



North East &
North Cumbria

**NHS North East North Cumbria Integrated Care
Board (NENC ICB)**

Tees Valley Place

Adult Palliative and End of Life Care Strategy

2022 - 2027

1. Executive Summary

NHS North East North Cumbria Integrated Care Board (Tees Valley Place) is committed to improving the quality of care for those in need of palliative or end of life care and supporting their carers and families. The need for good quality, community-based services is important in supporting people to achieve their preferred place of care, reducing the proportion of inappropriate hospital deaths, and ultimately supporting people to achieve their preferred place of death.

Current national estimates suggest that approximately 75% of people approaching end-of-life may benefit from palliative care. By 2040, annual deaths in England and Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659). If age- and sex-specific proportions with palliative care needs remain the same as in 2014, the number of people requiring palliative care will grow by 25.0% (from 375,398 to 469,305 people/year). Disease-specific projections show that dementia (increase from 59,199 to 219,409 deaths/year by 2040) and cancer (increase from 143,638 to 208,636 deaths by 2040) will be the main drivers of increased need.¹ This ageing and more complex population will have a significant impact on health services and collaboration across statutory, primary, community and voluntary organisations will be more important than ever to ensure people receive the best possible quality of care.

For people to receive the appropriate support and care in their last stage of life, early identification is required. There are several tools available to clinicians to identify and record patients in the last stage of life; the Gold Standards Framework tool (GSF) supports GPs to identify patients who are in the last year of life, assess and record their needs and plan their care appropriately. Another tool available is the SPICT (Support and Palliative Care Indicators Tool). Those identified should be placed on the palliative register. It is estimated that approximately 1%² of patients within every general practice are likely to die within the next year and therefore should be identified within the register. The identification of these individuals can enable appropriate conversations and care planning as early as possible, leading to a higher quality of end-of-life care, fewer unplanned hospital admissions and a good death in their preferred place of death.

The aim of this strategy is to ensure the Tees Valley commissions and delivers high quality, cost effective and resilient systems of care across so that patients approaching the end of life and their families have a positive, high quality and personalised experience wherever they wish to be cared for.

The strategy summarises the work undertaken to date by Tees Valley to engage, review and co-design the future of local palliative and end of life care services in line with national and regional direction but shaped by local learning and locally identified need.

Through this process, a range of key focus areas have been identified that aim to improve palliative and end of life care and deliver against the collective vision that has been drawn out of this local work. The high-level focus areas resulting from this programme are as follows:

1. People who require palliative or end of life care are identified early, they receive the care and support they want in their preferred place of care and are empowered to make decisions about their care.
2. People approaching their end of life will have access to end-of-life healthcare support 24 hours a day, 7 days a week.
3. Good information on all options of palliative and end of life care and support is available for patients and their families and carers and the process of accessing this support is simplified.

¹ [How many people will need palliative care in 2040? Past trends, future projections and implications for services \(biomedcentral.com\)](https://www.biomedcentral.com)

² National End of Life Care Programme, Find your 1%

4. People die in their preferred place of death and have a positive experience of palliative and end of life care.
5. All providers across the Tees Valley work collaboratively and communicate with each other to provide palliative and end of life care that is patient-centred, personalised, integrated, and patient led according to their preferences.
6. Staff feel confident and capable of delivering high quality palliative and end of life care and are supported to access training to do so.

Work to date demonstrates that there is already a strong focus on partnership working between the Integrated Care Board (ICB) and local Partners such as primary care, secondary care, Local Authorities, and Hospices. Working in close partnership with our providers has already helped us to achieve many changes in clinical services and improved quality, safety, and patient experience within the services we commission.

It also demonstrated, however, that across the Tees Valley there is huge variation in how palliative and end of life care is commissioned and delivered. This reflects the historic Clinical Commissioning Group (CCG) footprints and has resulted in significant disparity in services and specialist provision and inequitable funding mechanisms, resulting in expensive and siloed services in some areas and paucity of services in others. It also demonstrated the impact of the historic split between health and social care.

It is, therefore, imperative that we advance this strategy to ensure a joined-up approach with our social care partners, third sector and voluntary organisations, moving towards a system of integrated care and partnerships, where providers work together in flexible teams: formed around the needs of the patient, their families, and the communities in which they live. We need the right people, in the right place, at the right time, supported with technology that meets the needs of our workforce and patients.

The key outcomes the ICB expects to achieve through implementing this strategy include:

1. An increase in the number of people on practice palliative care registers, identified in a timely manner to support shared decision making, referencing the 1% target.
2. An increase in the percentage of people achieving their preferred place of care and preferred place of death, in comparison to current levels.
3. An increase in the number of advance care plans, as all those identified as in need of palliative and end of life care will be offered the opportunity to have an advance care plan.
4. System interoperability across the Tees Valley area to enable joined up, coordinated care across organisations and providers.
5. A single care plan document available to be used by all stakeholders in clinically appropriate settings.
6. Access to improved, coordinated care with streamlined points of access.
7. A reduction in unnecessary hospital admissions for those receiving end of life care.
8. Fair, equitable and where appropriate, consistent contracting mechanisms across all commissioned providers of care.
9. Fair and equitable access to care for all patients depending on need.
10. Reduction in health inequalities for patients who require access to PEOl care and social support.
11. The availability of consistent training across Tees Valley providers to ensure high standards of patient care and compassion.

2. Introduction

This strategy outlines how the Tees Valley proposes to improve palliative and end of life care over the next 5 years (September 2022- September 2027). It is intended that the strategy is considered as a framework, with detailed action plans subsequently being produced to deliver the overarching principles stated within this strategy. Detailed action plans will be developed and monitored locally via appropriate forums and governance processes.

The strategy identifies and sets out the commissioning and service developments needed to ensure that end of life care for the population of Tees Valley is personalised and well-co-ordinated, enabling real choice for individuals. It details the current understanding of need, service provision and plans to commission end of life care pathways for all patients with active, progressive and advanced disease regardless of their underlying condition or setting.

The scope of this strategy encompasses:

- All adults (defined for the purposes of this document as over the age of 18 years old) with any advanced, progressive, incurable illness. A separate strategy is also in development for the under 18 population. Transition between children/young people and adult services is also in scope of this strategy.
- Care provided in all settings such as and including Care Homes, Hospitals, Hospices etc.
- Care provided in the last year(s) of life.
- Support for patients, carers and family members (including care after bereavement)

For the purpose of this strategy the definitions of palliative care and end of life care are:

2.1 Palliative Care

Palliative care is defined by the World Health Organisation 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.

Palliative care also helps those receiving care, families and carers deal with emotional, spiritual or practical issues arising from the illness. People of all ages can benefit from palliative care at all stages of their illness.

2.2 End of Life Care

People who are likely to die within the next 12 months are 'approaching the end of life'. This also considers people whose death is likely to be imminent in the next few days or hours. The General Medical Council (GMC) defines people 'approaching the end of life' as being those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months.
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- life-threatening acute conditions caused by sudden catastrophic events.

3. Background

3.1 National Context

There are few certainties in life, but there is one thing we can be sure of: we will all die. So, we all need and deserve high-quality end of life care. Current estimates suggest that approximately 75% of people approaching the end-of-life may benefit from palliative care. By 2040, annual deaths in England and Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659). The North East was the region of England with the highest mortality rates and London was the region with the lowest, for both males and females.

The Department of Health launched the national Strategy for End-of-Life Care in 2008, following extensive consultation with families, NHS teams, social care, Hospices, voluntary groups, and other stakeholders. Since then, the National Institute for Health and Care Excellence (NICE) has released a guideline “NG31 Care of Dying Adults in the last days of life” and quality standards “QS13 End of life care for adults” and “QS144 Care of the Dying Adult in the last days of life” to promote clinical best practice in end-of-life care.

The National Palliative and End of Life Care Partnership released the “Ambitions for Palliative and End of Life Care” in 2015 and relaunched in 2021 to build upon the national strategy. The framework sets out the national vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England. The framework outlines 6 high-level ambitions (see Figure 1) that providers and commissioners should seek to achieve for people to have the best end of life care.

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



The COVID-19 pandemic has shone a light on the importance of PEOL care in most places and the power of PEOL services working collaboratively across all boundaries. It has also exposed the gaps and weaknesses which need to be addressed collectively to achieve the Ambitions Framework.

The NHS Long Term Plan commits to improving personalised palliative and end of life care for people of all ages and to address health inequity. Death and dying are inevitable. Being able to live as well as possible until we die is something that we all value. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities, must be addressed, considering their priorities, preferences and wishes. Personalised care in the last year(s) and months of life will result in a better experience, tailored around what really matters to the person, and more sustainable health and care services.

3.2 NHS England Palliative and End of Life Care: Policy and Guidance

The Health and Care Act 2022 states a legal duty on ICBs to commission palliative care services under s3(1) NHS Act 2006 (as amended):

(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 service³

In line with the above, NHS England have been working in conjunction with partners across the broader system to develop a set of guidance documents and policy requirements in relation to the commissioning and delivery of palliative and end of life care services. Recent policy documentation, the Palliative and End of Life Care Statutory Guidance, (July 2022) builds on clear ICB legal duties in respect of PEOL with a set of key considerations each ICB must reflect on to ensure they meet their respective legal duties. These include:

- Ensuring access to in and out of hours PEOL support
- Ensuring a range of providers are available to meet the needs of patients.
- Ensure ICBs have a clear vision, based upon the Ambitions Framework, of the package of services required to meet PEOL need and actively seek out the commissioning resources to achieve this.
- Ensure sufficient workforce in all settings, paying particular attention to specialist palliative care services, hospice beds, bereavement services, pharmacy services, equipment, spiritual care (as part of mental health and wellbeing support) and access to information.
- Developing and implementing a service specification that aligns closely to the national version.

The **Commissioning and Investment Framework for Palliative and End of Life Care (March 2022)** goes further with detailed guidance on how to identify and address gaps in commissioning arrangements. It also clarifies the key service commissioning categories for palliative and end of life, to underpin the agreement of commissioning responsibilities at a local level.

The guidance document sets out three classifications of service delivery, with expectation that these should be used to support the design and implementation of PEOL services.

³ [Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf](#) (england.nhs.uk) (April 2023)

Core Services
Funding source: ICBs and local authorities
These form the majority of services required by people of all ages with life-limiting or life-threatening conditions. They are key activities that should be commissioned and funded by ICBs, Local Authorities or a combination of both.
Specialist Services
Funding source: ICBs and local authorities
Specialist palliative and end of life care is required for people of all ages living with more complex long-term conditions which are life-limiting or life-threatening. The needs of this group cannot be met by core services alone. This care requires a workforce with specialist skills and experience. They should be commissioned and funded by ICBs, local authorities or a combination of both.
The main components of specialist level palliative care include, but are not limited to: <ul style="list-style-type: none"> • In-depth specialist knowledge (specialist consultant, specialist nursing services, specialist multi-disciplinary teams) to undertake assessment and management of physical, psychological, emotional, social, and spiritual needs to reduce symptoms, suffering and distress. This includes complex symptom management. • Supporting analysis of complex clinical decisions-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment. • Provision of multidisciplinary specialist advice, support, education, and training to the wider care teams who are providing core level palliative care to the person. • Provision of specialist palliative care inpatient beds. <p><i>These activities are not to be confused with specialised services as these are services commissioned by NHSE/I Specialised Commissioning. As of July 2020, no specialised services were formally identified as commissioned by NHSE/I Specialised Commissioning. Therefore, at present, all specialist services are commissioned and paid for by ICBs.</i></p>
Enhanced Services
Funding source: Predominantly charitable and other non-NHS funding streams (some services may be funded by ICBs or local authorities as part of local arrangements)
These are services which provide support to patients with palliative and end of life care needs, and in some cases their families and carers, which are neither health nor social care. They should be funded by charities and not commissioned by the NHS nor local authorities.

Further information is outlined below which details the types of services included within each classification, with the aim of highlighting/offering guidance as to which services ICBs are expected to fund. The full document has been attached at Appendix 1.

Although the document is considered guidance, it is widely accepted that this is a standard framework within which commissioners should construct their commissioning models. By comparing these classifications to current local delivery, we have found some inconsistencies that require review, mainly focussed on the type of Hospice care we currently contract/grant fund.

Classification	Health Services included	Implications for Tees Valley
Core	Community nursing, CHC, therapists, psychological support, medicines	Minimal. Commissioning arrangements in place to fund these services across Tees and no risk to the acceptance of these being defined as 'core' services, however as highlighted in the rest of the evidence gathered, there are inconsistencies in how much and what we fund of these core services across locality areas which requires review.
Specialist Services	Specialist nursing consultants in palliative	Specialist nursing and specialist bed-cased care includes provision in a Hospice setting and we

	medicine, palliative care MDT teams, medicines, specialist bed-based care	currently grant fund some of our Hospices or have block contracts in place that may not constitute to these services being commissioned appropriately for our population. This classification therefore has implications on what and how we commission from our Hospice providers and current affordability envelopes. We have also identified crossover between funding specialists to deliver core activity and this will require review.
Enhanced Services	Complimentary therapies, support groups, emotional support	The current block or grant funded arrangements with our Hospice providers include elements of this care. There is recognition that commissioners do not have a responsibility to fund this activity therefore there would need to be clarity in the future regarding what our commissioned pathways with these providers encompass.

Recognising the wide variation and sometimes inequity in how palliative and end of life care services are funded and building on the classification guidance as above, NHS England have developed a **Palliative and End of Life Care Funding and Contracting Approaches (June 2022)** guidance document to support commissioners (at the time of writing the document is a final live draft). It aims to set out the steps to apply a fair and sustainable model for PEOL services and to offer support to commissioners to transition from current state to a model that aligns to national guidance and national policy where applicable.

The guidance recognises that commissioners across the country have varied and historic ways of commissioning PEOL services, particularly when it comes to Hospice services. It makes a clear statement that this needs to change and that informal grant arrangements with Hospices should be replaced with more robust arrangements, leading to greater accountability and increased funding for the services they offer which are core or specialist.

The guidance document provides a suggested phased approach to implementation of contractual change which includes:

- Building relationships
- Assessing population need
- Undertaking a gap analysis against the Ambitions Framework
- Identifying opportunities for shared economies of scale
- Agreeing contractual approaches
- Ensuring patient choice where there are multiple providers.
- Ensuring data sharing
- Confirmation of financial baselines
- Collation of new MDS/KPI requirements

The guidance offers advice on various payment models that could be implemented in the future such as blended payment models. It also recognises that change will take time, but that a commitment to this change should be agreed.

The first three steps of this phased approach have already been completed by the Tees Valley following the award by NHSI of exemplar site monies specifically to pilot this type of strategy development. We are, therefore, well on the way in our journey for change. This analysis has also exposed risks and challenges in our current approaches to funding Hospice providers; findings which concur with conclusions in the guidance document.

Based on the local evidence we have found alongside issued national guidance it is clear that we need to consider making change in how we plan and commission services including the mechanisms for funding our Hospices. We need to transform our current state to one that aligns with the needs of our population and best practice guidance one that is both envisaged by our partners and nationally enshrined in law.

Aspects that will require consideration, include but are not limited to:

- Agreement to review and change the way in which these affected providers are commissioned.
- Affordability of any change and how any transition is managed – it is expected that any change may require investment from the ICB which will potentially need to be transitioned from other contracts or new monies sourced.
- Implementation of the right contractual arrangements for the Tees Valley
- Agreement of the transition period to take us from current state to future state.
- Agreement of the right clinical models for the Tees Valley delivered by these providers, taking into consideration need and affordability.

3.3 Local Context – The Tees Valley Picture

Tees Valley has a total combined population of 719,245 people, served by 80 GP practices.

The NENC ICB is responsible for commissioning physical and mental health care for the population within the boundaries of Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton on Tees. This includes people who are registered with a GP practice and those who are not.

Figure 2: Tees Valley map



Intelligence has been collated to demonstrate the current landscape across the Tees Valley. The following data covers the period April 2015-March 2022 and provides a summary of local need and local performance. The full data report can be located at Appendix 2.

The following information utilises data/intelligence available at the time of writing. Please note: that this therefore may not be fully representative of the local population however, there is adequate local information available to allow us to draw some conclusions for the purposes of the strategy.

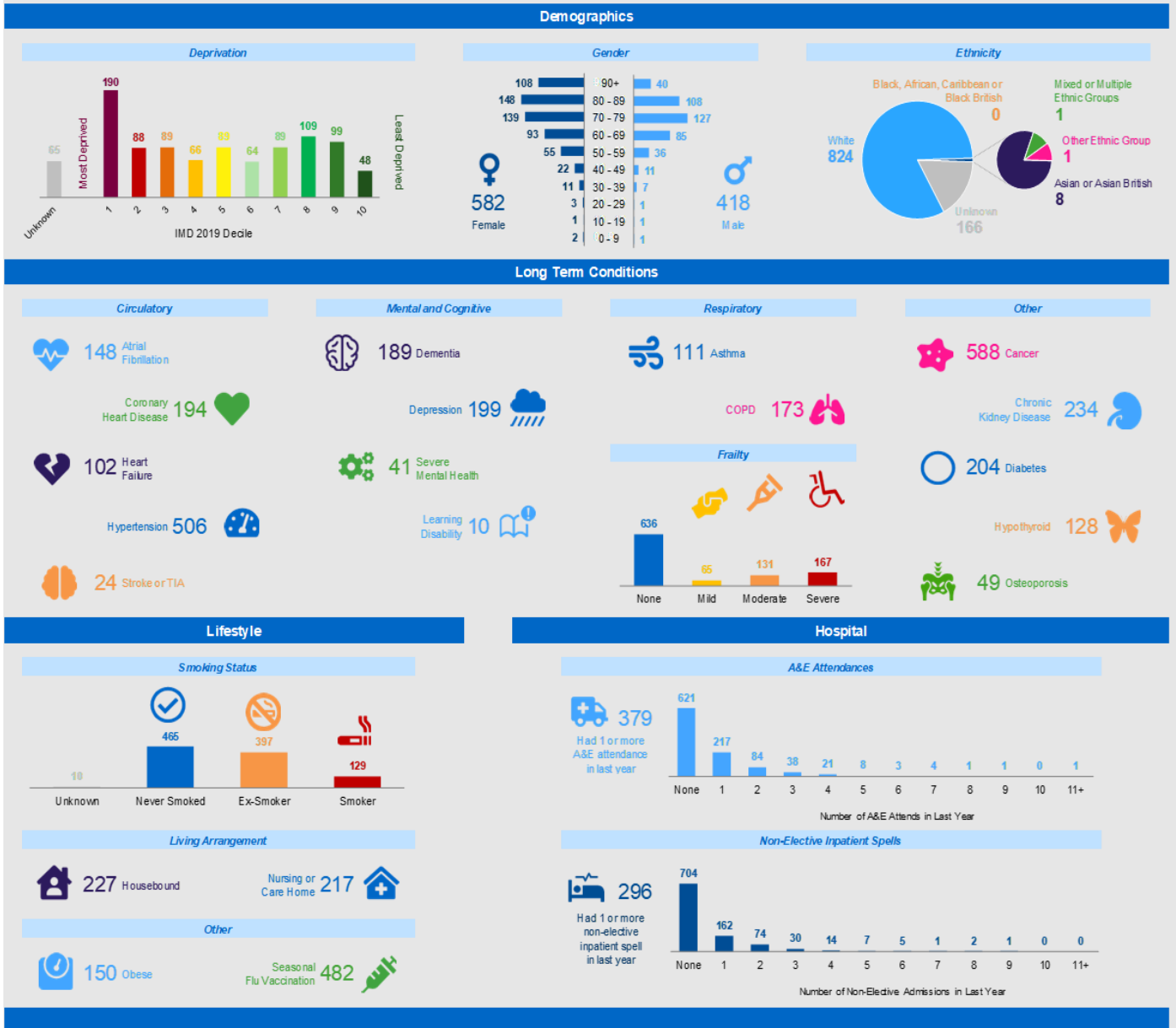


Figure 3 - Tees Valley Palliative and End of Life Care System represented as a village of 1000 people.

The infographic above demonstrates a snapshot of the population of how Tees Valley would look if it was a village of 1,000 people, and all were on the palliative care register. It depicts the demographics, long term conditions and levels of hospital admission for people on our PEOl registers alongside indicators such as smoking status, obesity, living arrangements and how many are screened for a seasonal flu vaccination. This high-level overview shows that:

- Most patients on our PEOl registers are between the ages of 70-89
- There is a fairly even split between men and women.
- The majority identify as white.
- A high proportion of patients have cancer.
- A high proportion suffer from a range of long-term conditions such as hypertension.
- Around 30% had one or more non elective inpatient admissions in their last year of life.

3.3.1 Palliative care register – Target 1% of GP Practice Population

The following table shows the published QOF palliative care prevalence in the Tees Valley footprint.

Published QOF Palliative Care prevalence:						
Area	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21
Tees Valley	0.51%	0.72%	0.69%	0.65%	0.76%	0.70%
Cumbria and North East	0.55%	0.54%	0.53%	0.54%	0.67%	0.64%

Table 4: Published QOF Palliative Care prevalence.

All areas of the North East and North Cumbria have seen a gradual increase over time in the proportion of patients on the palliative care register; recognising the target of 1%. The table is formatted to show the change in Tees Valley prevalence over time. It is possible the increase is due to a genuine increase in palliative care patients based on increasing population estimates, as well as an improvement in the identification and coding of patients who are recognised as having palliative needs. Although encouraging that the % is improving year on year, there is still a way to go to achieve the required 1% level and ensuring we are identifying and therefore supporting all local patients with a palliative care need.

3.3.2 Palliative Care and Deprivation

The following map shows the prevalence of palliative and end of life care patients compared to the level of deprivation across Lower Super Output Areas (LSOAs) in the Tees Valley.

A Lower Super Output Areas is a geographic area. There is a LSOA for each postcode in England and Wales and provides a geographic hierarchy designed to improve the reporting of small area statistics.

The map shows the numbers of patients with a flag of Palliative and End of Life Care need across Tees Valley Primary Care records, for each Lower Super Output Area in the Tees Valley. Each LSOA has a dot, and the size of that dot represents the number of palliative and end of life care patients with a postcode in that LSOA; the larger the dot the more patients with a flagged PEOLC need.

The map also shows levels of deprivation according to Indices of Multiple Deprivation (IMD) deciles; the Indices of Multiple Deprivation (IMD) are a measure of relative deprivation used to rank neighbourhoods across the UK. Deprivation is essentially defined as ‘a lack of...’, and the IMD is intended to offer multidimensional information on material living conditions in an area or neighbourhood based on a ‘lack of’ living necessities causing an unfulfilled social or economic need, relative to the rest of the country. The indices rank every small area (LSOA) in the country on a scale of deprivation, with 1 being the most deprived areas.

Working with Business Intelligence colleagues to review the map and the background data, we can summarise that the most deprived areas have some of the youngest populations with a PEOLC need.

Some of the biggest dots on the map are in areas of higher deprivation but this is not consistent and there are also pockets of significant palliative care need in less deprived areas also. However, this could be because in general palliative patients tend to be older (over 70) and some less deprived, more affluent areas have an older population.

There is the potential for some of the more deprived areas to include populations who are less likely to seek support for their conditions and as such, we could also argue that there is the potential for a greater palliative care need in these areas than is currently understood. As such, it may be sensible to investigate this correlation further to seek to enhance the number of patients from these deprived areas in accessing the support they require.

Research to date (funded by The Legal Education Foundation and NIHR Applied Research Collaborative North East and North Cumbria) shows that there is generally increased vulnerability within populations nearing the end of life. One project identified a number of groups which were recognised as

disadvantaged, including: people with more complex needs (including homeless, challenging behaviours, learning disabilities, dementia, mental health issues, communication difficulties); people in deprived or isolated communities; frail elderly; people in marginalised or discriminated groups, (including asylum seekers, people of different ethnicity or faith, Lesbian, Gay, Bisexual, Transgender (LGBT) people, travellers and prisoners). Issues included access to specialist health or social care services, access to SWL support services and the attitudes and behaviours of professionals that impact negatively on service users. In the context of palliative and end of life care, diagnosis can be a barrier, with non-malignant diagnoses often under-represented in specialist palliative care services.

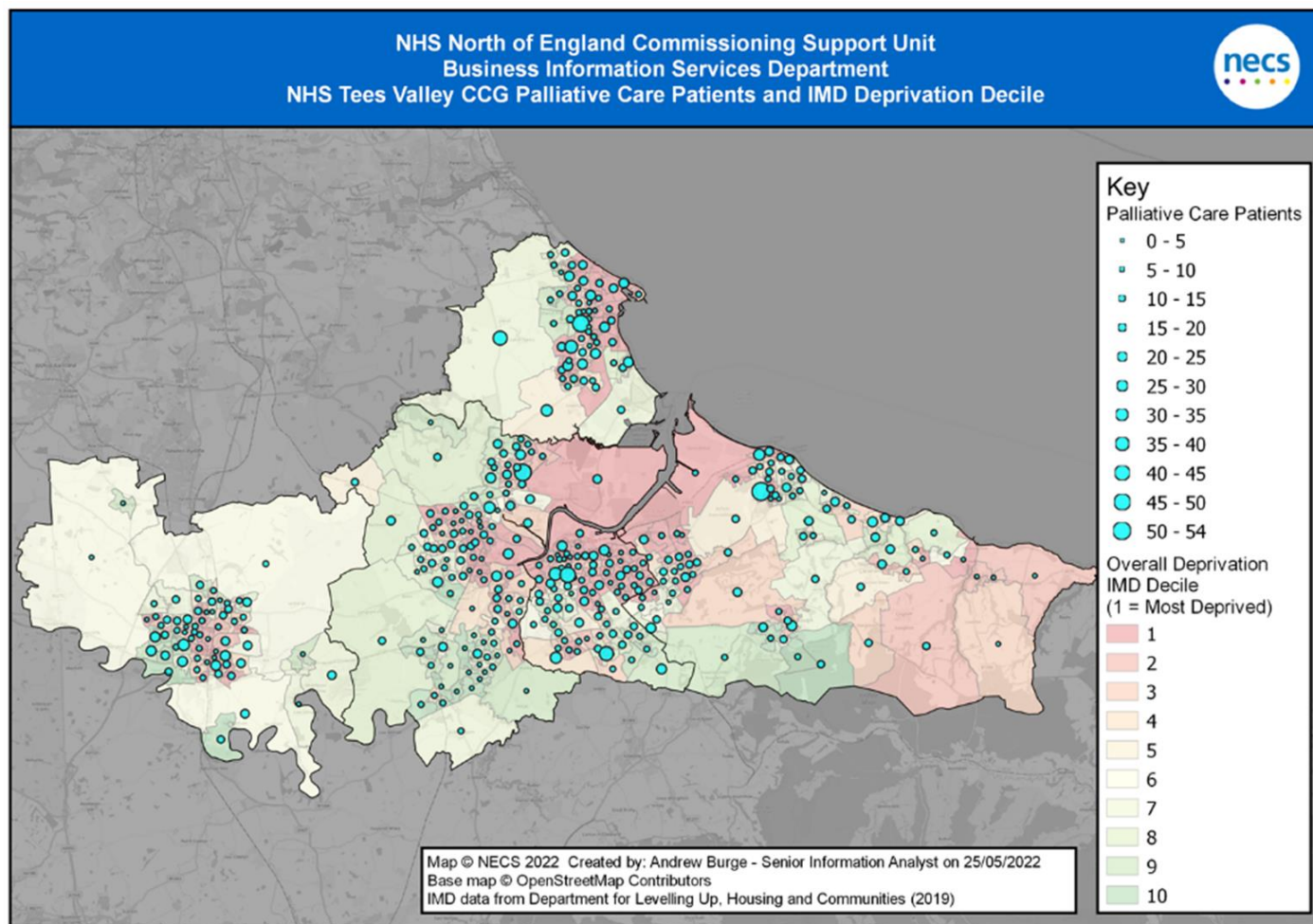


Figure 4 - LSOA Deprivation across the Tees Valley and the rate of PEOLC patients.

3.3.3 Future Palliative Care Need

As of April 2022, there were 4,696 patients on the palliative care register in Tees Valley, which calculates as 0.7% prevalence. It is possible to predict future prevalence and need in the short to medium term, but this is dependent on the ageing population and the increasing prevalence of some diseases such as cancer, dementia and diabetes, which impact on life expectancy and quality of life. Long term projection is complicated by unknown factors such as potential improvements in longevity from improved disease management or emergence of a new condition, such as we saw in the Covid Pandemic.

A study on the future of palliative care in England and Wales found that from 2011 to 2014 palliative care need increased by 0.37% annually⁴. Four projection methods were used and overall, these predicted that an average of **82.7%** of all deaths would have a palliative care need by 2020. This 'need' was defined by looking at deaths from defined chronic progressive illnesses such as dementia, cancer and organ failure.

⁴ <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

Applying this figure to the number of deaths registered in 2020 for Tees Valley suggests that 6,811 of the 8,236 registered deaths will have had a palliative care need at their time of death however 2020 was an abnormal year for the level and causes of death. The 5 years preceding 2020 all had death registrations of 7,000 and 7,200 in the calendar year with an average of 7,117 which suggest in a "usual" year 5,886 people who die will have had a palliative care need.

Although there are exceptions, with over two thirds of the current palliative care register aged over 70 and above, areas with high proportions of their population over 70 tend to have higher rates of their population on the palliative care register.

The proportion of the population that are aged over 70 years old is expected to grow significantly over the next 2 decades. This growth is shown in the graphs below which take data from Office for National Statistics Mid-2018 based population projections.

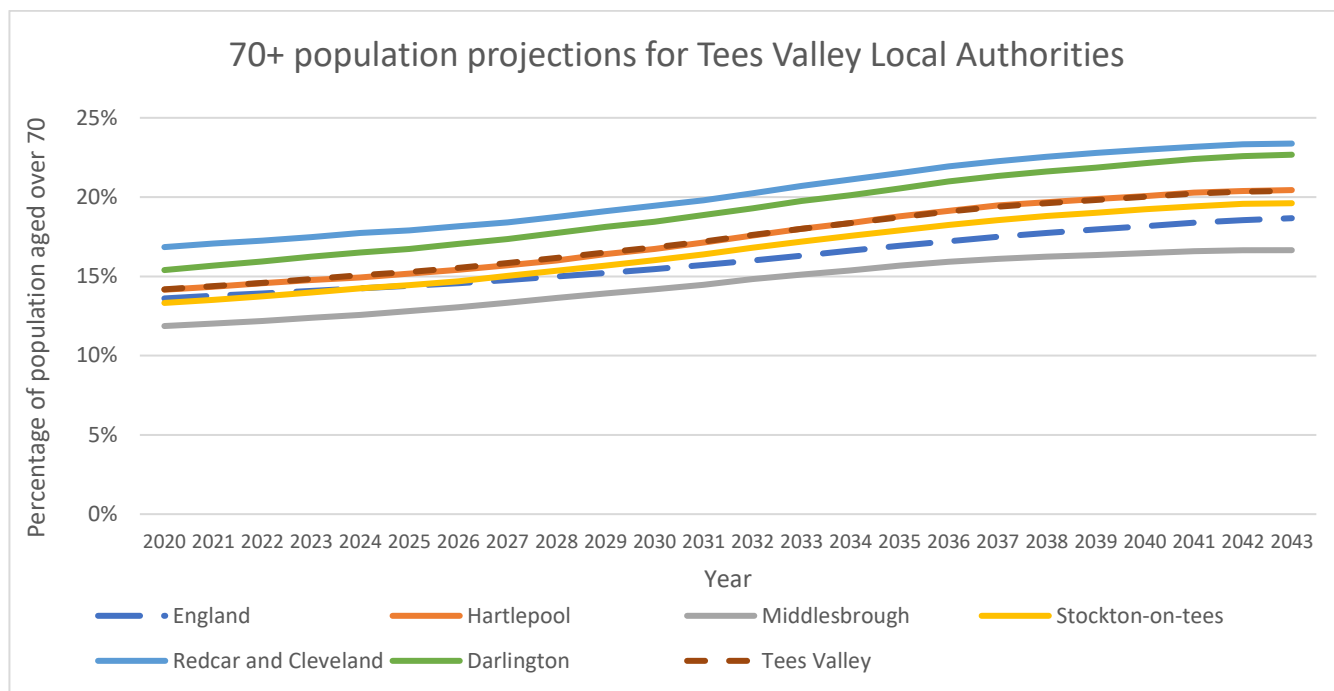


Figure 5 - Project population growth for Tees Valley in those aged 70+.

Around 96,000 people in 2020 were aged over 70 in the Tees Valley. By 2030, this is expected to grow by 18.7% to 114,684 and will reach 136,715 by 2043. This is an additional 40,736 people aged 70 and above in the Tees Valley population, growth of 41.2%. From the above we can ascertain that the requirement for adequate palliative and end of life care services will increase in the coming years.

3.3.4 Specialist Palliative Care Beds

A locality area should ensure access to all appropriate palliative and end of life care to meet the needs of an individual, which will include generalist and specialist inpatient provision, alongside routine and urgent care in the community and in a person's place of residence.

There is limited guidance available which supports specific analysis of specialist inpatient provision, the most recent guidance being from 2012. This guidance however was designed to support development of commissioning plans and includes some specific sections relating to the provision of SPC beds for a defined population size.

More recent commissioning guidance focuses on the provision of SPC care in a Hospital or Hospice setting, or delivery of this SPC care in a person's usual place of residence.

The [commissioning guidance](#) from 2012 suggests consideration should be given to a provision of a minimum of 20–25 specialist palliative care beds per 250,000 population. The guidance also provides consideration for staffing models of these beds including:

- One consultant for each 20-specialist in-patient palliative care (hospice) beds, including outpatient and day care provision, or at least 3 physicians (consultant and other grades) per every 20-specialist inpatient palliative care beds (with at least one whole time SPC physician for every 5-6 beds)
- One SPC nurse to oversee each 7.5 hospice beds, whether in-patient or Hospice at Home – note that additional nursing will be needed to provide the nursing care.
- 1:4 overall Nurse to bed ratio is recommended

The guidance is clear that some data utilised to develop the recommendations is from European countries which reflect very different health service systems and cultural expectations, and that actual numbers/ratios will need to be determined by additional local/place-based factors. Therefore, it is stipulated that it is purely a guide to support local decision-making.

In the absence of further guidance however, the beds per population ratios have been used as an example to support decision making across the Tees Valley as below. This 2012 guidance was also used in a needs assessment process developed by NHS England in 2014 which demonstrated similar outcomes based on bed availability and population sizes at that time.

Area		Adult Population	Beds @ 20-25 per 250k Weighted Population		Median Number of Specialist Palliative Care Beds
Code	Name		Min	Max	
16C	NHS Tees Valley	677,170	54	67	61

Figure 6 – A guide to potential rates of specialist palliative care beds

There are a nominal 32 dedicated adult specialist palliative care (SPC) beds available to Tees Valley patients, all of which are confined to Hospices and have variable occupancy rates. Current access to these beds is not uniform but depends on admission processes and staffing levels. Butterwick Hospice has had very few patients admitted recently due to involvement and restrictions imposed by CQC, and bed occupancy rates of other Hospices have been historically variable. Not all Hospice beds are also aligned to a locality area and some beds will be primarily used for patients from neighbouring places such as County Durham. This means, therefore, that the number of Specialist Palliative Care beds available to Tees Valley patients at any given time may be less than this.

Palliative care specialist clinicians work in all care settings including *generalist* bedded facilities (care homes, acute hospitals) but these do not fulfil SPC specifications. For these patients, the specialists are advisory to the clinicians responsible for that patient’s care. These beds, therefore, do not equate to SPC provision, however across Tees Valley the number of occupied beds where patients are receiving palliative care averages at 45.

Location Name	Number of adult beds in each location	Number of SPC beds generally aligned to Tees Valley	Average % of occupied capacity rate (2019-2022)	Source of Figure & Notes

Teesside Hospice Care Foundation	10, all generally used for patients across Tees Valley	10	82%	Website
Butterwick House	10, all generally used for patients across Tees Valley	10 <i>(All have been closed recently due to CQC inspection outcomes)</i>	N/A	Nov 2021 CQC Inspection Report
Alice House Hospice	18 bedded unit of which 8 are commissioned for SPC. 6 are for Tees valley and 2 for Durham. In addition: 2 beds for pilot end of life rapid transfer for Tees Valley patients (funded till March 2024)	6	78%	Discussions with provider July 2023
St Teresa's Hospice	10 bedded unit of which 6 are currently commissioned for SPC. These are open to patients from Durham and North Yorkshire as well as Tees Valley. An additional 1 can be opened for CHC admissions as needed.	6	74%	Discussions with provider July 2023

Figure 7 - Notional SPC beds in Tees Valley

The nominal number of beds available to Tees Valley patients, therefore, is a maximum of 32.

In practice, any of the 6 beds in Darlington may be occupied by patients from other localities and the 10 in Butterwick have been closed for several years and are expected to take time to come up to full SPC capacity again. Therefore, for the last 2 years there have been a maximum of 22 beds for TV and often less than this actually available at any one time.

However, when we reflect on current availability and demand, we see from occupancy rates that usage of these beds is very variable, even with the closure of one Hospice inpatient setting. Our local engagement work with families also did not suggest that beds were required but were not available, however, we know that this feedback may not be representative of all patients/families and there will always be an element of potential unmet need.

Nationally available intelligence/research suggests there should be a focus on care in a patient's usual place of residence and this is backed up by key themes that run through guidance documents such as the Long Term Plan.

We recognise however that looking to the future, there may be an opportunity to increase this local bed base for the benefit of patients, the exact number and location in each part of the Tees Valley to be determined by further ongoing analysis. Local consultants have feedback that increasing this bed base should be part of considerations for the future as part of good palliative care planning and should be scoped as part of all potential opportunities to continually transform palliative and end of life care including consideration of specialist palliative care virtual ward models.

We know at the moment that there is work to be undertaken to improve the commissioned pathways for the SPC inpatient beds we do have access to, and this should be a priority. Ensuring these arrangements are right will also support more informed planning for any future potential expansion. Right now therefore, the focus should be on maximising the availability of current SPC inpatient beds for those patients that need them most, however actions should be agreed to continually review this overall capacity for the Tees Valley moving forward.

Any work to scope expansion of an SPC bed base/consideration of transformational pathways of SPC inpatient care needs to be mindful of the availability of specialist palliative care consultants across the Tees Valley and all work should be undertaken in conjunction with relevant workforce strategy forums to ensure we have a resilient and sustainable workforce to meet the requirements of any future changes agreed.

Although of secondary importance, and recognising that funding is often limited, it is possible that community-based care could be more affordable, quite apart from the reduction in avoidable hospital admissions which would result. In addition if we are able to reduce unwanted/avoidable admissions, we can invest this funding into other parts of our PEOLC system such as the community, hospices or nursing homes.

3.3.5 Admissions for PEOLC patients

The following table and graph show a Summary of Non-Elective Admissions, for patients registered to a GP Practice aligned to Tees Valley, where the patient had any diagnosis code of palliative care. We can see that there is an underlying trend of increased admissions for patients with a PEOLC diagnosis since 2015. This correlates with the above information that there is potentially the opportunity to support people more effectively outside of a hospital setting.

Financial Year	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total
15/16	93	84	109	116	102	106	94	94	131	110	107	110	1,256
16/17	114	99	122	128	92	97	142	111	133	105	88	99	1,330
17/18	90	104	117	116	100	101	102	97	115	119	117	101	1,279
18/19	81	88	92	109	107	99	104	99	91	101	105	104	1,180
19/20	74	122	115	135	138	122	128	142	158	155	137	129	1,555
20/21	159	152	134	147	134	129	148	141	140	135	120	137	1,676
21/22	135	128	130	145	104	155	123	138	119	130	135	150	1,592

Figure 8 - Non-Elective Admissions for patients on the PEOLC register.

Percentage of deaths with three or more emergency admissions in the last three months of life. (All ages) 2019 Proportion - %

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↑	40,260	8.1	8.1	8.2
Cumbria and North East	↑	2,830	9.0	8.7	9.3
NHS North Tyneside CCG	→	245	11.0	9.7	12.3
NHS Northumberland CCG	↑	375	10.3	9.3	11.3
NHS South Tyneside CCG	→	170	10.1	8.8	11.7
NHS Sunderland CCG	→	300	9.6	8.7	10.7
NHS Newcastle And Gateshead CCG	→	415	9.1	8.3	9.9
NHS Tees Valley CCG	→	620	8.8	8.1	9.4
NHS County Durham CCG	→	475	8.4	7.7	9.2
NHS North Cumbria CCG	→	230	6.5	5.8	7.4

Figure 9 - Percentage of deaths across NENC with three or more emergency admissions in the last three months of life.

The table above shows that for Tees Valley, 8.8% of deaths in 2019 had three or more emergency admissions in the three months prior to the death. This level is higher than the national average of 8.1% but is relatively consistent with the Cumbria and North East average of 9.0%.

A 2017 draft JSNA report on End of Life / Palliative Care from Stockton Borough Council stated that "Hospital costs are by far the largest cost elements of EoLC with care in the final three months of life averaging over £4,500 per person who died. The bulk of this cost is due to emergency hospital admissions where hospital costs increase rapidly in the last few weeks of life."

Source: End of life care Sustainability and Transformation Partnership support tool

There is clearly still work to do to improve this position across the Tees Valley and it would be appropriate to ensure targeted actions are developed that focus on a reduction in the number of emergency admissions for patients on the PEOl register. Consideration should be given to improved care planning and communications to support people to remain at home and/or be supported in a community setting.

3.3.6 Advance Care Planning & Preferred Place of Death

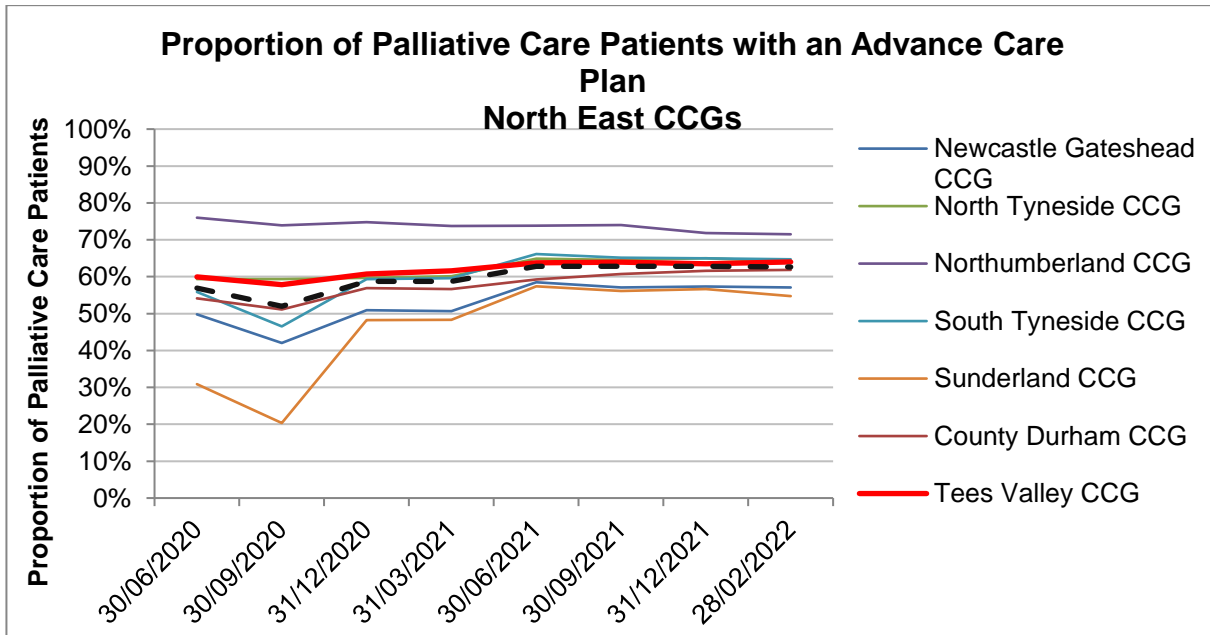


Figure 10 - NENC ICB Advance Care Plan rates

Tees Valley closely follows the North East average for proportion of palliative care patients with an advance care plan. The proportion has increased from **55.6%** in Sep-19 (earliest data available) to **64.0%** in Feb-2022.

- In Feb-22, **41.8%** of Tees Valley patients on the palliative care register had a **preferred place of death specified**.

- In Feb-22, **49.7%** of deceased patients who had been on the palliative care register **had died in their preferred place of death.**

Although the current performance is encouraging compared with some peers, there are still improvements to be made and benefits to be realised from an improvement in advance care planning. Advance care planning should also support an increase in the number of patients who die in their preferred place of death.

3.3.7 Summary

Based on what we know from our population analysis we can conclude that:

- We expect to see a rise in the number of palliative care patients across our locality.
- We need to increase the numbers of patients who are on the palliative care register and there are opportunities to support some targeted work around this increase.
- There is an opportunity to ensure our populations with the greatest health inequalities are being offered access to the PEOl support needed.
- We have a potential deficit in the number of specialist palliative care beds, but there is an opportunity to shift care towards a community/home setting in line with patient expectation.
- We need to increase the number of patients with advance care plans, specifying their preferred place of death to 70% based on regional guidance.
- A significant proportion of patients on the palliative care register also have other long-term conditions and therefore we need to ensure care is joined up across health and social care teams.
- There is an opportunity to reduce the number of non-elective admissions a patient has in their last year of life.
- We need to review reporting templates utilised across primary care to ensure consistency in reporting of ACP and DNACPR and ensure completeness of datasets.
- We need to provide education on coding of palliative and end of life care interventions to ensure consistency.

3.4 National Audit of Care at the End of Life (NACEL)

NACEL is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland.

North East and Yorkshire region reviewed the NACEL data (audit included deaths from the first two weeks of April and May 2019) to provide some key recommendations for Integrated Care Systems/ Commissioners/ Health Boards, working with providers.

- Ensure adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management. 'Adequate' means specialist palliative medical and nursing cover 9am-5pm, 7 days a week and a 24-hour telephone advice service (One Chance To Get It Right). This would most often be provided by nurse specialists face-to-face supported by medical telephone advice. Where this service does not exist, an action plan committing to provision of such services within a specified timeline should be developed.
- Create and implement an action plan to ensure the local findings and national recommendations of NACEL are reviewed, and that all providers of NHS funded care at the end of life are supported by commissioners in developing, implementing and monitoring this plan.
- Ensure systems and processes for anticipatory prescribing for patients transferring from hospital to home or care home to die are aligned across the health and social care system. 'The system' refers to locality, Integrated Care System (ICS) or other networks of provision.

The Tees Valley has an opportunity and a responsibility to build these recommendations into our plans for the future of palliative and end of life care services. This information therefore has been taken into consideration whilst such plans have been developed and proposed as part of this strategy.

3.5 Local Service Provision

Palliative and end of life care across the Tees Valley is not provided by one single source, but through a multi-organisation approach designed to support the needs of the individual. As the needs of the person become greater, the level of support available should increase.

Palliative and end of life care is commissioned for the population of Tees Valley from three secondary care providers covering acute and community care, four Hospices and numerous primary care practices and voluntary sector support services. Five Local Authorities also support the social care needs of patients. Core services, such as primary care, community nursing and pharmacy provision are supported by specialist disease specific services in the community and hospitals, plus specialist palliative care services in the community, hospitals, and Hospices. Our local Hospice providers also offer a range of pain management services which complement those provided by community and acute care teams, plus a range of complimentary therapy services.

There is variation in the way in which palliative and end of life care services are currently commissioned and funded, largely down to historic ways of working. Some Hospice providers are funded through grant agreements and other providers are contracted through Standard NHS Contracts. Different providers who offer the same services also have differing service specifications and therefore different pathways of care depending on which locality a patient resides.

Tees Valley (which came together in 2020) is made up of previous separate Clinical Commissioning Groups (CCGs) - Darlington CCG, Hartlepool and Stockton-on-Tees CCG and South Tees CCG. This coming together as a Tees Valley highlighted differences in the delivery of services across each area, different delivery models of care with differing staffing models and in some cases, differing outcomes.

The following table details current providers of palliative and end of life care services and a high-level summary of the current service available for information *purposes (information correct at the time of writing)*.

Provider	Service	Contract/Grant	Service description
North Tees Hospitals Foundation Trust	Specialist palliative care	NHS Standard Contract	<ul style="list-style-type: none"> The SLPC Team is made up of Senior Doctors, Nurses, Physiotherapists, Occupational Therapists and Therapy Technicians, with further multi-Disciplinary support from Chaplains and Clinical Psychologists Patients may be seen in a variety of settings, in hospital, in their home or care home, in clinic or at a hospice. 9am-5pm 7 days a week (urgent advice only by a clinical nurse specialist over weekends)
South Tees Hospitals Foundation Trust	Specialist palliative care	NHS Standard Contract	<ul style="list-style-type: none"> The SLPC Team is made up of Senior Doctors, Nurses, Physiotherapists, Occupational Therapists and Therapy Technicians Patients may be seen in a variety of settings, in hospital, in their home or care home, or in clinic. Access to psychology provision. 8.30am – 4.30pm Monday to Friday
County Durham and Darlington Foundation Trust	Specialist palliative care	NHS Standard Contract	<ul style="list-style-type: none"> The SLPC Team is made up of Senior Doctors, Nurses, Physiotherapists, Occupational Therapists and Therapy Technicians

			<ul style="list-style-type: none"> • 9am-5pm 7 days a week Mac CNS service. • OOH 5pm- 9am service provided by SPC consultants within the team
Alice House Hospice	Inpatient unit Day services	Grant	<ul style="list-style-type: none"> • Consultant-led model • IP Unit – Symptom control and EOL. 8 beds; 6 are funded by TV and 2 funded by Durham. • Long-term residential unit: 9 beds funded via CHC. • Respite care; 1 bed • Day hospice for symptom management • 24/7 helpline • Counselling and support services • Therapeutic holistic support
Teesside Hospice	Inpatient unit Day services	NHS Standard Contract	<ul style="list-style-type: none"> • Consultant-led model • IP Unit – 10 beds • Wellbeing Day Service • Counselling service • Outreach Nurse Practitioner. Prior to admission the nurse liaises with patients and attends weekly MDT to provide additional nursing care • Hospice social worker • Hospice OT/Physio
Butterwick Hospice	Inpatient unit Day services	Grant	<ul style="list-style-type: none"> • Consultant-led model • IP Unit – 8 beds for pain & symptom control, respite, EOL • Day services – appointment based. • Symptom control physio. • Complementary therapies. • Family Support Service – Counselling
St Teresa's Hospice	Inpatient unit Day services	NHS Standard Contract	<ul style="list-style-type: none"> • Nurse-led model • IP Unit; 10 beds but some specific for Durham • Hospice @ Home – HCA-led interim support whilst awaiting admission or after discharge. • Home Care • Rapid Response Service • Complementary therapies • Lymphedema • Bereavement counselling • Family support social worker • Day Unit – complementary therapies
GPs across Tees Valley	General palliative and end of life care	NHS Standard Contract	<ul style="list-style-type: none"> • GPs provide palliative and end of life care to their patient population, seeking specialist advice where needed from specialist palliative care services. • GPs identify patients approaching the end of life, carry out assessments, care planning and anticipatory prescribing
District nursing across Tees Valley	General palliative and end	NHS Standard Contract	<ul style="list-style-type: none"> • Provide evidence-based care and support to patients in their own homes. Predominantly providing diabetes care, general wound care (including pressure ulcer and leg ulcer

	of life care		management), administration of medications via a variety of routes, intra venous antibiotics, palliative and end of life care, diagnostic testing and phlebotomy, catheter care and complex patient management
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3.5.1 Local services- Gold Standard Framework (GSF) accredited

The Gold Standards Framework was founded by Professor Keri Thomas OBE in 2000. It is the UK's leading training provider for generalist frontline staff in caring for people in the last years of life. GSF helps teams in all settings provide more proactive, better supportive care, enabling people to live well until they die. Many thousands of doctors, nurses and carers have received GSF quality improvement training. GSF Accreditation is awarded to health and social care organisations and practices across the country who have demonstrated that quality end of life care is embedded within their organisations.

There are six GSF accredited care homes across Tees Valley (details correct at the time of writing), which are as follows:

- Middleton Hall Retirement Village (Darlington)
- Kirkdale Nursing Home (Stockton-on-Tees)
- Allison House (Stockton-on-Tees)
- Westmoor View (Middlesbrough)
- Ann Charlton Lodge (Redcar)
- Sea View Care Home (Saltburn)

There are two GSF accredited GP practices across Tees Valley (details correct at the time of writing), which are as follows:

- Linthorpe Surgery (Middlesbrough)
- McKenzie Group (Hartlepool)

3.5.2 Local Services- Workforce

The Association for Palliative Medicine (APM) in collaboration with the National Council for Palliative Care and other organisations recommended the following minimum requirements per population of 250,000 in its 2012 commissioning guidance for specialist palliative care:

- Consultants in palliative medicine – 2 full-time equivalent (FTE)
- Additional supporting doctors (e.g., trainee/specialty doctor) – 2 FTE
- Community specialist palliative care nurses – 5 FTE
- Inpatient specialist palliative care beds – 20–25 beds with 1:2 nurse to bed ratio.

In 2015, the APM recommended that population-based requirements should be increased to 2.5 FTE consultants per 250,000.

The Tees Valley current local provision is as follows:

Acute and Community provider	Palliative care consultants (FTE)	Population (ONS 2021 census)	APM recommended palliative care consultants 2.5 (FTE) per pop	Palliative care consultants (FTE) Gap per population
North Tees Hospitals FT	3.5	288,900	2.9	0
South Tees Hospitals FT	0.6	280,400	2.8	2.2

County Durham and Darlington Hospitals FT	5.2	629,900	6.3	1.1
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**Information was gathered in 2022 and is subject to change.*

The information per local Trust requires further detailed work to better understand the consultant split across acute and community services, as the APM guidance of 2 FTE palliative care consultants per 250,000 population covers only community provision. The guidance recommends different requirements for acute areas with increased requirements for tertiary and cancer centres. The splits and associated impact will require further work as part of the agreed outputs of this strategy to understand the impact and associated actions as required.

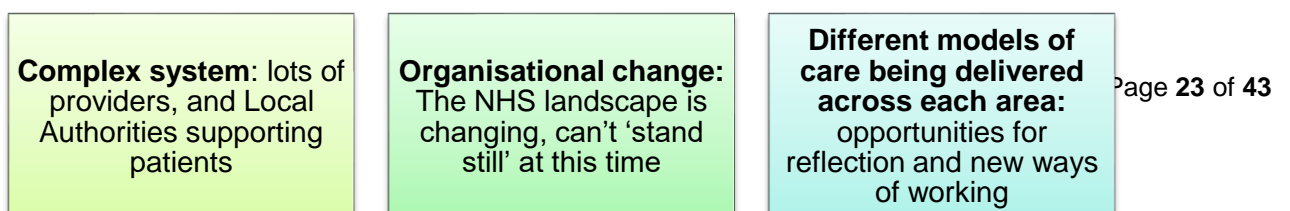
3.5.3 Local services: Challenges

Although there is a range of comprehensive services available across Tees, there is an opportunity to reflect on where, what and how these services are commissioned to maximise equity, efficiency and outcomes for our patients. Although there are mechanisms for providers to currently come together, some of these historic ways of working are creating barriers across our PEOl system. Some challenges that require addressing include:

- Inconsistency in contracting mechanisms; some providers are formally contracted, and some are grant funded. This goes against emerging NHSE guidance and can also impact the commissioner's ability to be aware of and take contractual steps to address any quality and variation in patient care. Although there are some instances where a grant is a sensible commissioning mechanism, it can lead to limited information being available to the commissioner to gain assurances regarding the quality of care being provided and to support a review of activity and key performance information to plan effectively for the future of services.
- Inconsistency in how specifications have been developed and how funding has been historically allocated, leading to frustration between providers and lack of equity in service delivery.
- Lack of investment in palliative care services over a number of years, with significant local variability
- Risk that services deliver care in silos, not sharing information or joining up care consistently for patients leading to inequity in provision and outcomes. This in turn makes the system more difficult for a patient to navigate.
- There are varying skill sets between the historic CCG footprint areas leading to inequity in provision and access.
- There is a gap in the number of palliative care consultants required for our population across the Tees Valley. Although in part this can be supported by skill mix across palliative care teams, there should be a focus on ways to try and address this.
- Addressing any change to funding models would be challenging for the ICB as this would require new investment to be identified, or a shift of committed funds from one part of the system to another.

4 NHSE Exemplar site opportunity

Palliative and end of life care services are commissioned by the ICB across the Tees Valley footprint. This coming together as one ICB offered an opportunity to undertake a wider review of the provision of services and to better understand equity of access to services. It is felt that there are aspects of good practice, and equally, an opportunity to review our care pathways and implement the benefits a co-ordinated vision might bring. The following shows the key challenges the Tees Valley faces:



In 2020 NHS England offered CCGs the opportunity to bid to be one of 3 commissioning exemplar sites for palliative and end of life care. The aim of the pilot was to test the approaches outlined in three resources, namely: the introduction of the commissioning framework in practice, the commissioning of the service specifications to improve services and contracting methodologies for delegated budgets or innovative contracting approaches to support new ways of working. The opportunity allowed for financial and NHSE support into a CCG programme of work and in return, local learning would be shared with the national team as they develop new commissioning models and best practice guidance for all commissioners across the country. The aim was that the work which the three exemplar sites undertook during 2021 would inform a new palliative and end of life care strategy due to be released in 2022.

Tees Valley recognised the opportunity the exemplar site project afforded and as such agreed to bid for, and was later awarded the opportunity, to become a palliative and end of life commissioning exemplar site in late 2020.

Our local bid was focused on developing a palliative and end of life care strategy for the Tees Valley, recognising that the Tees Valley had only recently come together as a commissioning organisation when the bid was submitted (previous strategy development was limited to the HAST CCG Area and completed in 2015). Our focus was to undertake a comprehensive programme of engagement with our public and stakeholders in order to develop a vision and subsequent strategy. A separate document is available that encompasses the learning from a children's and young people's services perspective.

4.1 Exemplar Site Engagement

On the 17 May 2021, Tees Valley launched a period of engagement to look at how services provided to people who are in the last months of their life, known as end of life and palliative care services, are currently delivered, what currently works well and what can be done to improve them, so they are patient centred, offering individuals and their families access to collaborative, co-ordinated care.

4.2 Patient Engagement

The engagement ran for a period of eight weeks from 17 May 2021 to 9 July 2021, focused on gathering feedback from those who had supported a loved one with a long-term condition or cancer, during the end stages of their life (in the last two years). This was in the form of an online survey, which achieved 100 responses and was loosely based on the national VOICES survey questions which was in-depth and sought to gather feedback across a various range of services that could support a palliative or end of life care patient.

Overall (57%) of survey respondents rated their care positively as good, excellent, and outstanding in the last three months of life with 27% rating their care as poor. Respondents provided comments to help improve palliative and end of life care services in Tees Valley, including what else they might need or felt might be useful that was not provided. The executive summary below provides some of the key headlines from the engagement and full details can be found in the main body of the report at Appendix 3. Key points emerging from the online survey were:

Services

- A slightly higher proportion (35%), stated that the person close to them had been ill for one year or more before they passed away with 24% confirming that they had been ill for one month or more.
- In the last three months of their life whilst spending time at home, most people (68%) received help from a district or community nurse. 33% received help from a Specialist Palliative Care nurse, Hospice home care nurse or specialist with 22% receiving help from a home care worker, home care aide or home help.
- Overall, most felt that services provided in the home 'definitely' or to some extent worked well together during the last three months of life (51%), however 27% felt they did not work well together.
- A slightly higher proportion (36%) felt they got as much support as needed from health and social services, however 32% felt whilst they received some support, it was not as much as they needed.
- Those who were not given the help or support needed were asked to specify what would have made a difference to them and common themes included more help and support from a variety of services such as District Nurses, Macmillan, Marie Curie, Mental Health and Social Services for both the patient, families, and carers. Sadly, for some they received no help and support, or only when they reached crisis point or when it was too late. Further themes also included joined up care, a single point of contact with regular contact and an emphasis for individuals to be given more information on what could be provided and what to expect.

Urgent Care

- Whilst at home in the last three months of life, 34% needed to contact a health professional once or twice for something urgent in the evening or at the weekend. 25% needed to contact a health professional three or four times with a slightly lower proportion (23%) contacting them five times or more.
- The last time this happened a variety of services were contacted with a slightly higher number (28%) using the GP or Out of Hours provider, with 26% contacting the District Nurses service and 19% contacting NHS 111.
- The majority (64%) felt the required services responded right away.
- Overall, the care individuals received when they needed care urgently in the evenings or weekends was excellent or good (51%), however 23% disagreed with this and felt the care was poor and 21% felt it was fair.
- When given the opportunity to elaborate further on what could be done to improve the care, common themes included empathy from services, respecting families/patient wishes, more accessible district nurses/community nurses, more joined up care/services and respondents felt that the out of hours was difficult to access with an emphasis on telephone calls either being placed on hold for too long or repeated calls and 111 being too slow.

Individual Experience of Care

- Feedback was varied in relation to specific services such as District Nursing, Macmillan, Palliative Care, GP services and care homes where individuals had both positive and negative experiences which included requiring more support, improved communication, and empathy. However, individuals had mainly positive experiences in relation to Hospice care and emergency care.
- Overall, the majority (45%) felt they were always treated with dignity and respect by health care professionals, with 32% feeling that it was most of the time.
- A slightly higher proportion (47%) strongly agreed or agreed that there had been enough help available to meet their personal care, however 38% strongly disagreed or disagreed that there was not enough help available.
- Just under half of the survey respondents (48%) strongly agreed or agreed that they received enough help with nursing care, such as administering medicine and assisting them in finding a comfortable position in bed, with a third (35%) strongly disagreeing or disagreeing that they did not receive enough help.
- The majority (62%) strongly agreed or agreed that the bed area and surrounding environment had adequate privacy.
- Regarding their emotional needs being considered and supported, the majority (53%) strongly agreed or agreed with this statement, with just under a third (31%) strongly disagreeing or disagreeing with this.
- A high proportion (65%) strongly agreed or agreed that efforts were made to make sure they were in a place they most wanted to be cared for.
- A higher proportion (61%) strongly agreed or agreed that they were kept informed on their condition and care.
- The majority strongly agreed or agreed (57%) that they were given adequate time with staff to ask questions and discuss their condition and care.
- In relation to understanding information provided to them, the majority (69%) strongly agreed or agreed that they understood the information.

Choice of Location

- Most individuals (39%) died in their own home and 43% died in a hospice or a care home.
- The majority (76%) knew the location where they wanted to die.
- Most chose to be at home (60%), when asked where they would like to die.
- The majority (58%) stated that healthcare staff had information of where they wanted to die on record.
- In terms of choice, over half of survey respondents (55%), felt they had enough choice about where they died.
- On balance, most survey respondents (77%) felt that they had died in the right place.

Support at Time of Death

- Most (67%), felt they were definitely or to some extent, provided with enough help and support by the healthcare team at the actual time of their death, however 31% felt they were not provided with enough health and support by the healthcare team.
- The majority (74%) felt that support from staff after they died was carried out in a sensitive manner.
- Most respondents felt that they had received no support at all and when asked for feedback on what could have been done to improve the support provided at the actual time of death and after death; alongside the need for more support, comments included quicker response times to certify the death with the appropriate services attending. More information about end of life and what to expect during and after death with support such as counselling or even contact numbers for support services felt would be useful. Whilst there was an acknowledgement that services can be busy, some felt there should have been more compassion together with end-of-life training for staff. A third of individuals nonetheless did feel that there was nothing that could have been done to improve the support with some adding how amazing the staff were.

Overall Experience

- Respondents provided comments to help improve End of Life and Palliative Care services across Tees Valley, including what else they might need or might be useful that they felt isn't currently provided. Common themes included:
 - More support for patients and families, including additional staff with support on evenings and at weekends.
 - More information on the end-of-life process
 - Information on available support services with contact details
 - A single point of contact
 - Person-centered care and joined up care to help support families to make more informed choices.

Respondents were given the opportunity to share in their own words the most important things for patients and carers in the last year of life (e.g. from how they were treated on diagnosis, how they were supported right the way through their illness, what other support was needed as well as excellent medical care and if there were any small things that would make a big impact). Overall, the most common themes were:

- The importance of receiving support, advice and information for families/carers and patients from diagnosis and throughout their illness with effective and clear communication.
- The importance of spending their last days with families, being listened to including involving patients and families in decision making.
- Treating them with honesty, dignity, compassion, sensitivity, ensuring they are respected and made comfortable throughout the process.

When asked what the most important thing to them at the end of life (when they die), common themes revealed that for the majority, having access to Hospice care and being at home with family or being surrounded by family with adequate support, pain free and having a choice of where they would like to die, overall was the most important thing to them at the end of life. Further comments included being made comfortable, treated with dignity and respect, and cared for close to home and family with appropriate support networks.

To further expand the survey work undertaken, Tees Valley offered respondents the opportunity to attend 1-1 sessions to share their story in more detail. 5 individuals came forward and individual sessions were arranged where the experiences and thoughts of the family member or carer was collated. The

detailed feedback gathered in these 1-1 sessions was in depth and varied, but some common themes can be drawn out which include:

- A need for improved communication
- Improved points of contact for the families and carers
- More co-ordinated care across health professionals
- Continuity of care from health care professionals

Each 1-1 session was translated into a case study for the purposes of the project. The full details of each case can be found at Appendix 4. The case studies were also discussed within one of the Tees Valley Exemplar Site workshops (see section 4 of this report) where a multi-organisational group of partners reviewed them to consider what could have happened differently to generate an improved experience.

4.3 Patient Engagement Summary

The engagement feedback provided to the Tees Valley as part of the process has been considered, detailed and has acted as a rich source of information to support reflections on current service provision. Tees Valley is extremely grateful for families and carers for taking the time to complete the survey and be part of 1-1 sessions.

Although the information shared is wide ranging, it is felt that some key themes have emerged. These are:

- A need to improve communication with patients, families and carers, both at diagnosis, during the provision of care and at the end of life
- Improved ways for patients, families and carers to make contact with services, helping them to navigate the system to gain access to care in a quick and easy way when this is needed and provide improved co-ordinated care to them.
- Opportunities to reflect on the way care is provided to patients, increasing continuity where this is possible and, in some cases, increasing the compassion provided to patients, families and carers.

5 Stakeholder Engagement

To compliment the patient engagement undertaken, a programme of stakeholder engagement was also launched as part of the project. To aid this process an external facilitator, Change and Transformation, were asked to provide guidance and develop a programme of workshops.

To achieve the aim of the exemplar site project the Tee Valley developed a local plan that focussed on several key factors:

1. Creating the vision for palliative and end of life care: undertaking a comprehensive engagement programme- encompassing a range of activities including surveys and an offer of 1:1 sessions with families
2. Understanding the system: reviewing how the end-of-life services operate in order to see who does what, where success is achieved and where any blockages might occur. This involved some open and honest sharing between the various partners.
3. Identify existing good practice and areas for improvement: reviewing the current system informed by the existing Ambitions framework to determine where current practice can be rated as good and where any significant gaps might be found.

The exemplar site project commenced in 2021, delayed initially due to COVID, with a 12-week period of public engagement as per section 4 of this strategy. Three workshops were developed with the aims of:

1. Bringing different providers together
2. Mapping the system
3. Gathering insight into priorities for future work.

Due to the at the time restrictions because of the pandemic, all workshops were delivered online using ZOOM.

- 7th July 2021 – *Bringing the System together and gathering visions for the future of work*. This workshop was communicated to and open to all stakeholders to try and ensure a range of participants attended, sharing diverse views, thoughts and opinions.
- 14th October 2021 – *Mapping the system and developing a shared understanding and need*. Attendance at this workshop was focused on those who provide care across our locality areas, to gather the thoughts and intelligence of those at the front line of service delivery.
- 24th March 2022 – *Sense checking back and developing a shared vision*. This workshop replayed back learning so far from the engagement and mapping exercises completed in previous workshop sessions to start to gather a shared vision across the Tees Valley.

The following summaries the key findings and themes from the workshops that were held.

5.1 Workshop 1- Bringing the system together

The first workshop aimed to:

- Bring the wider system together.
- Gather hopes, fears, and concerns over the current EOL care.
- Collect key insights and suggestions.

41 people attended the first workshop from across the NHS End of Life Care system, with the following key themes emerging.

- **Funding:** The group discussed that new models of funding need to not only provide parity of services, but also facilitate basic and develop services across the area.
- **Strategic change:** A joint fear that change was either not happening fast enough, or that there lacked a cohesive and collective vision to deliver the right change.
- **Services:** Choice, personalised care, and holistic services across the region does not match the demand nor is consistent.
- **Collaboration:** A strong feeling that the system should be working together more to deliver services and integrate care for people in the area.

5.2 Workshop 2- Mapping the system

There is recognition that there is variation in services across the localities. The key aim of the second workshop was to gain a better understanding of palliative and end of life care services across the three locality areas of Tees Valley: North Tees (Hartlepool and Stockton-on-Tees), South Tees (Middlesbrough and Redcar and Cleveland) and Darlington.

Participants were put into locality groups and each group mapped the current palliative and end of life care services across that system from their perspective. This mapping highlighted the complexity of the system, the difficulty in navigating the system for patients and families and the number of services that could be involved in the patients' care.

A number of real-life patient pathway case studies were produced (based on the 1-1 sessions as detailed in section 3) to support stakeholders to review patient journeys and discuss what worked well and how care could have potentially been improved. On reflection of the case studies and general discussion regarding current provision of care for these families, the groups recognised that there were a number of key areas where care could have been improved, these were:

- **Co-ordination of care:** The workshop highlighted the complexity of the system and the number of services available to patients. Feedback suggested that improved co-ordination of palliative and end of life care is needed, this could be through developments such as single points of access and end-of-life co-ordinators who can navigate the system for patients/families. We need to ensure that the co-ordination of care across providers is seamless, this could be through developing standard referral forms for hospice care, developing services around the patient and recognising that delivering personalised care will mean services will need to adapt to deliver the care needed. True co-ordinated care means that data needs to be shared across providers.
- **Communication and Information:** Upon reflection of the case studies, feedback from stakeholders highlighted the need to improve communication. This spans across the system and includes greater awareness in the system and among the public/patients regarding what services and options are available to them. Better communication across services with signposting for carers and families is required. It was suggested that a single point of access/contact for patients and families would be beneficial. Clear information should be provided to patients and families including where they can get support, this could be a directory of services, written information, and online support.
- **Identification and Care Planning:** One of the key themes that emerged from stakeholders was the importance of early identification of palliative care patients, professionals starting 'what matters to me' conversations with patients and carers at the earliest possible stage and providing simplified information. It was agreed professionals should instigate care planning which is personalised to the patient, taking into account their needs and those of their carers and families. This identification of the palliative care patient should include a range of illnesses and not just cancer.
- **Funding and Education:** It was highlighted that resources need to reflect population need. There also needs to be the right training in place for staff to deliver advance care planning, individualised to the patient and their family, ensuring staff have the time to provide holistic care.



Figure 11: Word cloud generated from workshop 2.

5.3 Workshop 3 - Assessment against Ambitions Framework

The aim of the third workshop was to finalise the system maps developed at the second workshop, and to then assess the current system against the ambitions framework to support in developing the vision and associated implementation plan to achieve this vision. Prior to the third workshop a survey with a set of questions designed around the key themes in the ambitions was shared with partners for review and feedback.

The table below demonstrates the Ambitions Framework ambition and description, plus the key themes identified by participants from the survey and the discussion in the workshop.

Ambition	Description	Key themes
Each person is seen as an individual	I, and the people important to me, have 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.	<ul style="list-style-type: none"> Timely identification needed. Better information for patient and families about disease course and what to expect. More advance care planning needed, initiated by all providers. Potential insufficient social care to support patients with complex needs. Education and training on personalised care approaches such as shared decision making required. Continuity of care to be improved. Inequalities in terms of people accessing the right care, cancer vs non-cancer

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.	<ul style="list-style-type: none"> • Population needs assessment to determine need across the Tees Valley to be carried out. • Sharing of patient records across providers needed • System interoperability needed. • Measure patient outcomes consistently and act on learning from this
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.	<ul style="list-style-type: none"> • Providers are delivering good quality care to patients when they are referred into the services. • Not all patients receive SPC who need it, inconsistency, can depend on where the patient presents. • Need more holistic assessment of patients. • Ongoing education and training needed to develop generalist staff
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	<ul style="list-style-type: none"> • Patients and families can get confused regarding who to call when support is needed. • Informal agreements for joined up care at present. • Patients accessing SPC receive more joined up care. • SPA would streamline and speed up processing of referrals and reduce the confusion for patients and families on who to call
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.	<ul style="list-style-type: none"> • Funding needed to invest in staff education and training, particularly generalist staff. • Maximise digital technologies such as tele medicine, requires investment.
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.	<ul style="list-style-type: none"> • Need to understand what is available in our communities. • Hospices have a strong volunteer workforce and raise awareness of PEOlc in the community

5.4 Summary of Exemplar Programme Learning

In summary, our learning from a reflection of current and emerging healthcare policy plus engagement with our local stakeholders through workshop sessions, surveys, and the real experience of bereaved patients' families through undertaking a period of public engagement, demonstrates that there is variation in the experiences of palliative and end of life care across Tees Valley.

Our aim is to utilise these findings to drive our place-based vision and strategy towards greater integration and seamless journeys for patients through community, hospital or Hospice-based care at the end of their lives. The feedback also recognises that there are significant elements of good practice occurring across all levels of the system; where patients were able to access the care that they needed at the time that this was required. Our engagement work has shown that at times some people feel that patients receive an outstanding level of care, but this is not consistent. We need to ensure that this outstanding care becomes the norm across the Tees Valley.

Taking the above into consideration, it is apparent that the Tees Valley Palliative and End of Life Care economy needs to develop opportunities to ensure that the model of care provided for all patients equitably delivers integration and co-ordination of care. Services should have an awareness of their role within the wider system of PEOLC and should be able to support patients and their families to access the appropriate care that they need. The patient should feel supported and confident to express their wishes and desires throughout their journey, recognising that situations can be variable. Experiences should be personalised wherever possible; our mapping work identified that the current system is complex and non-linear, but it is recognised that this is an essential element of personalised care. There can be 'no one-size fits all' pathway for patients at the end of life.

Families should also feel supported and listened to, both throughout the end-of-life experience and after the patient has died.

The following are overall themes that link back to the population needs analysis, outcomes from the engagement workshops and public engagement and align to the executive summary at the beginning of this document.

- **Improved System Interoperability**

Providers should be able to share patient records across the system to ensure seamless care for patients. Personalised care plans need to be shared with all those who may be involved in a patient's care and shared plans should be in place where possible. To ensure a better response to dying, death and bereavement, the local organisations that provide care need accurate and up to date information that can help them improve services.

- **Funding and contractual mechanisms**

Funding approaches should be in place that meet the needs of the population and support care in the right place. These approaches should also recognise the ICBs requirements to appropriately commission core and specialist health services and allow our broader system the capacity therefore to deliver enhanced services via charitable funds. Consistency, where appropriate, should be in place across providers on contracting methods, service specifications and funding arrangements. The ICB will be required to source new investment, or redirect funds based on future potential patient flow, to ensure that required pathways are commissioned as appropriate and a move away from grant agreements is achieved.

- **Resilience and sustainability**

Providers will be required to work closely together and consider innovative ways of working to ensure sustainability of services across the Tees Valley longer term, recognising ongoing pressures on workforce and recruitment challenges for PEoL posts.

- **Education and Training**

Every professional needs to be competent and up to date in the knowledge and practice that enable them to play their part in good end of life care. Staff need the time to undertake training, plus time with patients and families to have honest conversations and develop personalised care plans. This is essential to ensuring that the patient and their family feel that their opinions are being taken into consideration. We should ensure that where possible, patients have access to continuity of care and that staff act with compassion.

Integrated Care Systems (ICS) have a key role to play in ensuring that people with palliative and end of life care (PEoLC) needs can access and receive high quality personalised care and support and as outlined, there is a duty for ICBs to commission palliative care services within ICSs. Guidance has been developed by NHS England to support that duty as summarised in this strategy.

There is a duty that all organisations who provide palliative and end of life care should understand and ensure that they comply with their other legal duties and professional obligations. This includes addressing health inequalities for PEoLC, by improving equity of access to services and reducing inequity of outcomes and experience. This will be done by utilising population health management approaches to identifying underserved populations.

Locally, our ambition is to deliver our organisational obligations and implement a PEOL vision that builds upon the learning from the exemplar site work undertaken to date, enabling us to enact a co-designed strategy.

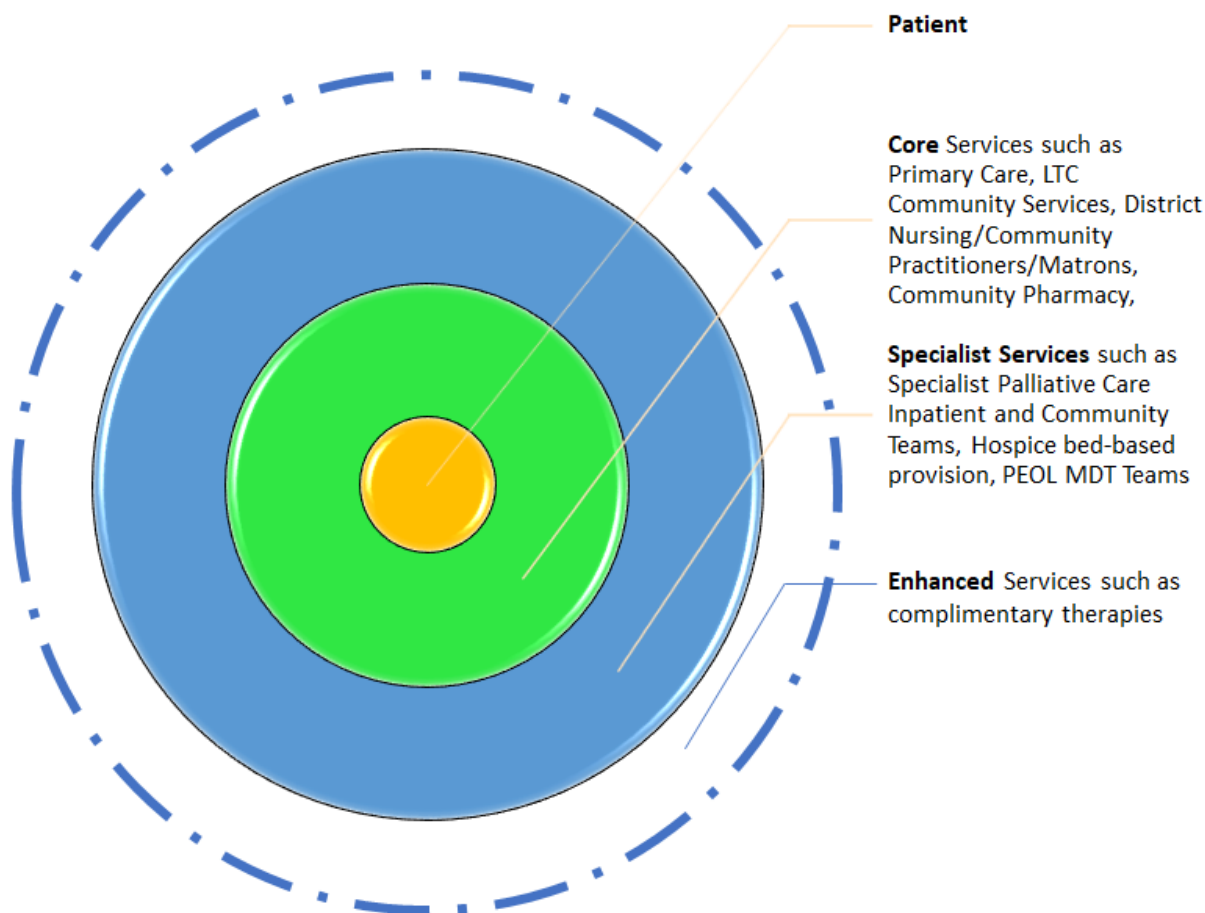
Throughout the strategy we have summarised learning taken from each activity undertaken, be that a review of national policy and guidance, through to learning from patient engagement feedback. The model below sets out a high-level vision for PEOL across Tees Valley and requires specific action plans and timescales to be agreed to enable this vision to come to reality.

The Tees Valley has a rich source of existing providers who offer added value to our PEOL system. There is no evidence to suggest that we need to increase or change the amount of providers across our system, however we need to better utilise what we already have. Plans are based on keeping existing individual contractual arrangements in place and updating these to make them fit for purpose. There is no required need, at this stage, to instigate a procurement process so the following vision is based on the ability to negotiate and agree changes to existing models of care.

6.1 Tees Valley Vision for Palliative and End of Life Care

***Vision:** To enable patient-centred care across all sectors for people with progressive, life-limiting conditions, from diagnosis to death. Supporting our palliative and end of life care system to feel appropriately equipped to deliver high quality palliative and end of life care to our population. Providing greater integration and seamless journeys for patients through primary, community, hospital, or Hospice-based care at the end of their lives.*

Services will wrap around the needs of patients, with patients, their families and carers at the heart of everything we do. Services will build around the needs of the patients, enabling access to more complex care as required throughout the patient journey, plus being supplemented by enhanced services as and where these are available across our system.



Primary care will be empowered to identify patients with a palliative care need and start advance care plan discussions and implement personalised care and support plans (PCSP). There will be a focussed effort to identify and target those patients who may be suffering from health inequalities, to support their PEOL needs as soon as possible.

The care planning process will be more personalised for PEOL patients, improving their experience of care and therefore outcomes.

When and where required, the model will enable a clinician to refer a patient into a single point of access (SPA), to support management of their core needs, plus referral on to any required specialist services where needed. This SPA will be able to refer patients across a number of different providers commissioned by the ICB. Again, the care provided will be more personalised, building on any PSCP implemented by primary care, or starting this discussion/documentation with a patient. Our aim is that patients will have one PCSP throughout their journey across all providers who support the patient to ensure consistency.

The SPA will act as the clinical triage point to determine what care is best suited to each individual patient and will be able to support routine and urgent care provision in line with broader community SPA models. The SPA will have access to up to date directory of service information for each core and specialist service in the locality area and will be able to transfer required patient data safely and securely.

Access to required social care will be triaged and made available via the SPA where needed based on integrated ways of working across health and Local Authority areas. In line with this, it is therefore appropriate to overlay this new way of working into each existing SPA model across Tees Valley (South Tees, North Tees and Darlington) making best use of the systems and processes we already have in place and expanding on these.

The required specialist palliative care community model will be available 7 days a week and there will be OOH provision for access to suitable advice and guidance, co-ordinated via the SPA. Service specifications will be aligned so that there is consistent provision of care in the community, leading to no inequity of care across the Tees Valley. SPC teams will provide guidance and support into other core services where needed and will also manage a caseload, where clinically appropriate, of more complex patients who require symptom management/pain management.

Commissioned Hospice care from a health perspective will be primarily focussed on the provision of specialist palliative care to help support symptom management and care for patients at the end stages of their life. This will be in the form of bed-based provision if this is the patient's choice, but will also encompass access to a range of day Hospice services plus care at home.

Day Hospice and home services will focus on provision of symptom management and rehabilitation where clinically appropriate, incorporating physio and OT support. The support will focus on the wellness and wellbeing of the patient, helping them to self manage where appropriate and manage their symptoms plus offering help with psychologically managing the dying process. This support will compliment community care provided by SPC community teams and District Nursing teams. In addition, Hospices will offer access to bed-based and home-based care for symptom management and end stages of life care, again complimenting and work in partnership with the community offering.

In addition to health commissioned services and as part of their VCSE role and provision of enhanced services, Hospices will also offer a range of complimentary therapies and family support.

To supplement a coordinated approach to clinical triage and referral, patients will also have direct access to advice and guidance should they require it, co-ordinated via the SPA.

The system will strengthen links already in place to share clinical best practice and ways of working and utilise these existing forums to agree, across relevant providers, consistent admission and discharge criteria. The system will work together to ensure clinical systems are interoperable and share data between providers in a way that supports patient care appearing seamless to the patient and their families/carers.

The system will empower its workforce to engage and take part in relevant PEOL training and personalised care training that aids them in the provision of high quality, compassionate care. This training will also take into consideration greater awareness and utilisation of personalised care tools and techniques to enhance each individual patient journey.

6.2 Vision Action Plan

In order to achieve the above vision, a number of actions will need to be progressed, with support from across the system to design, mobilise and implement the required changes. It is important the system works together to deliver the high level vision and ensures that PEOL system leaders are empowered to drive forward these changes. It is expected that, due to the level of complexity of some proposed changes, various reports and impact assessments will need to be considered by relevant governance structures in the future to consider the component parts in greater detail.

Although the vision builds on what we have across the Tees Valley system, this transformation in parts is complex and can not be changed overnight. It is expected that continued considered effort will be required to drive forward the changes over the course of the coming months and years and the length of the proposed strategy reflects the expected time it may take to fully enact all of the proposed contracting, pathway and system changes to support improved PEOL care and associated outcomes.

Key theme: Improved System Interoperability			
Action	Owner(s)	High Level Timescales	Ambitions Framework link
Work with providers to better understand current IT systems used and the scope for data to be shared between these systems	Place commissioning, IT and digital leads All providers	April 2023	Each person gets fair access to care Care is coordinated
Agree an action plan to deliver required changes to enable data to flow between providers to support patient care	Place commissioning, IT and digital leads All providers	April 2025	Each person gets fair access to care Care is coordinated
Where required, scope opportunities to support providers to invest in systems so patient records can be shared between providers	Place commissioning	April 2025	Each person gets fair access to care Care is coordinated
Where required, enable access to shared care records (i.e. shared access to SystemOne)	Providers	April 2025	Each person gets fair access to care Care is coordinated
Agree one PCSP template that all providers are able to embed in systems where required	Place commissioning and providers	April 2023	Each person gets fair access to care Care is coordinated
Support providers to scope opportunities to improved the digital aspect of pathways	Place commissioning, IT and digital leads	Ongoing	Each person gets fair access to care
Ensure all providers Directory of Service is up to date	Providers Local Authorities	April 2023	Each person gets fair access to care
Scope opportunities to bring providers together to ensure that everyone is aware of what core, specialised and enhanced services are available to support good referral management and signposting	Place commissioning	April 2023	Each person gets fair access to care Each community is prepared to help Care is coordinated
Theme: Funding and Contractual Mechanisms			

Review and agree an appropriate, consistent contractual model for Hospice providers	Place commissioning, Provider Management	September 2023	Each person gets fair access to care
Review and agree a financial model for Hospice providers, taking into consideration the need to either source new investment or re-direct existing committed funds from one part of the system to another	Place commissioning, Provider Management	April 2025	Each person gets fair access to care
Agree the model of Hospice bed-based care we want to commission, consultant-led or nurse-led. This may vary dependant on the needs of each locality area	Place commissioning, Provider Management	April 2023	Each person gets fair access to care
Agree service specifications across each PEOL service that meet the needs of the locality, but aim to ensure consistency wherever possible	Place commissioning, Provider Management, Providers	April 2023	Each person gets fair access to care
Where not in place currently, ensure specialist palliative care services are available 7 days a week. This will require a review of some community palliative care services commissioned from Trust providers and may require investment into these services	Place commissioning, Provider Management	September 2023	Each person gets fair access to care
Theme: Resilience and Sustainability			
Work with providers to review current workforce capacity and scope any opportunities to share workforce across the system to support resilience	Place commissioning, Provider Management, Providers, HEE	September 2023	Each person gets fair access to care
Work with partners such as HEE and local providers to scope and plan to increase palliative care consultants across the Tees Valley	HEE, Place commissioning, Provider Management	Ongoing	Each person gets fair access to care
Work with providers and HEE to scope any skill mix opportunities	Place commissioning, providers, HEE	Ongoing	Each person gets fair access to care
Review current patterns of activity, particularly admissions, to better understand what proportion could be avoided by improving access to community and home-based care. In turn, re-direct this freed up resource to invest effectively into these community and home-based services	Place commissioning, Provider Management	September 2023	Each person gets fair access to care Each person is seen as an individual
Theme: Education and Training			

Empower providers to agree a forum and appropriate Memorandum of Understanding to work together to review current training programmes for staff and agree consistent programmes that focus on provision good quality PEOLC.	Providers, Place commissioning	April 2023	Each person is seen as an individual All staff are prepared to care Maximise comfort and well-being
Agree and support provision of relevant training courses where gaps are identified	Providers, Place commissioning	April 2023	Each person is seen as an individual All staff are prepared to care
Ensure access to any relevant personalised care training courses to the PEoL system	Providers, Place commissioning	January 2023	Each person is seen as an individual All staff are prepared to care
Theme: Co-ordinated Care			
Ensure PEoL services utilise where available efficient referral routes i.e. Single Points of Access across each locality to co-ordinate pathways of care	Providers, Place commissioning, Provider Management	September 2023	Care is coordinated
Ensure SPAs have access to the right information to effectively triage patients to ensure access to the right care at the right time	Providers, Place commissioning, Provider Management	September 2023	Care is coordinated
Explore existing forums and scope requirements for any new forums that allow providers the space to share information about their services and work in a joined up way when designing new services	Providers, Place commissioning	April 2023	Care is coordinated Maximise comfort and wellbeing
Review the PalCal Model in place at NTHFT to evaluate benefits and ascertain whether a patient advice line would be beneficial across the broader system	Place commissioning, Provider Management, NTHFT	April 2023	Care is coordinated Maximise comfort and wellbeing
Review the information available to patients and their families and improve this where required. This could be in the form of updating leaflets etc or scoping new ways of providing support such as support hubs	Providers, Place Commissioning	September 2023	Each person is seen as an individual Maximise comfort and wellbeing
Ensure all providers input into the same PCSP plan to ensure patient care is joined up and holistic	Providers	September 2023	Maximise comfort and wellbeing Each person is seen as an individual

Work with primary care to increase the number of Advance Care Plan conversations and in turn, the number of plans that are developed and implemented	Place commissioning, primary care	Ongoing	Maximise comfort and wellbeing Each person is seen as an individual
Ensure providers agree to consistent admission/discharge criteria plus appropriate hand over processes to ensure care is as integrated as possible and seamless from a patient perspective	Providers, Place commissioning	September 2023	Care is coordinated
Explore opportunities to maximise access to digital technology throughout PEOl pathways	Place commissioning, Providers, IT and Digital Leads	Ongoing	All staff are prepared to care









6.3 Risks and Issues

There are number of challenging risks and issues that will be evident along the journey to implementation of this vision/strategy. Some areas can be mitigated to a certain extent, but it is important to recognise the underlying challenges and potential impact they could have.

Risk/Issue	Mitigating Factors
There is a risk that the ICB will be required to invest in the PEOl system in order to achieve the desired outcomes and improvements to services.	<ul style="list-style-type: none"> • Ability to analyse existing activity and shift funds. • Plan any increase in investment over a number of years
The ICB will need to design and negotiate new contractual models which will need to be agreed by providers	<ul style="list-style-type: none"> • It is anticipated affected providers will welcome new contractual models and the clarity this will offer regarding expected levels of service provision. • Ability to build on existing working relationships to negotiate and agree changes. • Changes in line with NHSE guidance
The ICB will need to analyse existing business intelligence information to determine whether any existing activity/costs could be freed up to invest in other parts of the PEOl system. This will require buy in/agreement from affected providers	<ul style="list-style-type: none"> • Need to build on existing good working relationships to support any potential changes. • Utilise any ICB/provider collaborative levers that may be in place. • Utilise any opportunities available to pump prime the changes
There is a lack of skilled workforce available across the area to address the gaps as highlighted	<ul style="list-style-type: none"> • Work closely with HEE and other relevant organisations to support development of workforce plans. • Build on good working relationships between providers to increase system cross working where possible
Improvements to pathways require coordinated work and agreement between a number of providers	<ul style="list-style-type: none"> • Build on existing good working relationships. • Pathway changes in line with meeting ambitions framework so support will be

	available from the network to aid agreement
Pathway changes require new input from existing SPA models which may not have the capacity to support the desired changes	<ul style="list-style-type: none"> • Assess what capacity required and negotiate with existing providers. • Model looks to build upon existing SPA so makes efficient use of resources rather than set up separate arrangements. • Providers identified this as a solution during engagement so should be on board with proposed changes
Improvements to training and education require buy in from providers and for them to free up staff to attend	<ul style="list-style-type: none"> • Providers identified this as a requirement during engagement so should be willing to free up staff to attend. • Courses could be provided over a number of months to spread out any impact on workforce capacity. • Providers are being asked to co-design the training requirements so should be well engaged
Improvements to system interoperability requires buy in from providers to potentially make changes to their existing IT systems	<ul style="list-style-type: none"> • Provider buy in to the changes as this was identified as an area of importance during engagement phase. • System to identify any N/R funds to support any changes as required
System interoperability improvements may require investment in technology	<ul style="list-style-type: none"> • System to try and identify any funds available to pump prime changes. • Flag to NHSE to identify if any support available. • Providers may have budget set aside and they should be willing to engage in the piece of work as it was identified as an issue during engagement activities
If we do not appropriately commission Hospice pathways alongside providing clarity regarding what service model we require, there is a risk that these providers will completely disengage from Tees Valley discussions and reduce/stop the level of service they current offer via existing arrangements. This in turn could lead to displaced patients and a risk of increased hospital admissions. There is an additional risk that some of our hospice providers would have to cease operating due to lack of charitable funding.	<ul style="list-style-type: none"> • Prioritise actions to review Hospice models of care and investment into community/home based pathways. • Ensure honesty and transparency regarding any decisions/work to look at investment opportunities to try and retain good working relationships

Appendices:

Appendix Number	Item	
Appendix 1	Commissioning and Investment Framework for Palliative and End of Life Care (March 2022)	 Commissioning Investment Framework
Appendix 2	NECS Business Intelligence Report – End of Life Data Review Tees Valley	 Tees Valley CCG End of Life - June 20
Appendix 3	Patient Engagement Survey Results	 Survey Results - Support for End of I
Appendix 4	Patient Case Studies	 Angela's Story.docx  Clare's Story.docx  Denise's Story.docx  Rebecca's Story.docx  Trudy's Story.docx