as v2 *apart* from the addition on page 2 in relation to children and young people.
Version 2	The version shared with the strategic board members on 26th October and discussed at the 2nd Nov. Feedback received.
Version 1	First draft and working document – Started September 2023 and shared with a few individuals for early comment.

AUTHOR - LOUISE POTTER – CONSULTATION VERSION 4

Date started - 11 September 2023, version 4 updated on 20 November 2023

Foreword

Good palliative and end of life care is important for everyone across South Yorkshire - The Ambitions Framework quotes *"How we care for the dying is an indicator of how we care for all sick and vulnerable people[1]"* Research also tells us that palliative care is *'associated with improved patient outcomes, such as pain and symptom management, improved communication, higher satisfaction with care, improved quality of life, reduced healthcare costs and an increased likelihood of dying in one's preferred place[2]'.*

We have listened to our public and we have heard that currently, not everyone has a good experience.

Our vision is to ensure that everyone has a positive experience. This will not be easy, and our challenges may change over time – however, we need to transform our way of working to embrace the growing number of deaths over the next 10 years, to address medical and social complexity, variation across our systems and a challenging financial position – not just within the ICB but across all our partner organisations.

Getting it right is important - upwards of 15,000 people each year die across South Yorkshire[3], and one in three people[4] admitted to hospital will die in the next 12 months. Costs associated with this are significant. In one year over £120,000,000[5] was spent on hospital costs alone (this excludes costs for hospice and community provision including district nursing, primary care, and bereavement). Costs are important, but go hand in hand with delivering quality services, having the right expertise in the right place at the right time and having sufficient capacity to meet all needs.

Here in South Yorkshire, we have a wealth of services throughout our Places, and we have a real opportunity to further integrate and collaborate, learning from the success and challenges of each of our partners, and seek effective innovation and transformation to ensure everyone within our communities receive equitable and timely access to high-quality, personalised, and sustainable PEOLC services.

This strategy, whilst ambitious, outlines our vision and sets out how we will achieve this. The ICB and its partners are dedicated to working together to implement and transform our ways of working to ensure that everyone in South Yorkshire has access to the support and services they need to have a good quality experience at one of the most challenging and often traumatic times in their lives.

Emma Latimer, South Yorkshire Integrated Care Board's Senior Responsible Owner, Palliative and End of Life Care and Sheffield Place Executive Director

---

[1] *National End of Life Care Strategy 2008 as quoted in the National Ambitions Framework*

[2] Evidence on the economic value of end-of-life and palliative care interventions: a narrative review of reviews | BMC Palliative Care | Full Text (biomedcentral.com)

[3] ONS data

[4] Imminence of death among hospital inpatients: Prevalent cohort study - David Clark, Matthew Armstrong, Ananda Allan, Fiona Graham, Andrew Carnon, Christopher Isles, 2014 (sagepub.com)

[5] ICB data

Our Vision

This strategy outlines how we will work as partners across South Yorkshire to develop a, sustainable, personalised, inclusive and integrated palliative and end of life care system which achieves our vision and meets the legal duty placed on Integrated Care Boards.

Our palliative and end of life care vision is…

'To ensure that the people of South Yorkshire living with life limiting illness experience the best possible care in the last years, months, and days of life and that the bereaved continue to receive the support they need after death.'

Our vision is ambitious. Our aim is to lead the transformation of palliative and end of life care across the system, seeking opportunities to improve where needed, delivering care which works for all the people across South Yorkshire now and in the future.

To do this we need to adhere to the following principles -

- build on the good work already happening across South Yorkshire
- build a palliative and end of life care system which reduces unwarranted variation in access and outcomes,
- addresses health inequalities and equity of access to services.
- listen and respond to the needs of our public.
- maximize value for money, use public resources wisely and seek opportunities to increase budgets.
- deliver best models of health and care and adhere to evidence based best practice,
- commissioning, excellent partnership working and collaboration.

It is important we get this right because….

The system <u>must</u> work for everyone.

Our public consultations held in 2023, our professionals and benchmarking exercise[6] have told us the current system doesn't work for everyone. When services work together, people have told us that people die with their physical, psychological, emotional, social and spiritual needs met, have good access to primary, general and specialist care, understand who to contact when, have access to 24/7 care and where medically and practically possible die in the place where they prefer.

However, for many the system, which includes health, social care and voluntary sector provision is difficult to navigate, people are not being identified early enough meaning many don't have an opportunity to have access to palliative care which can improve their health and wellbeing at the end of their lives. It's a system which in some areas

[6] Each place has completed the benchmarking against the ambition's strategy in 2023. This is an audit against the national strategy.

has limited choice, where carers feel uninformed and are unsure where to turn to for guidance.

We need a future proof system which can support the needs of people who will need palliative and end of life care in the next decade; they are a significant section of our growing, aging population.

In 2022/23 14,991[789] people died in South Yorkshire (19.6% Barnsley, 19.7% Rotherham, 23.5% in Doncaster and 37.1% in Sheffield). Whilst it is estimated that around 80% of people who die are an 'expected death', in South Yorkshire less than half, 45% or 7,176 had been identified and were on the palliative care register (NHSE – Appendix 1). In addition to those who die each year, we have an estimated 10,000[10] who would benefit from being on the palliative care register (those who are newly diagnosed with a life limiting illness such as cancer, a respiratory condition, dementia, and / or heart failure) and an estimated 126,000 who are bereaved[11].

Projections indicate that over the next 10 years our 65+ population will grow by 19.7%, meaning our system's capacity needs to be prepared to support more patients, families, and carers.

We need a system which addresses health inequalities, particularly around early identification, and equity of access.

Unfortunately, people's experience of palliative and end of life care is often determined by their protected characteristics, demographics and societal position. People from deprived communities, those experiencing homelessness, have a learning disability, black and ethnic minority communities, have a disability and / or live with a mental health illness are more likely to die younger, are less likely to be identified as being at the end of their life, are less likely to have an advanced care plan, are more likely to attend A&E and access emergency services and are less likely to die at home.

We need the system to work for our children and young people.

The infant death rate for South Yorkshire is 4.2 per 100,000 population compared with a 3.8 per 100,000 population in England[12]. Nationally the number of children living with a life limiting condition is increasing and Sheffield one of our Places has one of the second highest rates across the Yorkshire and Humber region. Data is sensitive in this area and more work is required to understand data and patient and families experience.

Recent developments in children and young people's palliative and end of life care have heightened the need for a new model of care to transform the offer across South Yorkshire. The new system needs to be sustainable both now and in the future. There is no quick solution and local challenges include raising the profile of PEOLC across

---

[7] NHSE ICB Palliative End of Life Care Dashboard, September 2023
[8] Nationally, an estimated 1% of people will die each year.
[9] Additional data based on 15,067 deaths show that 2,959 (20%) of people were residents in Barnsley, 3,545 (24%) Doncaster, 2,973 (20%) Rotherham and 5,590 (37%) Sheffield.
[10] Research shows around 70% of deaths would be eligible for palliative care before death as around 30% will be sudden and unexpected deaths.
[11] Verdery AM, Smith-Greenaway E, Margolis R, Daw J. Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. Available from: www.pnas.org/cgi/doi/10.1073/pnas.2007476117
[12] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/childmortalitystatisticschildhoodinfantandperinatalchildhoodinfantandperinatalmortalityinenglandandwales

within organisations already stretched and building a system which includes 24/7 professional expertise and a choice on where to die – home, hospice and hospital. To do this we need to work more effectively across South Yorkshire and Bassetlaw and build on the partnership working between the children's hospital, our children's hospice and acute trusts whilst navigating the national issue of a reducing number of PEOLC paediatric consultants.

- **We have a statutory duty to make this happen.**

  On the 1st July 2022 the Health and Social Care Act (2006) was amended. It introduced Integrated Care Boards and arranging provision for palliative and end of life care became the ICB's statutory duty.

  '(1) An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—

  (h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service'

  Health and Care Act 2022 s3(1) NHS Act 2006

How have we developed this strategy

- Using current public consultation feedback about their experiences and satisfaction of palliative and end of life care across South Yorkshire.
- Using feedback from clinical and managerial professionals working in health, social care and the voluntary sector including hospices[13].
- Identifying key areas for development by all four Places auditing against the Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026[14] .
- Observing the South Yorkshire Integrated Partnership Care Strategy[15] and the South Yorkshire ICB needs assessment and our four Health and Wellbeing board Strategies; Barnsley, Doncaster, [16] Rotherham and Sheffield.
- Using NHSE guidance including the Palliative and end of life care: Statutory guidance for integrated care boards (ICBs)
- Using national and local intelligence and data (see appendix).
- By building on the work of previous Place palliative and end of life care strategies[17].

Our PEOLC scope – definitions, all ages, all conditions

[13] at our locality place-based groups, our strategic board and the palliative and end of life care vision day
[14] A process called 'benchmarking against the Ambitions'.
[15] ICS' four core purposes: I. Improving outcomes in population health and health care II. Enhancing productivity and value for money III. Tackling inequalities in outcomes, experience and access IV. Helping the NHS to support broader social and economic development.
[16] Updated strategies are under development in Doncaster and Sheffield
[17] Before the ICB became a legal entity, the four places were each independent clinical commissioning groups. There were EOLC strategies in Barnsley and Doncaster. Sheffield's end in 2019. Rotherham had an action plan, but no specific EOLC strategy.

This is an all-age and all medical conditions strategy and should be read as such. Priorities specific to children and young people and/ or a specific medical condition are made explicit.

Definition of Palliative Care [18] (see Appendix 1)

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 at ensuring the best possible quality of life for individuals at end of life or with advanced illness and their families.

Definition of End of Life Care (see Appendix 1)

Refers 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 and, for carers, can include care into bereavement.

Progress so far

The new statutory duty made PEOLC an ICB priority, sitting alongside another 17 ICB statutory duties. A range of new guidance from NHSE, an updated national Ambitions framework, the completion of the ICB's 'benchmarking against the ambitions', a professional vision day and public consultation has helped South Yorkshire understand its mandate. We have reviewed our current position and our strategic priorities outline what need to happen to have a quality and future proof system across South Yorkshire.

Thankfully we are not starting from the beginning, and we have many assets to strengthen and build upon; South Yorkshire has four acute trusts, a specialist Children's hospital, five hospices including a children's hospice and a specialist palliative care unit in one of our acute trusts, 28 primary care networks and many voluntary sector organisations who work with palliative patients and their families / carers every day. The offers are varied across South Yorkshire, with strengths and opportunities for transformation both at Place and across the region – the detail is found in the HealthWatch survey results and the benchmarking audits (Appendix) and will be addressed in the action plan.

We have moved positively towards building a system where more people can die at home, 10 years ago 22.8% died at home compared with the 28.8% in 2022. We know there is more work to do to address the variation (26.6% to 31.8%) across the four Places to support people to die in a place of their choice, which for many means their home.

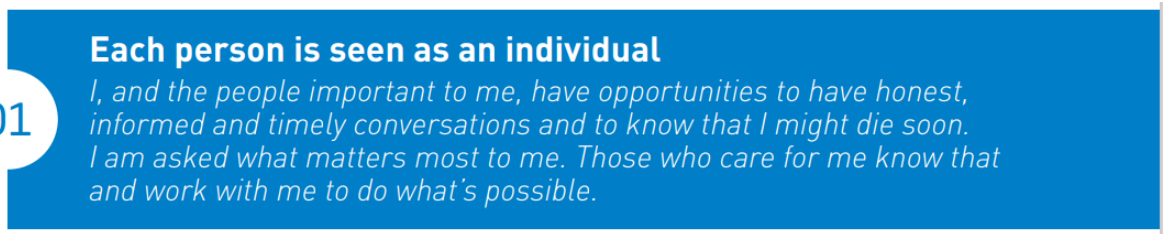
Identifying more people as palliative is imperative because advance planning 'what matters to you' conversations can be held; helping patients and health services to address personalised health and holistic needs. In the last 10 years the number of people identified as palliative has increased to 0.4% of the patient population, the England average is 0.5%. Again, there is variation across the four Places (0.4% to 0.5%) and this variation is significant (0.2% to 0.7%) when we consider our primary care networks.

[18] These are the short definitions as found in the NHSE PEOLC Health Needs Assessment Template. As found in Dixon et al. 2015. Equity in the Provision of Palliative Care in the UK: Review of Evidence

Although we will proactively seek new sources of funding, we know that we need to use the funds already allocated across South Yorkshire in different ways. We will create the conditions for quality improvement, stimulate innovation, and lead transformation of services, to ensure we can deliver better use of the resources we already to improve our patient, carers and families experience, access to and quality of palliative and end of life care services, which are outlined in our priorities.

Our strategic priorities

Our priorities are aligned to the national ambition's Framework.



1.1 We will continue to promote early identification of palliative care in the community to increase identification of palliative care to 0.6% of the adult practice patient population.

1.2 We will work with strategic and clinical professionals to promote the use of advance care planning especially with adults and children who have a long-term life limiting condition and increase multi-disciplinary team (MDT) co-ordination between services.

1.3 We will introduce a project to maximise the use of personalised health care budgets at the end of life and maximise the use of Fast Track referrals.

1.4 We will work together to seek opportunities to maximise budgets across the ICB by pooling budgets for high cost, low activity services.

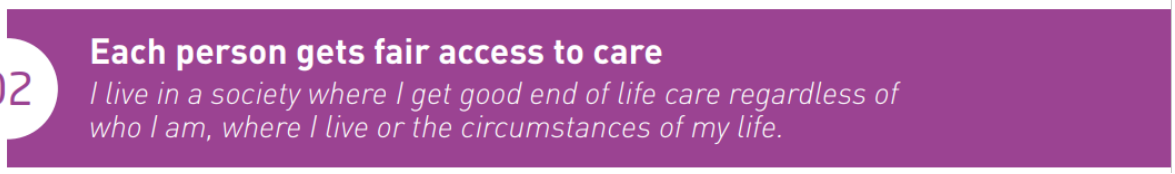
1.5 We will continue implementing the Resus UK ReSPECT initiative, providing a quality emergency planning process across South Yorkshire.

1.6 We will introduce and promote quality standards for end-of-life care across South Yorkshire for all places of death, share findings with the board and action plan where required.

1.7 We will introduce ways of making palliative and end of life care information accessible for the public, carers, patients, and professionals.

1.8 We will continue to support and develop a sustainable system for those bereaved due to a palliative and end of life care experience.

1.9 We will promote benefits available to patients and their families at the end of their lives e.g., special rules.



2.1 We will adopt a population health approach to palliative and end of life care; to develop a South Yorkshire wide PEOLC population health needs assessment for adults, children and young people and use the intelligence to inform planning.

2.2 We will listen to our public and adopt a co-production approach. We will use a variety of approaches to routinely hear the voice of our communities, including sections of the community which have been underrepresented and / or marginalised.

2.3 We will adopt an 'everyone's business" approach across South Yorkshire– so strategic and clinical professionals understand the role they can play in ensuring palliative and end of life care is factored into their thinking and planning, to support delivery of the Duty. E.g. long term conditions, dementia, frailty and mental health.

2.4 We will have specific projects to help all patients access palliative and end of life care including but not limited to

- **children and young people,**
- **black and ethnic minority communities,**
- **older people and those who are frail,**
- **those living with dementia**
- **those with learning disabilities.**

2.5 We will work with social care organisations to better understand key challenges they face in delivering PEoLC and work to empower staff in the care sector to fulfil patient's wishes and reduce unnecessary hospital admissions.

2.6 We will improve identification of carers, promote carer information and facilitate better access to carer support.

03 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.

3.1 We will introduce our new clinical reference group which will lead on ICB wide processes and pathways in clinical care to create a standardised level of expected practice across South Yorkshire.

This will include but not be limited to -

- **develops guidelines that promote consistent best practice**
- **address parity in access to specialist care and medication,**
- **27/4 symptom control,**
- **Access to specialist advice and information for professionals**
- **Advise on quality improvement initiatives and quality indicators.**

04

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.

4.1 We will promote the use of PEOLC champions in our health, social care and voluntary sector services. Champions will help to support the work of the strategy, share information, collaborate and can be part of our task and finish groups and where these are not currently identified, we will identify them.

4.2 We will work to improve electronic information sharing to help with sharing of information, integrated informed decision making and long-term service development within each Place and across South Yorkshire.

4.3 We will continue to support our local hospices and together explore ways hospices can contribute to the strategy's delivery.

4.4 We will work with our primary care, acute trusts and hospices to ensure delivery of good quality integrated community care.

4.5 We will work as a collective to develop and fund an equitable wide children and young people's model that builds on the foundations established and seamlessly links with adult services at transition.

05

All staff are prepared to care

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

5.1 We will develop and implement an all age South Yorkshire wide workforce plan building on the existing workforce training. The programme will include specialist, primary care and generalist workforce, along with and wider health and social care professionals.

5.2 We will connect with our national professional bodies to promote national training opportunities.

5.3 We will strategically connect with peers across the country to keep abreast of change and best practice.

5.4 We will continue to have a multi-agency partnership governance structure led by the ICB; providing leadership and accountability, clinical and peer expertise across South Yorkshire.

5.5 We will raise the profile of palliative and end of life care within the ICB and across the ICS, ensuring that it is reflected across relevant workstreams, and it features strongly in future iterations of the ICB Strategy and the Joint Forward Plan.

5.6 We will explore better use of technology across our organisations to maximise opportunities to support delivery of care.

5.7 We will strengthen links with academia and research to inform strategic and service development.

06

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.

6.1 We will continue to work as partners to deliver a public health approach to death and dying, connecting with our health and wellbeing boards.

6.2 We will work as partners to support and develop the voluntary and faith sector workforce and volunteers to have increased confidence in supporting people who are seriously ill and nearing the end of life and connect them in with the health and social care system.

6.3 We will work as partners to create a PEOLC network for faith leaders.

6.4 We will continue to work as partners to operate an annual dying matters week programme across South Yorkshire, which will be delivered at Place.

6.5 We need a palliative care system which supports sustainability of the health care system and environmental and climate change targets.

How will we deliver our priorities?

- Having a dedicated ICB Strategic and Transformation board and integrated care system with partners signed up to the strategy and accountable to the action plan and delivery.
- Leadership and a governance framework to ensure partnership delivery.
- Working as a palliative and end of life community which spans organisational boundaries in the Integrated Care System in its widest sense; using the insights, talent and energy which is present in all the sectors.
- Having dedicated PEOLC clinical and managerial leadership within the ICB and across partners
- Maximising opportunities to work across the South Yorkshire area, where possible and delivering at place where required.
- Improving South Yorkshire's response to the Ambitions strategy, with each partner having an action plan and routine auditing against it.
- By prioritising Palliative and end of life care in the ICB and all partner organisations.

- The work is not solely for those working as specialists in PEOLC and an ‘everyone’s business’ approach is need including with those working with people with long term conditions, dementia, frailty, and mental health.
- Creating and protecting the budget for PEOLC within the ICB and across partners, alongside maximising opportunities as partners to seek and bid for additional funding.
- Adopting a project management approach and having a dedicated work programme, including task and finish groups.

Governance and accountability

The ICB PEOLC Strategic and Transformation Board, with representatives from the whole sector is accountable to the ICB Partnership Board.

The following groups will be instrumental – with responsibility for the delivery of key priorities, developing the action plan and reporting to the PEOLC Strategic and Transformation Board. …

- Barnsley, Doncaster, Rotherham and Sheffield Place based (already established) PEOLC partnership locality groups,
- a new clinical reference group
- the rebranded children and young people’s steering group.
- a new peer leader, coproduction group.
- Other task and finish groups – e.g., SY ICB ReSPECT Champions Network.

How will we know that we have been successful? What will we see?

Our strategy will mean that…

What we will do	The outcome
We adhere to the statutory duty and the national strategy.	The ICB partnership board is satisfied with the progression of the strategy action plan.
Undertake a review of progress against the National Ambitions Framework.	Progress against the National Ambitions Framework has been made.
We will work with our patient and carers to agree patient experience outcomes. Use our Healthwatch survey results from 2023 as a benchmark.	Improvements made in PEOLC satisfaction levels for all services rated ‘*satisfied or very satisfied’*. Improvements on our ‘I’ statements (Appendix xxx).
Look to review how the palliative and end of life care system is funded and work towards recurrent funding.	There is a dedicated PEOLC budget within the ICB.
We will adhere to all national and local quality standards to ensure we have good quality services across	CQC standards are being met across all South Yorkshire acute trusts and hospice for PEOLC

South Yorkshire (and Bassetlaw for Children) and at Place.	We are on par or better than the national average for National Audit of Care at the End of Life (NACEL)[19] We identify and mitigate risks.
We will develop PEOLC quantitative outcome measures to monitor progress and introduce a data dashboard – using ONS data and local data.	We aim to make improvements in the following outcome measures. 0.6% of the practice population identified as palliative and added to the GP palliative care register (Baseline 0.4%) Similar to or better than the national average for the number of people admitted to hospital within the last 90 days of life. The number of people who are palliative who have an advance care plan. Deaths in the community continue to increase towards and above 30%. More people dying in the place where they want to die.
Have a workforce plan which ensures staff have increased knowledge and confidence in working with patients who are palliative and end of life care.	Feedback from training shows increased confidence and increased knowledge in palliative and end of life care. There is an active long-term plan in place to train, attract and retain specialist clinical expertise. Provide training opportunities across general sectors in care at the End of Life.
Our strategy and services are co-produced with people who have experience of the system.	SY ICB PEOLC public engagement is completed regularly. Peer network is established.

Signed off by

Emma Latimer, South Yorkshire Integrated Care Board's Senior Responsible Owner, Palliative and End of Life Care

And the PEOLC strategy and transformation board, including the reference groups, the steering groups in all 4 places and the ICB Partnership Board.

[19] National Audit of Care at the End of Life — NHS Benchmarking Network