

# Leeds Adult Palliative and End of Life Care Strategy

2021-2026

“  
*People will die well in their place of choice;  
carers and the bereaved will be well supported*”



Leeds Palliative  
Care Network

# FOREWORD

The importance of palliative and end of life care continues to grow and be recognised across Leeds and beyond. We are all aware of the projected growth in demand for palliative care over the coming years and the challenges posed by the increasing complexity and diversity of people's needs, the challenges of workforce capacity and capability and the multiple demands placed on the healthcare, social care and voluntary sectors. With this in mind, we have produced a strategy by bringing together diverse people, professions, perspectives and possibilities to help deliver a care system that is fit for the future and for the people of Leeds.

Although the social, political and clinical context is continuously evolving, the vision and values of palliative and end of life care remain constant: high quality person and family centred care to enable all people, irrespective of their background, to live and die as well as possible, and be confident the people important to them are well supported.

Leeds has a long and successful history of developing and delivering high-quality palliative and end of life care and is well placed to address challenges as they evolve. We have a service we can be proud of. We will build on that to develop services that are equitable, sustainable, informed by evidence and integrated into all health and social care systems where people require them.

Focusing on improving the care for people at the end of their lives not only improves their outcomes and experience but also has a broader positive effect on the whole health and care system. Improving end of life care is good for the patient, good for those who survive them and good for the city of Leeds.

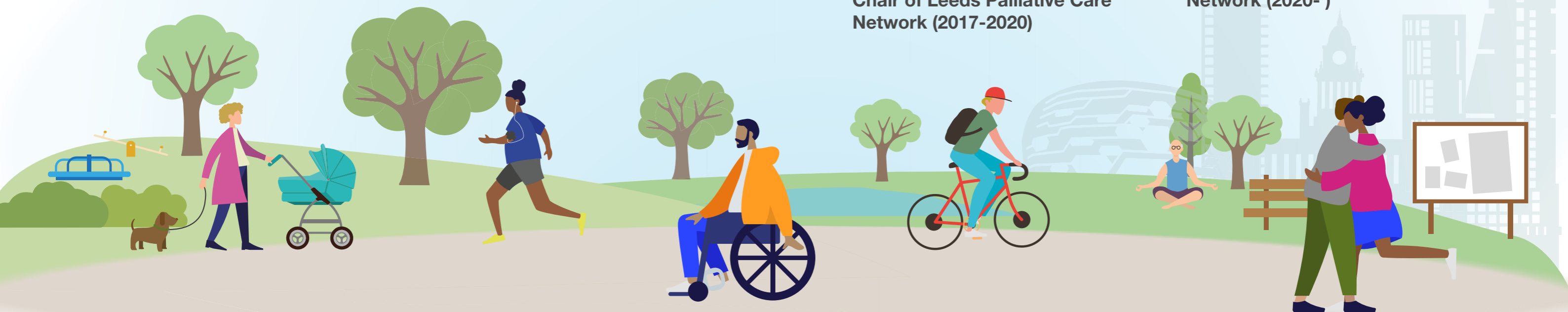
The unprecedented impact of the Covid -19 pandemic has shone further light onto the inequalities, needs and care for people and their families near to and at the end of life. Despite the challenges, we need to use this experience to further understand and improve the care needs of people who are dying. Technology, agility, innovation and collaboration have all played their part now and are likely to be important for the future. This is our time to be ambitious, bold and imaginative, listening to the people of Leeds and translating the research evidence into high quality patient centred care.

It is our aspiration that Leeds is a great place to live out our final years, months and weeks of life, to have great confidence in our care and comfort, and to have the assurance we will die with dignity and peace.

There is only one chance to get it right, and this is our opportunity.

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Hospice,  
Chair of Leeds Palliative Care  
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**“How we care for the dying is an indicator of how we care for all sick and vulnerable people”**

(Ambitions for Palliative and End of Life Care: A national framework for local action 2015-20)

**End of life care (EoLC) is defined as care that:**

*“helps all those with advanced, progressive and incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met through the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support”* (DH, 2008).

**Palliative care is defined as:**

*“The active holistic care of patients with advanced progressive illness. It is the management of their pain and other symptoms together with the provision of psychological, social and spiritual support”* (National Council for Palliative care)

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# Leeds Adult Palliative and End of Life Care 2021-2026

*People will die well in their place of choice; carers and the bereaved will be well supported*

**What factors will enable us to achieve these outcomes?**

## 7 Outcomes that we aim to achieve

*People in Leeds who need palliative and /or end of life care will:*

Be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care

Have their needs and conditions recognised quickly and be given fair access to services regardless of their background or characteristics

Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing

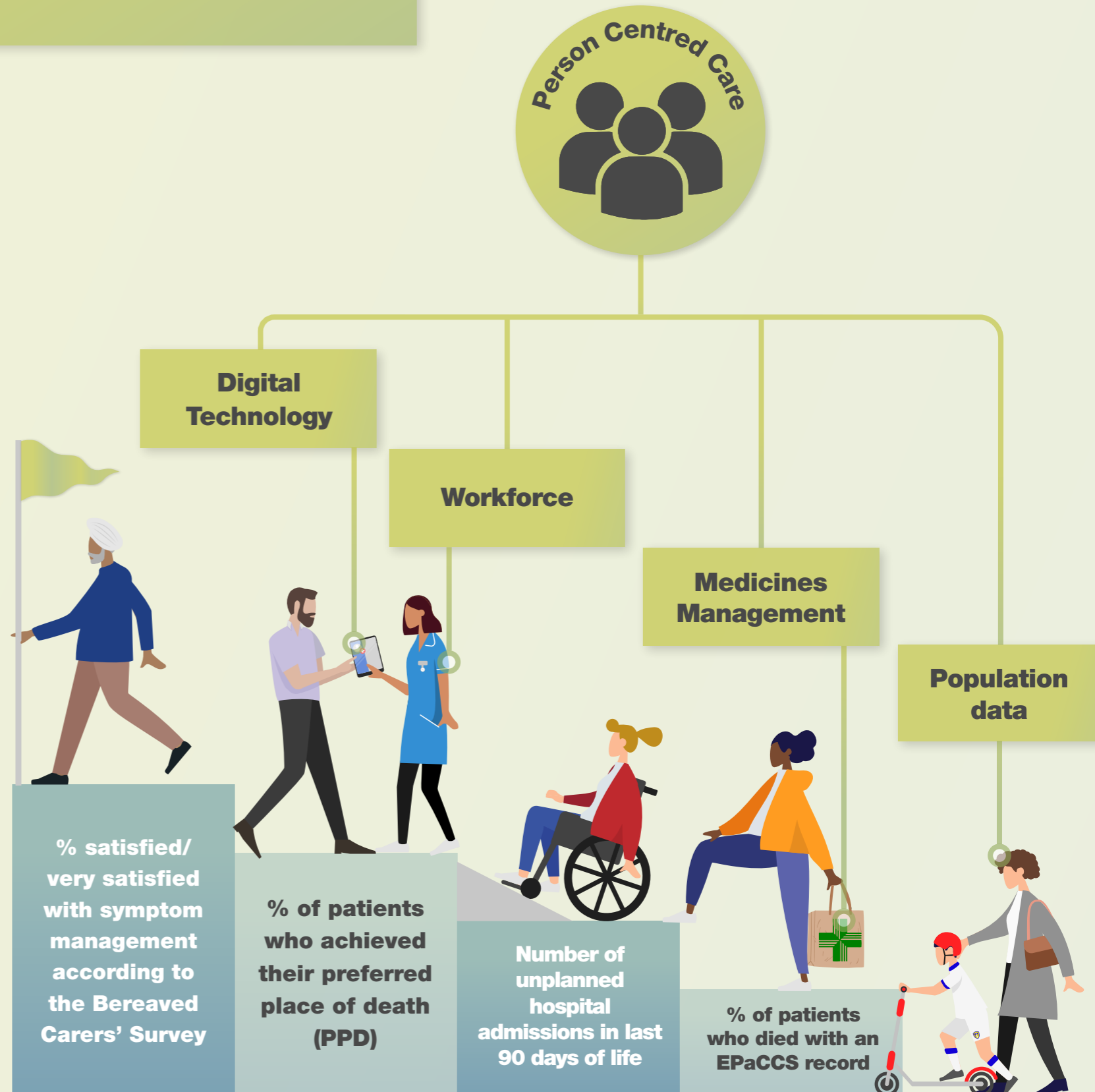
Receive care that is well-coordinated

Have their care provided by people who are well trained to do so and who have access to the necessary resources

Be assured that their family, carers, and those close to them are well supported during and after their care, and that they are kept involved and informed throughout

Be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed

**How we measure success:**



# EXECUTIVE SUMMARY

This strategy sets out our vision for palliative and end of life care in Leeds, detailing seven key outcomes that we will deliver over the next five years. It clarifies how partners in the city will deliver the key aim set out in the Leeds Health and Care Plan that:

**“People will die well in their place of choice; carers and the bereaved will be well supported.”**

## Outcomes

People in Leeds who need palliative and /or end of life care will:

1. Be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care
2. Have their needs and conditions recognised quickly and be given fair access to services, regardless of their background or characteristics
3. Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing
4. Receive care that is well-coordinated
5. Have their care provided by people who are well trained to do so and who have access to the necessary resources
6. Be assured that their family, carers, and those close to them are well supported during and after their care, and that they are kept involved and informed throughout
7. Be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed.

## Key principles:

In delivering the outcomes set out above, end of life care services in Leeds will:

- Meet the current and projected needs of the local population
- Involve those using our services in their development and evaluation
- Be delivered in a variety of settings so that people can use the service of their choice
- Be easy to access 24 hours a day, 7 days a week
- Be accessible to all patient groups who could benefit from them, working to identify health inequalities and putting in place measures to significantly reduce these
- Have low, or no, waiting times and no unnecessary waiting
- Be developed in line with patient need, including locations and timings of services
- Encourage and empower service users to be actively involved in planning their own end of life care and support them to make choices
- Treat all service users and carers with dignity and respect
- Offer treatment and care that is evidence-based and consistent across services
- Be cost effective.

# INTRODUCTION

This strategy sets out the vision and priorities that will help us meet national standards and address local priorities for improving end of life care for adults in Leeds over the next five years. It builds upon and replaces the *Leeds End of Life Care Commissioning Strategy for Adults 2014-19*.

The strategy takes account of the *Health Needs Data Update – End of Life Care Services for Adults in Leeds 2019* and feedback from the public, patients, health and care providers, family carers and the bereaved.

In recent years we have achieved significant improvements in end of life care across Leeds, addressing key strategic priorities identified in 2014. These include:

- An increase in the number of people with advance care planning conversations recorded
- A reduction in the number of people dying in hospital
- An increase in the number of people dying in their preferred place of care
- Increased investment in community and hospital based services
- The establishment of a managed clinical network, the Leeds Palliative Care Network (LPCN)
- The formation of the Leeds Dying Matters partnership and its annual citywide campaign to raise awareness of death and dying
- The publication of an annual survey of bereaved carers
- 7-day palliative care services in hospital and community settings
- Improved access to medications

- Enhanced hospital discharge services, care home support, bereavement services and out of hours medical support.

## **But there is still more to do.....**

In developing the strategy, we have reflected the move towards a population health management approach, working with the public and health and care professionals to develop the following population outcomes for people needing palliative and end of life care.

People in Leeds who need palliative and /or end of life care will:

1. Be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care
2. Have their needs and conditions recognised quickly and be given fair access to services regardless of their background or characteristics
3. Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing
4. Receive care that is well-coordinated
5. Have their care provided by people who are well trained to do so and who have access to the necessary resources
6. Be assured that their family, carers, and those close to them are well supported during and after their care, and that they are kept involved and informed throughout
7. Be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed.

In the pages that follow, we outline how we will achieve these outcomes.

# BACKGROUND

## Strategic Context

This strategy is informed by the framework provided in the NHS long term plan (the Plan), which clearly emphasises integrated and responsive out-of-hospital care to support people in the community, minimise disruption to their lives and utilise hospital-based treatment as effectively as possible. It stresses the need for increased personalisation, giving all people more say about the care they receive, particularly towards the end of life. It identifies tackling health inequalities as a central goal, highlighting the needs of people with a learning disability, people from Black, Asian and Minority Ethnic (BAME) backgrounds, those experiencing homelessness, and people providing care for loved ones, particularly young carers and those from vulnerable communities. Using data effectively and harnessing digital technology are recognised as essential means of achieving these strategic goals. The Plan emphasises the need for effective collaboration between organisations, including the formation of integrated care systems and primary care networks, and the importance of jointly designing services with the people who need them, helping to ensure that service users are at the heart of quality improvement and service development.

Nationally, around half of all deaths occur in hospital, but for many people, this is their least preferred place of care. More and more people are living with uncontrolled symptoms that result in hospital admission, with one in three emergency admissions being for people in the last year of life<sup>1</sup>. At any one time, nearly 30% of hospital patients are in the last year of life<sup>2</sup>, with hospital care in the last three months of life costing on average £4,500 per patient<sup>3</sup>. Timely

recognition of people with palliative and end of life care needs, individualised care establishing realistic goals and preferences, holistic assessment, effective symptom management and support, and advance care planning have the potential to improve people's experience of care at the end of life and deliver more cost-effective, high-quality services.

Locally, we are able to use population health management intelligence to collectively design solutions that improve patient and family experience. The 'Leeds Way' – our approach of "working with people instead of doing things to them" – is key to the personalised care model at the heart of end of life care. This approach is also at the core of the Leeds Health and Wellbeing Strategy 2016-2021, which describes an overarching ambition to improve health and care in the city.

The Leeds Health and Care Plan explains how some of the ambitions in the strategy will be achieved, and we have worked hard to ensure that the needs of people at the end of their life are included in the plan. Our collective aim is that **"people will die well in their place of choice; carers and the bereaved will be well supported."**

This reflects what people in Leeds have told us matters most about end of life care during recent engagements<sup>4</sup>:

- Staff are caring, considerate and supportive
- People's wishes are taken into consideration
- Information provided to people and their carers or families is consistent
- People have privacy
- People are able to choose where to die.

## Demographic Context

There are approximately 6,850 deaths per year in Leeds. Common causes of death for adults are cancer (27.1%), circulatory disease (26.7%) and respiratory disease (12.4%). By 2040 the number of annual deaths is projected to rise by 25%, with the greatest rise in those over 85. In Leeds this will be up to an additional 1,700 people dying per year. The demand for palliative and end of life care may rise by 40%, as those requiring care have increasingly complex needs and require support for longer. The main challenges will be caring for those with cancer, dementia, multiple long term conditions and frailty.

Over the last 10 years, the percentage of people dying in hospital has decreased from 56% to 45.4%, and the percentage of those dying at home, in a hospice or a care home has increased. However people are still dying in hospital when this was not their preferred place of death.

The latest Leeds End of Life Care Health Needs Assessment (HNA)<sup>5</sup> highlights that when a person has an advance care planning conversation recorded and shared in the Electronic Palliative Care Coordination System (EPaCCS), they are more likely to die in their place of choice than those who do not. There is, however, evidence of inequity of access to EPaCCS with people from some BAME groups, particularly black and mixed ethnicities, people under 65 years of age, males, and those from some of the more deprived wards having a lower proportion of recorded advance care planning or lower achievement of preferred place of death.

The percentage of people who have died with an EPaCCS record is increasing (54% as at end of June 2020), thanks to continued quality improvement work across the system. We will continue to work with partners to address unequal access and the health inequalities this results in and help ensure that more people are able to die in their place of choice.

## How we've developed this strategy

One of the recommendations from the [2014-19 End of Life Care Strategy](#) was to consider a partnership forum that would increase collaborative working and improve continuity of care and patient / family experience for people requiring palliative care and those at end of life. It was suggested that this could be achieved by forming a clinical network.

In response, we developed the Leeds Palliative Care Network (LPCN), a collaborative partnership constituted<sup>6</sup> through a formal Memorandum of Understanding and governed through clear terms of reference, reporting to NHS Leeds Clinical Commissioning Group (CCG) It was formed in 2016, and has representation from across the health and care system. The purpose of the LPCN is to help provider organisations work together to plan and deliver care in the best possible way for patients, their families and carers.

The LPCN has been working alongside the CCG and Leeds City Council to refresh the 2014-19 End of Life Care Strategy, taking account of the move towards delivering population level outcomes.

To support the strategy development, the LPCN organised and facilitated two events in November 2018 that engaged more than 60 people from 21 health and social care organisations, including statutory and third sectors.

The first event, [the future of palliative and end of life care in Leeds](#), resulted in the agreement of key areas and themes that are essential to good care and the production of a [framework](#) that has informed ongoing discussions.

The second event, [LPCN celebration and strategy event](#), led to recognition of priorities for future development.

<sup>1</sup> <https://pubmed.ncbi.nlm.nih.gov/24637342/>

<sup>2</sup> <http://endoflifestudies.academicblogs.co.uk/how-many-people-in-hospital-today-will-die-within-a-year/>

<sup>3</sup> <https://www.nuffieldtrust.org.uk/files/2017-01/end-of-life-care-web-final.pdf>

<sup>4</sup> Reports on the development of these priorities are available here: <https://www.leedscgg.nhs.uk/get-involved/your-views/frailty-what-matters/>

<sup>5</sup> The full HNA document can be found at [leedspalliativecare.org.uk/wp-content/uploads/2019/12/11-Health-Needs-Assessment.pdf](https://leedspalliativecare.org.uk/wp-content/uploads/2019/12/11-Health-Needs-Assessment.pdf)

<sup>6</sup> Further information about the Leeds Palliative Care Network can be found here: <https://leedspalliativecare.org.uk/about/partners/>

A strategy advisory group has been established so that senior representative from all partner organisations can guide, inform and influence future strategic developments. The group attended CCG population health management sessions during the summer of 2019 to start to agree key principles and the scope for the future strategy. Through consideration of the local framework and [Ambitions for end of life care](#) 'I' statements, the group developed the first iteration of a broad [outcomes document](#).

[This work](#) was presented to Leeds Health and Wellbeing Board in September 2019, who supported it and encouraged its progression. The outcome statements were further refined following feedback from the Leeds People's Voices group, facilitated by Healthwatch Leeds. These statements frame the structure of the strategy to ensure we remain patient and family focused.

Finally, it is important to recognise that this document has been developed during a significantly challenging time for health and social care resulting from the Covid-19 pandemic. It is worthy of note that during this time, there has been even greater collaboration, and it has highlighted areas that we need to focus on in the future. It has accelerated some changes and will impact how we provide services in future. This will be reflected in annual action plans that result from this strategy.

## Our vision and underlying principles

### Vision:

The vision for adult palliative and end of life care in Leeds is as follows:

***"People will die well in their place of choice, carers and the bereaved will be well supported"***

(Leeds Health and Care Plan 2020)

### Key principles:

End of life care services in Leeds will:

- Meet the current and projected needs of the local population
- Involve those using our services in their development and evaluation
- Be delivered in a variety of settings so that people can use the service of their choice
- Be easy to access 24 hours a day, 7 days a week
- Be accessible to all patient groups who could benefit from them, working to identify health inequalities and putting in place measures to significantly reduce these
- Have low, or no, waiting times and no unnecessary waiting
- Be developed in line with patient need, including locations and timings of services
- Encourage and empower service users to be actively involved in planning their own end of life care and support them to make choices
- Treat all service users and carers with dignity and respect
- Offer treatment and care that is evidence-based and consistent across services
- Be cost effective.

## Scope

The scope of this strategy includes adults (18+) with advanced progressive life-limiting disease and /or who are dying (last phase of life). However, we acknowledge that the transition from children's to adult services is particularly important, and we will continue to build relationships with providers of end of life care for children and to develop seamless pathways and services.

Although not directly in scope, other groups (such as people living with long term conditions, dementia and frailty), will also impact and be impacted by this strategy, particularly as we aim to increase advance care planning before people need end of life care.



# WHAT WE WANT TO ACHIEVE – 7 Key Outcomes

## OUTCOME 1:

***People in Leeds who need palliative and /or end of life care will be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care***

### Where are we now?

Working with people and providing personalised care that is guided by their individual goals, needs and preferences is a core principle of palliative and end of life care in Leeds. Central to this approach is having systems to support people to have honest well-informed conversations about their health, death, dying and bereavement; to say what matters to them, document this as an advance care plan and share it with services providing care, treatment and support.

Leeds was one of the first cities in the UK to establish an electronic palliative care co-ordination system (EPaCCS) over a decade ago. This enables the care preferences, treatment recommendations and other advance care plans of people approaching the end of their life to be shared in case they are too unwell to participate in decision making in the future.

We have subsequently introduced a digital version of the national “recommended summary plan for emergency care and treatment” (ReSPECT). This enables similar information to be shared, irrespective of someone’s diagnosis or prognosis, so that anyone at any time in their life can make their wishes known. More than 16,000 people have created a plan since its introduction in December 2018. The LPCN has supported the combination of EPaCCS and ReSPECT into a single record called Planning Ahead, which includes a ‘what matters to me’ section to enhance personalised care planning.

On-going education and training has enabled the workforce to offer and conduct these important and sensitive conversations in a supportive and person centred way. Specialist palliative care teams continue to collaborate with health and care colleagues across the city to improve recognition of people’s needs and support planning ahead.

This includes dedicated multi-disciplinary team meetings alongside quality improvement programmes, education and training with teams caring for people with heart failure and other cardiac disease, respiratory diseases like chronic obstructive pulmonary disease and lung fibrosis, neurological disorders such as Parkinson’s disease and motor neurone diseases, renal and hepatic failure, cancer, life-threatening conditions causing acute hospital admission and frailty.

This collaborative, personalised approach underpins the steady increase in the proportion of adults who die in Leeds with documented advance care plans and positive feedback in the bereaved carers surveys, with the majority of respondents replying that their loved one was cared for with dignity and died in the right place.

### Moving forward

Not everyone in Leeds with palliative and end of life care needs is recognised, and there is variation across the city in participation in advance care planning. Findings of an upcoming report into the use of EPaCCS carried out by the St Gemma’s Academic Unit of Palliative care will guide further quality improvement activity, education and training to ensure everyone has the opportunity to discuss, develop and share advance care plans. This will help to reduce health inequalities for groups of patients who are currently less likely to have recorded

advanced care plans in place. The development and implementation of the Planning Ahead template, with the increasing focus on ‘what matters to me,’ is an opportunity to empower people to have even more say in what their care is like whilst strengthening our collaboration with partners implementing the broader personalised care approach across Leeds.

Emerging digital developments such as Helm, the patient held digital record, may offer further opportunities to empower people to initiate and manage their advance care plans. On-going collaborations with digital partners will ensure we can make the most of emerging technologies.

Through continued LPCN collaboration with frailty, dementia, heart failure, respiratory and other long-term conditions, and other citywide work streams we can ensure individualised palliative and end of life care is embedded as a core part of services.



## OUTCOME 2:

***People in Leeds who need palliative and /or end of life care will have their needs and conditions recognised quickly and be given fair access to services, regardless of their background or characteristics***

### Where are we now?

We are committed to ensuring that all people in Leeds are able to access the right palliative and end of life care at the right time irrespective of who they are and where they live. In order to identify inequalities and drive improvement, we need robust systems to routinely collect and analyse data about access to, and experience of, care. We have collaborated with colleagues in public health, business intelligence, academia and population health management to understand what the existing data can tell us, identify gaps in existing data models, and to develop our metrics suite to improve data quality, include hospital alongside community data, and address diagnosis-related variation in advance care planning. However, there is still more to do.

We recognise the needs of different people can only be understood by working with them. To this end we have collaborated with organisations representing different communities across Leeds, supported the annual public health-led citywide Dying

Matters campaign and held a citywide community engagement event to guide the early development of the LPCN. We have worked with Leeds City Council and Healthwatch to conduct a city-wide bereaved carers survey to better understand experience of services.

We understand people from marginalised communities may require additional targeted services and support to ensure they are able to access care when and where they need it. We have started projects to understand what is required for people with a learning disability, people in prison, people experiencing homelessness or those from Gypsy and Traveller communities. As approximately 1 in 6 deaths are people with a diagnosis of dementia, Leeds has participated as one of three nationally funded regional sites aiming to improve palliative and end of life care for people with this diagnosis.

We work collaboratively across the city to promote equitable access: all specialist palliative care providers work to common

citywide referral criteria; Leeds Community Healthcare NHS Trust have a transparent service delivery framework for integrated palliative and end of life care; hospice and hospital specialist palliative care teams have collaborated to enhance equitable and timely transfer of care from hospital to both Leeds hospices; both hospices work to the same service specification and report their performance against common metrics to ensure consistency. Shared templates, tools and guidance promote consistent practice across settings. The quality improvement incentive schemes in primary care and ongoing training help to increase the use of these tools and templates.

### Moving forward

The recent Health Needs Data Update and EPaCCS reports have provided a greater understanding of inequalities and variation in participation in advance care planning and achievement of priorities such as preferred place of death. Whilst the majority of respondents to the bereaved carers survey described high quality across settings, it has also identified variation and indicated areas for improvement. It is vital that we address, and demonstrate measurable improvement in, those inequalities impacting on people from BAME groups, some areas of deprivation, men, and people under 65. All new citywide projects must address the issue of inequality. This will require engagement with current and potentially new partners across the healthcare, social care and crucially voluntary sectors.

Further collaborative work is required with partners across the city to enhance our reporting and data, for instance to include hospital and community ReSPECT activity and develop genuinely person-centred metrics concerning symptom and goal based outcome measures. Our data sets and metrics reporting need to be extended to ensure we can routinely measure known inequalities and understand access by groups that so far have not been analysed. The Health Needs Update makes specific recommendations about the development of a broader suite of outcomes measures, further analysis of known inequalities and variation with regards to EPaCCS work to explore the views and experiences of people with other protected characteristics such as LGBTQ+ people. Enhancing the bereaved carers survey and extending its scope across Leeds to cover all places where people die is also critical.

## OUTCOME 3:

### *People in Leeds who need palliative and /or end of life care will be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing*

#### Where are we now?

Over the last five years, Leeds has moved ahead in many areas that support people with palliative and end of life care requirements, enabling them to live well as they approach the end of their life and maximizing their comfort and wellbeing when they die. Much of this service improvement and transformation is now embedded within our routine services. We have:

- Created new palliative care lead roles within neighbourhood teams
- Established an end of life care home facilitator team
- Increased the number of non-medical prescribers and nurses able to verify death, in community, hospice and hospital settings, which ensures timely access to medication and minimises distress after someone has died
- Expanded specialist palliative care services in hospital, the community and hospices ensuring access to support

and advice 24/7 and seven day face-to-face clinical nurse specialist assessment across weekends and public holidays

- Established nurse led end-of-life beds in hospices to enhance timely access to hospice inpatient care
- Increased provision of syringe drivers to ensure symptom management across care settings
- Made available up to date and evidence-based symptom management guidance and training to care providers across Leeds
- Developed robust systems across care settings to ensure high quality individualised care for people in their last of days irrespective of whether they are dying in hospital, at home or a hospice.

Reflecting this, the majority of respondents to the bereaved carers survey expressed satisfaction with symptom relief, religious and cultural support and personal care in hospital, the community and hospices. In the last five years, the Care Quality

Commission has rated hospice services as outstanding at St Gemma's Hospice and good at Wheatfield's Hospice; end of life care provided by Leeds Teaching Hospitals NHS Trust and Leeds Community Healthcare NHS Trust has been rated as good.

#### Moving forward

It is essential that we maintain and improve the already high quality care provided by frontline teams, alongside the expert advice and treatment delivered by specialist palliative care services. This requires a commitment to on-going education, quality improvement, workforce and service development, collaboration with partners across the city and beyond, alongside sufficient funding.

Specific groups with cognitive and communication deficits, such as people living with and dying from dementia, may need further interventions targeted at identifying, assessing and managing symptoms. People from marginalised communities may need different approaches, guided by their specific lived experience, and we will work with these communities to develop these new approaches.

The role of care homes in the provision of palliative and end of life care, and the support needed to ensure high quality care across a range of different care providers, is ever more apparent and likely to increase as the population ages. Our experience during the first phase of the Covid pandemic has highlighted the need for further collaboration

with the care home sector. The 2020/21 GP contract, specifying the need for locally determined 'appropriate and consistent' medical input to care homes, provides a further opportunity to address the palliative and end of life care needs of residents, and we will work with primary care networks to ensure that this opportunity is maximised.

As the palliative and end of life care research base develops, it is essential that care and treatment remain evidence-based and up to date. Our existing links with academia, including the Leeds Academic Unit of Palliative Care, will enable us to develop and refine the process by which we ensure the emerging evidence base is translated into practice.

## OUTCOME 4:

### *People in Leeds who need palliative and /or end of life care will receive care that is well-coordinated*

#### **Where are we now?**

People approaching the end of their life receive care in multiple settings, moving between them as their goals and needs change. The establishment of the Leeds Palliative Care Network has provided a resourced, accountable and representative structure with links to key providers of health, care and support. It provides an integrated patient-centred approach to palliative and end of life care. This has enhanced our capacity to drive service improvements across the whole system, through collaboration between health and care providers, the voluntary sector, and community groups.

Shared advance care plans are central to coordinated palliative and end of life care, ensuring that critical information is available during emergencies and that people are not required to repeat information each time their care provider changes. Whilst electronic advance care planning tools (EPaCCS and ReSPECT) are embedded in practice, the information contained within them is not

available digitally to all health and care providers. Community plans are not visible in hospital electronic patient records, and ReSPECT plans created in hospital can be read, but not updated, by professionals outside hospital who have access to the Leeds Care Record. At present we are dependent on patient-held paper copies to ensure key information is available across all settings in an emergency.

The palliative care ambulance service enables safe, supportive, and timely transfer of care between settings by highly trained teams. We have collaborated with Yorkshire Ambulance Service, commissioners and the wider Leeds Palliative Care Network to maintain this highly valued service, secure sustainable funding, commissioning and governance arrangements, and have refocused clinical teams through transfer of care developments to use the service as effectively as possible. As part of regional improvement work, we have established a 24/7 specialist palliative care advice line for paramedic crews attending patients with

palliative and end of life needs to minimise the disruption of unplanned hospital admission, when hospital based interventions will not be of benefit, or are not wanted, optimising care in the person's preferred location.

#### **Moving forward**

To ensure that the right information is available at the right time and minimise duplication, it is vital that we continue to support the development of an integrated electronic advance care plan that can be used at any stage in a person's life, evolving as their needs and preferences change, and capable of being shared with and updated by any care provider so that the record of a person's wishes is always up to date. The LPCN has strong working relationships with key influencers leading digital development in Leeds and the region, and is well placed to ensure the integration of electronic advance care plans remains a priority and digital developments meet the requirements of people with palliative and end of life care needs.

An LPCN-led review of the coordination of palliative and end of life care for patients across the whole system is in development. Supported by Leeds Beckett University and funded by the Leeds Academic Health Partnership and NHS Leeds CCG, it aims to ensure people receive the right care at the right time in the place consistent with their wishes and preferences, avoiding the disruption of hospital admissions when they do not add value to care. This offers real

opportunities to join up services delivered by different care providers; minimise duplication and waste; promote flexible and responsive services; make the most of the skill set within and across health and care teams; and improve access to care, advice and support 24/7, particularly during the night, over weekends and public holidays.

The expansion and realignment of the existing discharge facilitation service with the health case managers supports this further. With improved capacity and capability, it presents an opportunity to enable more people to transfer from inpatient settings to their preferred place of care with continuing healthcare fast track funding to support them as appropriate. Continued participation in the citywide project to develop a Leeds single point of access presents an opportunity to help ensure that people get the right care at the right time in a user friendly way, to review current referral processes and empower patients to access care when they need it, and to provide their families (and professionals working with them) with a clear offer of the services available.

## OUTCOME 5:

### *People in Leeds who need palliative and /or end of life care will have their care provided by people who are well trained to do so and who have access to the necessary resources*

#### Where are we now?

The LPCN works with partners to ensure that education and training in palliative and end of life care have a high profile. We have clarified the skills and knowledge required of those delivering palliative care by implementing end of life care learning outcomes. These are helping organisations assess what their staff need and plan relevant training. For instance, within Leeds Teaching Hospitals, palliative and end of life care has been granted priority status, requiring all clinical staff to access a range of bespoke educational options and demonstrate completion as part of professional appraisal, and a training programme with associated learning outcomes has been developed for clinical nurse specialists.

To support organisations, we have well established programmes of education in communication skills, advance care planning, symptom management and care for dementia patients at the end of life. Increasing numbers of staff have accessed these programmes and we have also increased the number

of trained nurses across the system who are able to prescribe, verify expected adult deaths, and complete fast track referrals and do not attempt resuscitation forms.

Innovative ways of delivering training, including the tele-education and mentoring initiative Project ECHO, online programmes, videos and podcasts have enabled larger numbers of staff to access education and benefit from interacting with health care professionals from other settings. We've also established a central resource for education on the LPCN website, so information is easily accessible.

#### Moving forward

Having staff who are skilled and confident in palliative and end of life care underpins all that we want to achieve through this strategy. It is critical that all key staff are able to access robust and sustainable training programmes around communication skills, assessment, advance care planning, symptom management, comfort, family support and bereavement.

In order to tackle health inequalities in end of life care, it is crucial that we identify those staff groups who work with populations who are under-represented in advanced care planning and the receipt of specialist care. Having identified these groups, we can tailor our training offer and delivery to ensure that it meets their needs and to ensure that they are better able deliver support, advice and care to the communities that they serve.

Capacity, both of trainers to deliver and staff to attend education, remains challenging. However, the recent provision of additional education funding to support citywide strategic planning and delivery of education presents an opportunity to:

- Develop a system to better understand and identify learning needs across the city and formulate a key skills training plan for staff at all levels and who work with a broad diversity of patient groups
- Develop new and innovative ways of delivering education and training which align with staff working patterns
- Evaluate the current learning outcomes and explore ways of ensuring training is put into practice
- Develop consistent, measurable standards and robust evaluation methods for quality education and training and ensure it is delivered by skilled and qualified providers
- Develop the current education resource to help staff understand what training they need and how to access it.



## OUTCOME 6:

### *People in Leeds who need palliative and /or end of life care will be assured that their family, carers, relatives and others are well supported during and after their care, and that they are kept involved and informed throughout*

#### Where are we now?

We recognise that the well-being of friends, family and other loved ones is a priority for people approaching the end of life who worry about the impact of their health on the people important to them. Moreover, loved ones provide care that enables people to stay in their preferred location that would otherwise need to be delivered by health and care providers; whilst it can be rewarding, this role may have enduring impact on their health and well-being.

Support for and engagement with the people close to someone approaching the end of life is a core part of palliative and end of life care in Leeds, helping to alleviate the emotional, social, spiritual, psychological, financial and physical impact of witnessing a loved one's health deteriorate, care-giving and bereavement. However, the bereaved carers survey found variation in the support offered and identified areas for improvement, chiefly in hospital and community settings.

Adult social care, part of the Adults and Health Directorate of Leeds City Council can assist in many ways and works closely with a broad range of health partners and other agencies across the city. Adult social care takes a strengths-based approach to supporting residents and their carers, assisting in connecting people with community resources, signposting to organisations and by providing assessments under the Care Act 2014. This may lead to a formal package of domiciliary support at home or placement in a residential setting if appropriate, as well as resources to

support carers.

In Leeds, a range of organisations from health, care and voluntary sectors collaborate to provide this support. For example, the Leeds Oak Alliance (LOA), a partnership of five city-wide third sector organisations (Care & Repair Leeds, Carers Leeds, Age UK Leeds, St Gemma's Hospice and Sue Ryder Wheatfields Hospice) has been established to improve information, support and care for individuals, families and carers living with frailty and at the end of life. By working together, the LOA aims to achieve more in collaboration than they can as individual organisations.

The partnership approach adopted by the LOA is most visibly represented by the third sector hub located at St James's University Hospital. The hub, staffed by colleagues from across the alliance, offers on-site direct support and information to people receiving treatment, their family members and carers, as well as staff working with LTHT. The hub team will also take referrals where the support needs or advice required necessitates longer-term interventions from one or more of the LOA partner organisations.

A range of services can be accessed through the LOA:

- Carers Leeds provides information and advice for all adult carers and can link them into support services. The organisation also provides individual and group bereavement support for up to a year after the person they cared for died

- St Gemma's and Sue Ryder Wheatfields hospices provide support to the friends and family of people in their care, and this continues after death
- Age UK Leeds provides a range of support and advice in particular assisting people to access the full range of financial benefits to which they may be entitled and offering help that can reduce social isolation and loneliness which may result from bereavement
- Care & Repair Leeds offer a range of services that improve people's living conditions, promote independence through enhancing health and quality of life, and enable people to remain living in their own home or return to their home following discharge from hospital.

Leeds Bereavement Forum (LBF) signpost people to over 100 support organisations, both locally and nationally. Bereavement support from a range of providers within Leeds includes peer group bereavement support or individual sessions with a counsellor, depending on what the services offer and what people prefer. LBF also run [monthly "death cafes"](#) in partnership with Leeds Libraries. Whilst these are not bereavement-specific groups, they do give people the opportunity to talk about their bereavement. Their Dying Matters training course is open to staff and volunteers at Leeds City Council, third sector organisations and council commissioned services. The course includes end of life as well as bereavement information and training.

In response to bereaved carers survey feedback, Leeds Teaching Hospitals launched the SUPPORT campaign to establish a consistent approach for the provision of practical information and support to the relatives and friends of dying patients. The appointment of a bereavement nurse has provided a direct point of contact for bereaved people and enabled tangible improvements. These include early opportunities to discuss

concerns or ask questions about care; the provision of Trust-wide bereavement cards and information to all bereaved relatives; and the analysis of all complaints relating to people who die in the Trust, with feedback provided to clinical teams to drive improvement.

#### Moving forward

In order to raise the profile of carers looking after people at the end of life and who experience bereavement, it is critical that we inform and influence the Leeds Carers Strategy to ensure that their needs are addressed. The needs of loved ones can only be properly understood and met if they have a voice in the design and development of palliative and end of life care services, necessitating a pro-active approach to co-design.

Employers within Leeds need support and encouragement to enable people to have time off to care for or to be with loved ones at the end of life and be given a period of paid leave of absence to do so. More support for bereaved carers to return to work if they wish is also needed.

Continued funding and support for third sector and charitable organisations whose income is less secure or relies on public income generation is essential, reflecting the broad range of organisations offering support. The collaborative approach demonstrated by the Leeds Oak Alliance highlights the commitment and willingness to develop innovative ways of working that exists within the third sector in Leeds; this should be harnessed and supported to ensure that the care and support provided meets the identified needs of the community.

## OUTCOME 7:

***People in Leeds who need palliative and /or end of life care will be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed.***

### Where are we now?

Despite it being the one certainty we all face, death and dying continue to be taboo subjects in mainstream British culture. Being open to the fact that we all die makes planning for end of life care much easier, but unsurprisingly, people are often not prepared for the last years of life. Only one in four has talked to someone about their own end of life wishes and fewer than one in ten have written down their wishes about their future care<sup>7</sup>.

The 2013 Health Needs Assessment for End of Life Care identified the need for a citywide campaign to encourage people to talk about death, dying and loss. In response Leeds has successfully adopted the national Dying Matters campaign, drawing from a strong collaborative network of local organisations represented in the Dying Matters Partnership, tailoring it to the needs and goals of the city, to raise awareness of death and dying and challenge taboos. In 2016 this success was recognised nationally when the group

received The National Council of Palliative Care Dying Matters Awareness Initiative Award.

### Moving forward

Engaging a city as large and diverse as Leeds on a subject that most people don't like to talk about is a challenge. There are also cultural differences in perceptions about and reactions to death and dying. Despite limited capacity, we remain committed to making a difference for all communities of Leeds. Central to this collaboration is engaging valuable resources such as a social prescribing and a strong third sector, which are uniquely placed to support person-centred care and engage people in conversations around death and dying.

Taking into account what people in Leeds have told us matters most about end of life care during recent engagements, we aim to develop, implement and evaluate a programme of work, delivered through the Dying Matters Partnership. This will engage

with communities about end of life planning and addresses the inequalities that exist for different groups to ensure that:

- People in Leeds will feel more comfortable talking about death, dying, grief and loss and will discuss their end of life wishes with family members and/or health and social care professionals, who in turn will focus on what is important to the person at end of life
- People will plan for their death, including writing their will and communicating their funeral wishes
- We work with communities to ensure the diverse needs, and wishes of people at end of life are met and ensure they are supported by the people who are closest to them
- People are ready, willing and confident to have 'better conversations' about living and dying well and support each other in emotional and practical ways
- We work together to improve the quality and continuity of the care experience.



<sup>7</sup> [https://www.dyingmatters.org/sites/default/files/files/NCPC\\_Public%20polling%2016\\_Headline%20findings\\_1904.pdf](https://www.dyingmatters.org/sites/default/files/files/NCPC_Public%20polling%2016_Headline%20findings_1904.pdf)

# KEY ENABLERS

In order to achieve the outcomes we've outlined, we've identified four essential enablers:

- Understanding population needs
- Medicines management
- The use of technology to improve care
- Workforce

## Understanding population needs for care

Around 5,000 people who could benefit from palliative or end of life care die in Leeds each year. However, challenges around data, information governance and lack of shared systems and information currently mean that we don't fully understand what they need or wish for at the end of life.

As well as improving the quality of care we could provide for people, population data would provide invaluable information for strategic development, service improvements and resource investment by giving us more evidence, clarity and certainty. This in turn would help us more consistently identify those who would benefit from palliative care, improve access for them, increase choice and result in better care.

Leeds is very fortunate to have an [Academic Unit of Palliative Care \(AUPC\)](#), a partnership between St Gemma's Hospice and the University of Leeds School of Medicine, in addition to resources such as the Leeds Data Model and established collaborations with organisational business intelligence and informatics teams. National and local research undertaken by the AUPC, alongside metrics development, routine collection and analysis of advance care planning data and engagement in population health management has helped to inform changes to Leeds services and identify information deficits – for example understanding local

population demand for end of life care and the EPaCCS data collection system and the training required by professionals that use it.

Working across the system, by analysing population data, patient outcomes, research, clinical audit and feedback from patients and carers, we will increase our understanding of our city's palliative care needs and will use this understanding to further develop services and to tackle health inequalities.

## Medicines management

We want to make sure that medication issues are not a barrier to people receiving the best care and management of their symptoms, wherever they are being cared for.

Currently, we have a medicines management lead for end of life care in the city who helps ensure that medication issues are identified, reviewed and resolved. We also have a system for producing palliative care guidance that links in with medicines governance processes already established across the city to ensure clarity and consistency. We will continue to work with partner organisations to ensure work isn't duplicated but is supported and implemented effectively.

We've improved how we transfer medications from hospital to hospice and have supported the development of a service for the urgent supply of palliative care drugs by community pharmacies. Increased use of electronic prescribing by community teams will help ensure accurate and safe dispensing. In addition, we provide training and resources for GPs, paramedics, and clinicians at Leeds and York Partnership NHS Foundation Trust.

We've begun a project to review anticipatory medication at the end of life and will also be engaging with care homes to address specific end of life medication issues. Together, our

work on medicines management will help ensure that the right drugs are available at the right time in the right quantities across care settings and help to reduce unnecessary waste.

## Use of digital technology to improve care

Taking maximum advantage of digital solutions and innovations will be core to delivering our strategy.

The emerging digital landscape offers real opportunities for:

- Direct clinical care
- Co-ordination of services
- Workforce efficiencies
- Communication
- Patient empowerment and self-management
- Quality improvement
- Understanding the population needs and impact of services
- Education and research.

In Leeds, we have made significant progress in a number of areas, particularly around the uptake of digital advance care planning tools, shared electronic patient records and electronic prescribing. We have also established virtual referrals, innovative remote-education and training and an enhanced website for the public and professionals.

The LPCN has established key relationships with digital partners within Leeds and across the region in order drive further development and improvement.

Potential areas for future development include the introduction of artificial intelligence, processes to aid the recognition of patients with palliative care needs and /or approaching the end of life, and the use of tele-health to further support patients in their chosen place of care.

In order to make the most effective use of opportunities presented by digital working, the LPCN may need to enhance its digital expertise, capacity and leadership.

## Workforce

Our health and social care workforce is our most important resource. An extensive range of staff roles with a wide variety of skills and specialisms are involved in caring for dying people. We want to ensure they have the skills, confidence and resilience they need to deliver holistic, compassionate care for dying people and their families, regardless of where they are cared for.

At the same time, our workforce is also one of our biggest challenges. Difficulties recruiting and retaining health and care staff and maintaining stable teams with manageable workloads is a local, regional and national problem that poses a real threat to the delivery and quality of care over the next 10 years. Addressing this problem requires work at a local, regional and national level.

Locally, all partner organisations are part of the 'One Leeds Workforce' group, which aims to create a single, joined up approach for innovative learning and development for everyone working in the city's health and care services. We are committed to working together to make employment in the Leeds health and care sector, and particularly in palliative and end of life care, an attractive career. New ways of working between different care providers are making better use of the skills of some existing staff and we're looking at developing new roles within health and care. This may result in further joint appointments and integrated posts. We're also committed to addressing inequalities in recruitment, pay and career progression across the city to ensure staff feel valued and supported.

Increasingly, providers of palliative and end of life care are working collaboratively to recruit new staff together and offer rotational posts to broaden staff experience and help them find their ideal role and place to work, so keeping them within the Leeds system. We're also looking at how we can expand training to help staff feel more confident and competent to care for people who are dying and their families.

## ACCOUNTABILITY AND GOVERNANCE

Delivering the outcomes set out in this strategy will be the responsibility of dedicated working groups consisting of citywide partners and operating within the Leeds Palliative Care Network. Progress against delivery will be monitored by the Leeds Palliative Care Strategy Oversight Group which is attended by senior colleagues from provider organisations from across the city and is chaired by commissioners from the Leeds Clinical Commissioning Group.

## HOW WE WILL MEASURE SUCCESS

In order to ensure that the actions that we are taking are helping to improve services, improve patient and family experience and deliver the seven outcomes set out in this document, we will track our progress against the following metrics:

- Increase the **% of patients who died with an EPaCCS record** (to be superseded by **% of patients who died with an Electronic Advance Care Plan, incorporating EPaCCS and ReSPECT when data is available**)
- More patients will receive effective care, treatment and symptom control in the community. This will be demonstrated by a reduction in the **number of unplanned hospital admissions in last 90 days of life**
- Services will be set up to enable more patients to achieve the wishes set out in their advanced care plans. There will be an increase in **% of patients who achieved their preferred place of death (PPD)**
- More carers will be well supported during the last phase of their loved one's life and services will be put in place to ensure that symptoms including pain are well managed. This will be measured by: **% satisfied/very satisfied with symptom management according to the bereaved carers survey (combine all symptom scores from across all settings)**

This reflects high level metrics that we are currently able to measure on a routine basis. We are committed to further developing a broad suite of metrics to drive improvement for all people in Leeds, particularly in regard to inequalities identified in the HNA data update 2019.

## NEXT STEPS

Following publication of this strategy, colleagues from across the Leeds Palliative Care Network will refresh the work programmes that they are currently delivering in order to ensure that they are aligned with the priorities and outcomes that we have set out. Each LPCN work stream will develop a plan identifying short, medium and long term actions which will help to deliver the seven outcomes that we are aiming for.

Progress against the action plans will be measured periodically and reported back to the Leeds Palliative and End of Life Care Strategy Oversight Group. It will also be summarised in the LPCN's annual report. The action plans will be kept up to date and will develop as the local and national context shifts over the next five years.

Where investment is required to deliver the priorities and actions identified, the LPCN will work with providers to consider a range of options including reallocating funds, seeking funding through national and local grants, and securing further CCG / statutory investment through discussion with commissioners. Where seeking to identify funding for developments, the LPCN will ensure alignment with the seven key outcomes set out earlier.

### Useful resources

- [Care of dying adults in the last days of life NICE guideline \(NG31\)](#)
- [Care of dying adults in the last days of life Quality standard \(QS144\)](#)
- [End of Life Care for Adults: service delivery Quality Standard \(QS13\)](#)
- [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#)
- [The NHS Long Term Plan](#)
- [Leeds Health and Wellbeing Strategy 2016-2021](#)
- [Leeds Health and Care Plan](#)
- [West Yorkshire and Harrogate 5 Year Strategy for Health and Care](#)
- The Leeds Palliative Care Network website: <https://leedspalliativecare.org.uk>

### Abbreviations

<b>AUPC</b>	Academic Unit of Palliative Care	<b>HNA</b>	Health Needs Assessment
<b>BAME</b>	Black Asian and Minority Ethnic	<b>IT</b>	Information Technology
<b>CCG</b>	Clinical Commissioning Group	<b>LGBTQ+</b>	Lesbian, Gay, Bisexual, Transgender, Queer/ Questioning, Others
<b>DHSC</b>	Department of Health and Social Care	<b>LOA</b>	Leeds Oak Alliance
<b>DNACPR</b>	Do Not Attempt Cardio Pulmonary Resuscitation	<b>LPCN</b>	Leeds Palliative Care Network
<b>EoLC</b>	End of Life Care	<b>LTHT</b>	Leeds Teaching Hospitals Trust
<b>EPaCCS</b>	Electronic Palliative Care Coordination Systems	<b>NCPC</b>	National Council for Palliative Care
<b>GP</b>	General Practitioner	<b>PPD</b>	Preferred Place of Death
<b>HCA</b>	Health Care Assistant	<b>ReSPECT</b>	Recommended Summary Plan for Emergency Care and Treatment



# APPENDIX 1: Health Needs Assessment Summary

## Leeds City Council health needs data update: end of life care services for adults in Leeds, December 2019

This Health Needs Data Review is an update on the Health Needs Assessment (HNA) on End of Life Care Services in Leeds published in 2013. The Health Needs Assessment 2013 outlined some of the key end of life statistics to inform a number of recommendations for change. This review provides an update of the most up-to-date information relating to End of Life Care and considers the changes that have been made, to see where improvements have been made, and where there are still challenges in Leeds. This review looks at Leeds demography, especially in relation to End of Life; a comparison of data from the Health Needs Assessment 2013 to current data; a qualitative review of the data.

A summary of the key findings from this update are as follows:

- Common causes of death in Leeds for adults are: cancer (27.1%), circulatory disease (26.7%) and respiratory disease (12.4%).
- Cancer deaths for people aged 65 and over are projected to rise by 16.1% (from 1,836 in 2011 to 2,132 in 2031). Non-cancer deaths expected to rise by 16% (from 4,523 to 5,249).
- The trend in where people died continues to change. Hospital deaths in Leeds have decreased by 10.6% since 2003 (from 56% to 45.4%), whilst the proportion of deaths at home, in hospice and in a care home have all increased.
- There has been an improvement in the number of people who have discussed

their care preferences and treatment recommendations which were shared in the Electronic Palliative Care Coordination Systems (EPaCCS) record. 45% of people that died in Leeds in 2018/19 had an EPaCCS record (2627 out of 5841 people). A primary care quality improvement programme has been developed to further improve this and increase the number of people offered advance care planning.

- Three quarters (73%) of people achieved their preferred place of death between April 2018 and March 2019. This demonstrates that when preferred place of death is discussed during advance care planning, and shared effectively, people are likely to die in a place of their choice.
- 1 in 3 people who had an EPaCCS record would prefer to die in their own home (31.8%). It is also the place where a large proportion of people did die at home in 2018-19 (26.8%), however there were 5%, or 131 people during this 12 month time period, who would prefer to die at home, that did not achieve it.
- There is a big gap between the proportion of people who said they would prefer to die in a hospital (1.4%) compared to those that did die in a hospital (19.9%). This equates to around 484 people during this 12 month time period that died in a hospital when this was not their preferred place of death.
- People aged under 65 are slightly less likely to have a preferred place of death recorded or die in their preferred place of death
- Males are slightly less likely to have a preferred place of death recorded. Males are also less likely to die in their preferred place of death when compared

to females (70% and 76% respectively). A higher proportion of males die in hospital when compared to females.

- Lower proportions of Mixed (e.g. Mixed - Any other mixed background; Mixed - White and Asian; Mixed - White and Black African; Mixed - White and Black Caribbean) and Black ethnic groups have a preferred place of death recorded and die in their preferred place of death when compared to other ethnic groups.
- Some areas have a lower proportion of people dying in their preferred place of death (e.g. LS2, LS4, LS23).
- Feedback from service users and carers showed that there were high levels of satisfaction with care provided across all settings especially in relation to management of pain and other symptoms, and privacy and dignity.
- The qualitative review demonstrated that the majority of health and care professionals that responded felt that progress had been made against the recommendations of the 2013 HNA. However, a few respondents also felt that there was still room for improvement.
- Responses suggested that the area for greatest improvement: was around the recommendation to 'Invest further in community services to support increasing care outside of hospital'. Whilst some of the comments showed that investment in community service had been made, capacity was still stretched and further investment was needed.

A summary of the recommendations from this updated HNA are as follows:

Implications for the end of life care strategy:

- Resources and services - ensure that sufficient resources and services are in place to meet the needs of increasing numbers of people dying in Leeds.
- Communication - Increase the number of people offered quality conversations about advance care planning. Ensure these conversations happen regularly with people at end of life so that goals

and preferences can be kept up to date and accurate and their care is tailored to their needs.

- Outcomes – achieving preferred place of death is only one of a number of outcomes important to people approaching the end of life. Leeds need to develop a broader suite of patient centred outcome measures to guide care and service development.
- EPaCCS – Further develop tools for digital sharing of patients' treatment recommendations and care preferences to incorporate patient goals and priorities and emerging initiatives such as ReSPECT. The digital infrastructure needs to be developed to ensure electronic records are accessible across all care settings.
- Unique referrals – collect data about unique referrals on an annual basis to enable analysis to be completed and trends explored.

Gaining a deeper understanding about people at end of life:

- Conduct further analysis in order to identify whether health inequalities exist between those who do and do not have an EPaCCS record.
- Develop a deeper understanding about the complex nature of people at end of life, this will enable a more accurate picture of where growth needs to be for end of life care.
- Gain further insight into why inequalities exist in relation to end of life for different equality groups (e.g. under 65's and 65-74, males and mixed and black ethnic groups).
- Explore why a higher percentage of men die in hospital than women and whether this impacts on the lower levels of males dying in their preferred place of death.
- Explore the views and experiences of patients and carers from other protected characteristics for example LGBT and people experiencing a disability.

## APPENDIX 2: Key Data Informing the Strategy (up to Q2 2020/21)

This document provides a summary of palliative and end of life care data as it relates to metrics described in this strategy. It is largely derived from quarterly Electronic Palliative Care Co-ordination System reports provided by the NHS Leeds CCG Business Intelligence Team alongside additional analysis provided by Public Health, Leeds City Council and the Academic Unit of Palliative Care, University of Leeds, in addition to the Bereaved Carers Survey supported by Healthwatch Leeds.

### Prevalence of Advance Care Planning

#### Metric

**Percentage of patients who died with an EPaCCS record** (to be superseded by % of patients who died with an Electronic Advance Care Plan, incorporating EPaCCS and ReSPECT when data is available)

**Source: NHS Leeds CCG EPaCCS report**

**Where we are now: 53%**

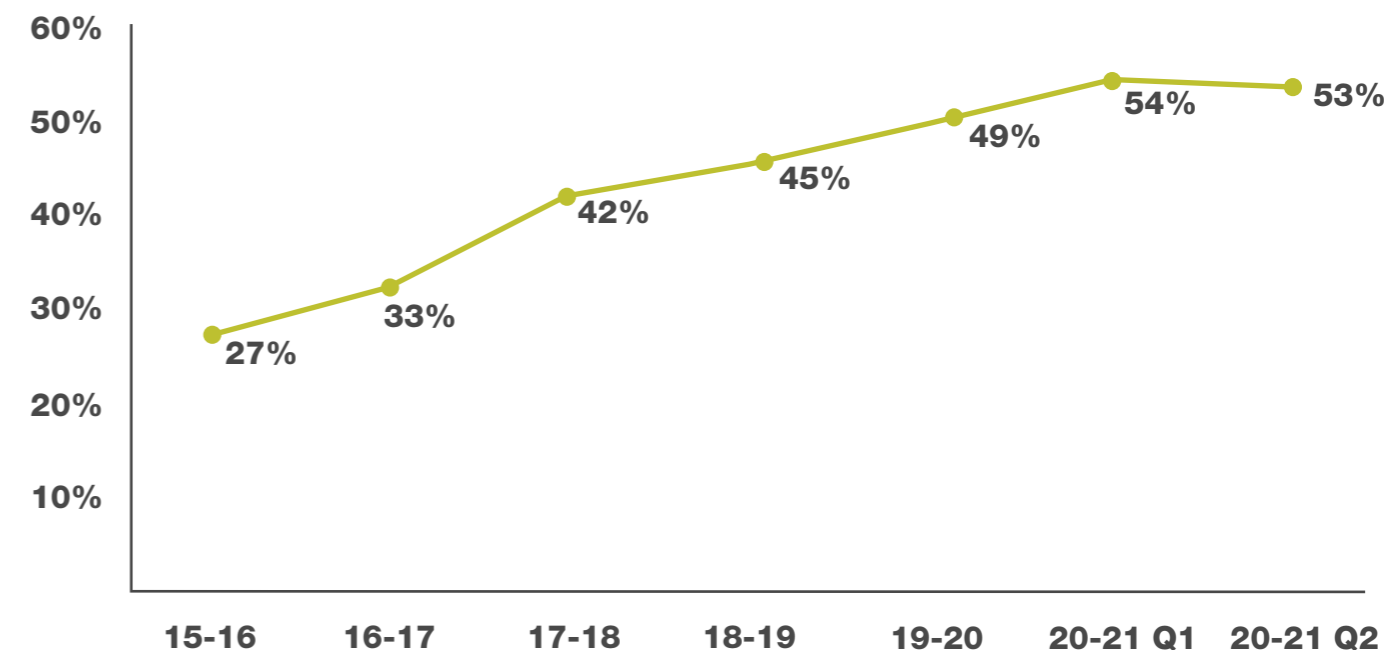
Advance care plans, detailing care preferences and recommendations, shared between all health and care providers are central to the delivery of well-co-ordinated personalised palliative and end of life care. The Electronic Palliative Care Co-ordination System (EPaCCS) and more recently the Recommended Summary Plan for Emergency care and Treatment (ReSPECT) have been adopted in Leeds to promote

effective sharing of advance care planning. Current reports draw on data from EPaCCS templates in community electronic records and Secondary Use Service hospital data; they do not include ReSPECT; though work is in progress to address this.

In Leeds, there has been an increase in the proportion of adults with an EPaCCS record in place at death, from 26.9% in 2015 - 2016 to 50% in 2018-2019 (AUPC). This has been maintained with 49.3% of adults who died in 2019-20 having EPaCCS and 54% in quarter one and 53% in quarter two 20-21 (NHS Leeds CCG)(Graph 1). A recent systematic review reported up to 54% of patients known to specialist palliative care services as having an EPaCCS record (Leniz et al, 2020).

These figures describe the proportion of all adults who die, rather than all adults whose death is expected. It is estimated that 25% of all deaths are due to sudden acute causes and cannot be anticipated (Murtagh et al, 2014). Of the 75% of adults whose deaths that can be planned for, at least two-thirds in Leeds currently benefit from advance care planning. This may be an underestimate, as reports do not include people whose only advance care planning is recorded as ReSPECT. It is critical that within the next five years the LPCN works to identify, understand and optimise access to advance care planning for the missing one third of adults and enhance reporting to reflect the planning offered by all providers.

Percentage of Adults in Leeds who died with EPaCCS in Place



### Unplanned admissions in the last 3 months of life

#### Metric

Percentage of people with three or more **unplanned hospital admissions in last 90 days of life**

**Source: NHS Leeds CCG EPaCCS report**

**Where we are now: 5% of adults with an EPaCCS record**

Unplanned hospital admissions in the last 90 days may reflect poor recognition of people at risk of death, poor planning and provision of services and poor communication, co-ordination and information sharing. The proportion of people with three or more unplanned admissions is impacted

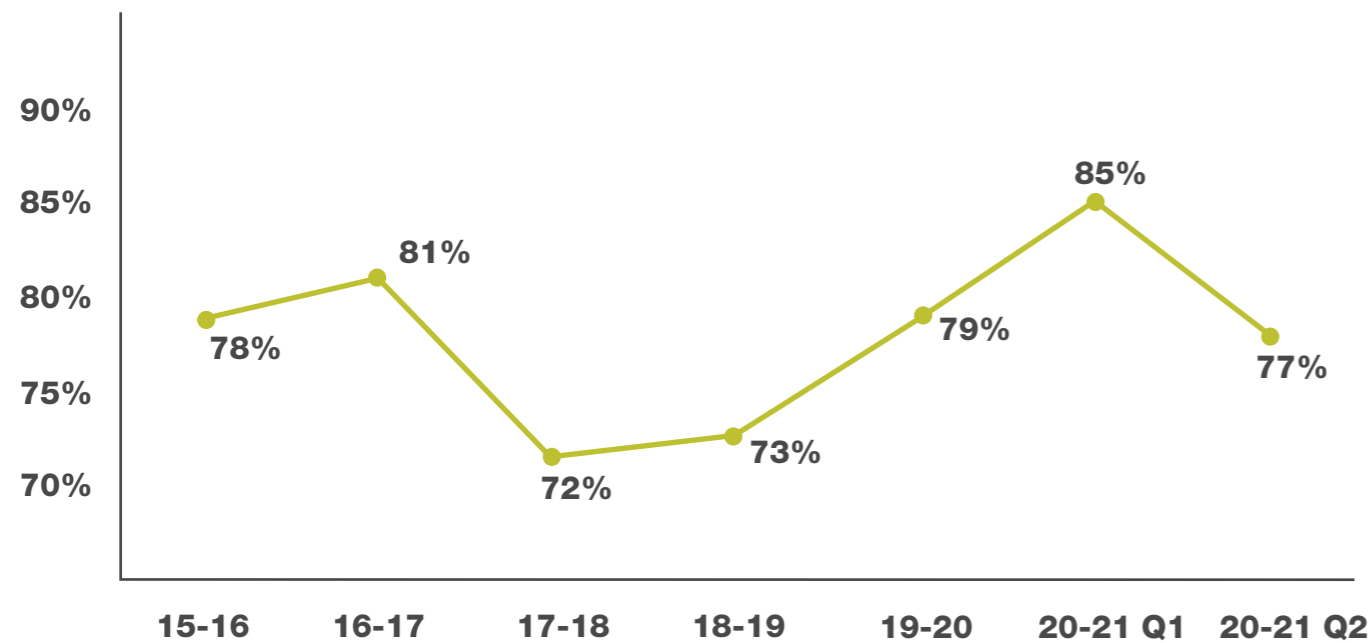
by ethnicity, diagnosis, sex, age and deprivation. In 2018, 7.8% of all those who died in England had three or more unplanned hospital admissions and this had increased by 33.9% from 5.6% in 2009 (PHE, 2020). Aggregated data from 2014-18 shows that in Leeds 6.5% had three or more admissions compared to a national median of 7.5% (4.5-12.3) and a North East and Yorkshire median of 7.8%. The smallest percentage reported was 4.1% in NHS South eastern Hampshire CCG (PHE, 2020).

Data specific to people in Leeds with EPaCCS has only been reported since 19-20. It shows that 7% had 3 or more emergency admissions in 19-20 and 4% in quarter one and 6% in quarter two 20-21 (NHS Leeds CCG).

### Achievement of preferred place of death

**Metric**  
**Percentage of patients who achieved their preferred place of death (PPD)**  
**Source: NHS Leeds CCG EPaCCS report**  
**Where we are now: 81% with a preferred and actual place of death recorded**

**Achievement of Preferred Place of Death**



This year achievement of preferred place death shows early signs of returning to 2016-2017 levels having dipped in the intervening years (NHS Leeds CCG). As a comparison, a recent systematic review of EPaCCS reported achievement of preferred place of death between 55% and 79% (Leniz et al, 2020)

Analysis shows those wishing to have a home death had the lowest level of achieving this preference (69.1%) when compared to those achieving their preferred place of death for hospice (81.3%), care homes (85.6%) and hospital (89.8%) (AUPC). Of note a small minority of patients (2.3%, 2019-20) with an EPaCCS record specify hospital as preferred place of death but

a greater proportion die in hospital (20%, 2019-20) (NHS Leeds CCG).

It is important to note this analysis may not fully reflect achievement of preference, particularly if they change close to death, as it does not include data documented in LTHT ReSPECT records. Moreover, not all people with an EPaCCS record have a preferred and/or actual place of death recorded. In 2019-20 15% of adults who died with an EPaCCS record did not have a preferred place of death recorded and 12% of records lacked an actual place of death. People can also specify first and second choice place of death preferences in EPaCCS but current reporting only considers achievement of their first choice.

### Carer's satisfaction with symptom management

**Metric**  
**Percentage satisfied/very satisfied with symptom management according to the Bereaved Carers' Survey (combine all symptom scores from across all settings)**  
**Source: Bereaved Carer's Survey**  
**Where we are now: Average Pain-91.5%, Average Other symptoms- 90%**

Leeds does not currently collect patient reported clinical outcomes across all providers. The Bereaved Carers Survey provides a proxy assessment of care quality including symptom management in the last days of life for adults receiving care from neighbourhood nursing teams and primary care, LTHT or a hospice. The survey is time limited, conducted over 3 months, with a variable response rate (22%-79%, 2019-20) across organisations.

Satisfaction with pain management and with management of other symptoms varies with place of care, higher in hospices compared to community and hospital settings, ranging from:

#### 2018-19

- Average across all settings, 92.8% (range: 86% -100% satisfied to very satisfied with pain management)
- Average across all settings, 91.3% (range: 83-100% ) satisfied to very satisfied with management other symptoms

#### 2019-20

- Average across all settings, 91.5% (range: 86% - 97%) satisfied to very satisfied with pain management
- Average across all settings, 90% (range: 80-100%) satisfied to very satisfied with management other symptoms

## Equality and Diversity

### Ethnicity

Compared with Leeds ethnicity demographic data, there may be a slight overrepresentation of patients coded as White amongst people with an EPaCCS record in place in 2018. All other groups may be underrepresented against the city demographic data. However:

- 4.42% of data is missing, which may have affected the distribution of ethnicity codes further if they were available (AUPC)
- this compares 2018 EPaCCS data to 2011 census data, which may have changed
- this is based on whole population census data which may have a different ethnic make-up to the population that die

Ethnicity	Number of Patients	Proportion of EPaCCS records	2011 census proportion
White	5131	87.55%	85.0%
Mixed/Multiple ethnic groups	15	0.25%	2.7%
Asian/Asian British	131	2.23%	7.7%
Black/African/Caribbean/Black British	70	1.20%	3.5%
Other ethnic group/not defined	255	4.34%	1.1%
Missing data	259	4.42%	-

In a secondary analysis of 2018-19 EPaCCS in the Health Needs Data Update people of black and mixed ethnicity were less likely to have preferred place of death recorded and achieve preferred of death if recorded than all other ethnic groups (Public health, LCC):

- Preferred place of death recorded: 63.6% (black) and 54.5% (mixed/multiple ethnic groups) vs. 75.1% (all other ethnic groups)
- Preferred place of death achieved: 63.6% (black) and 57.1% (mixed/multiple ethnic groups) vs. 75.4% (all other ethnic groups)

Focussed action to understand and address inequalities in EPaCCS uptake, achievement of care preferences and access to other key elements of P&EoLC is needed.

### Deprivation

The Health Needs Data Update found no overall correlation between deprivation and achievement of preferred place of death however of the three postcode districts with achievement of less than 60% two were in more deprived wards (LS2/LS4).

### Sex

There has been a consistent pattern of women accounting for a greater proportion of people with EPaCCS (AUPC):

- 2014-15: 52% female and 48% male
- 2018: 55% female and 45% male

Whilst, this may in part reflect the population of Leeds (50.9% female, 2019 Leeds Observatory/ONS) this may also reflect engagement of men with advance care planning. Suggestive of this, lower proportions of men had a preferred place of death recorded and achieved (Public Health, LCC):

- Preferred place of death recorded: 74.3% male vs. 75.9% female
- Preferred place of death achieved: 70.1% male vs. 75.7% female

### Age

Of all adults who die with an EPaCCS, under 65's are the least likely to have a preferred place of death (PPoD) recorded or die in their preferred place of death (Public Health, LCC):

- Preferred place of death recorded: 72.5% vs. 74%-76.4% for those over 65 years of age
- Preferred place of death achieved: 71.3% vs. 72.1%-75.2% for those over 65 years of age

### Diagnosis

The proportion of people with EPaCCS who have had a cancer diagnosis recorded at any time within their GP record has shown signs of falling: 61% 18/19, 58% 19/20, 47% Q1 2021 and 62% q2 20-21 (NHS Leeds CCG). Of note, the presence of a cancer diagnosis does not necessarily mean that person died from cancer, or that this was their main or contributory palliative care diagnosis.

In the 2018 analysis of EPaCCS data around a quarter of all patients with an EPaCCS had a dementia diagnosis recorded, with three quarters having at least one long-term condition other than dementia (AUPC). In 2019 dementia was cited as cause of death in 12.8% of deaths in (ONS). Monitoring cancer diagnosis alongside presence of a long term condition, frailty and dementia codes will enable us to ensure advance care planning is offered to the majority of people in Leeds regardless of diagnosis and cause of death.

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