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Palliative & End of Life Care Strategy 2021-2026



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This strategy has been co-designed with input from a wide range of partners and voluntary organisations, taking into account the experiences and insight shared by individuals, relatives and local people.



Primary Care Networks

Integrated Care Partnerships



Foreword

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“In Spring 2020, I was appointed as the Executive Lead for End of Life Care for Surrey Heartlands, alongside Dr Sian Jones as Clinical Lead. We were asked to work with partners to develop a strategy and a set of ambitions to improve palliative and end of life care across Surrey Heartlands.

The care a person receives at the end of their life - and how and where they receive it - can not only make it easier for them as an individual but it can also have a profound impact on their family, friends, loved ones, and the people that deliver the care. It can also leave a lasting impression of the

health and care system on all those involved.

Surrey’s Health and Wellbeing Strategy identifies ‘helping people in Surrey to lead healthy lives’ as one of its high level strategic priorities, with partners working together to improve outcomes across the county. A key focus within this is to help people to live independently for as long as possible and to help them die well.

We have a wide range of providers involved in providing palliative and end of life care across Surrey Heartlands. Currently end of life care looks different in different parts of Surrey, with different standards and services across different providers. The aim of this strategy is to look at the collective ambitions we want to achieve across Surrey Heartlands as an Integrated Care System so that Integrated Care Partnerships and local partners can then work together to plan and design the right services for their local communities to realise these ambitions and enhance end of life care for our whole population. We are also working closely with colleagues across other parts of Surrey, including the Frimley Integrated Care System, to ensure our ambitions and priorities are aligned across the whole county.

In developing this strategy we have worked closely with a range of organisations that are involved in providing palliative and end of life care in Surrey, their staff, local voluntary organisations and other partners. We have also looked at previous research in this area and sensitively carried out our own insight work with individuals who are receiving end of life care and relatives - and their experiences have been invaluable in helping us to develop this strategy, making sure individuals and their families and carers are at the centre of our plans to enhance end of life care across Surrey.

At an unprecedented time as we continue to work together in our response to the Covid-19 pandemic, I have been hugely impressed by the willingness of partners to come together to find solutions and provide the best possible care.

With our shared ambition, and the care and compassion we see every day from frontline staff, I believe that together we can make a real difference to the end of life care experience of our citizens and their loved ones for years to come.”

Vicky

Vicky Stobbart
Executive Lead for End of Life Care
Surrey Heartlands Integrated Care System

Executive summary

Improving palliative and end of life care has been identified as a priority of the Surrey Health and Wellbeing Board. The publication of this strategy is the culmination of many months of work that has brought together partners involved in every part of end of life to look at how we can further enhance palliative and end of life care for our citizens.

In developing this strategy we have spoken to health and care staff, our local and system partners and the voluntary sector. We have also spoken to people receiving end of life care and their families and carers, and we have used this insight to develop our own local ambitions which set out our plans to improve care.

Our Surrey Heartlands ambitions build on the NHS' national priorities for end of life care. As a system our ambitions are that:

- Everyone is seen as an individual, with care tailored to meet their needs and wishes
- Everyone has equal access to palliative and end of life care
- People are made to feel comfortable and their wider wellbeing needs are met
- Care is coordinated, with different services working together
- Staff have the skills and knowledge to provide the best care
- Communities come together to provide help and support

These overarching ambitions encompass a range of projects and initiatives that will together enable us to meet our vision and future aspirations for end of life care across Surrey Heartlands.

The following areas are central to our plans:

- Increased use of advance care planning
- More support for carers
- Continued roll out of the Surrey Care Record to create shared records
- A digital workstream that will design innovative solutions to support end of life care at every stage
- Providing more support to our workforce, including further training and education to ensure health and care staff have the right skills and knowledge
- Improvements to the Medical Cause of Death Certification process
- Further targeted insight and engagement work to understand the barriers to accessing end of life care for some groups and communities
- A coordinated approach across the ICS to understand people's experiences of end of life care, in all settings, to inform future commissioning and service delivery

Delivery of this ambitious strategy will be led at a local level by our Integrated Care Partnerships. It will be for these partnerships to work together with local service providers and other partners to look at how they can best meet the aims of this strategy and how they can work together to improve care for their local populations. Recognising that these partnerships are still evolving and working through their own local priorities to meet local needs, as a system we are not mandating a timescale for delivering these improvements. However, we will work with local partnerships to ensure improvements are delivered as soon as possible in line with this strategy.

Currently, end of life care quality indicators are predominantly monitored at an organisation level by individual providers. As a result, there is no clear picture of end of life care experiences across all services and across the whole of Surrey Heartlands. To address this, working with partners, we have developed a set of detailed outcome measures that will measure performance across the ICS.

Progress against this strategy will be monitored by the Surrey Heartlands Integrated Care System, working with local Integrated Care Partnerships. Success will be measured against the following high level outcomes:

- People die with dignity and their wishes are respected
- Care is provided in the community, wherever possible, and palliative and end of life care is available when people, families and carers need it
- Palliative care needs across all health conditions are identified early and support is provided
- Palliative and end of life care is coordinated
- After someone has died, families and carers are supported, and the certification process is quick and easy so they can make arrangements swiftly if they wish to do so

Performance against these areas will be monitored through both qualitative and quantitative methods and adopt a holistic approach, considering people's wider wellbeing and the extent to which their wider support needs are being met. To ensure improvements are being implemented, we will also measure delivery of this strategy against specific metrics relating to a range of areas. These include a planned reduction in unplanned hospital admissions in the last three months of life, increased use of palliative care registers and advance care planning tools and increased compliance against required timescales in relation to the Medical Cause of Death Certification process.

Following engagement with system partners, this strategy was presented to the Surrey Heartlands Health and Care Partnership System Board in February 2021. It is being presented to the Surrey Health and Wellbeing Board in March 2021 for final approval.

0.1 Introduction

In June 2019, Surrey's Health and Wellbeing Board made a commitment to identify Surrey-wide opportunities for partnership working around end of life care to improve outcomes for citizens, as part of the new ten year Health and Wellbeing Strategy.

Discussions were paused briefly as the system focused on its response to managing the Covid-19 pandemic. However, these were quickly picked up to support the development of a strategy, taking into account our learning as a system from Covid-19 and where there are opportunities to work together with partners to further improve care.

It was recognised that senior leadership to support this work would be essential and an executive lead and clinical lead were appointed to support, and oversee, the development of a Palliative and End of Life Care Strategy for the Surrey Heartlands system.

0.12 Development of this strategy

A Reference Group, comprised of representatives from across Surrey Heartlands, was formed to lead the development of this strategy, making sure our vision and ambitions for end of life care are driven by the experiences of staff from organisations that provide end of life care and support, as well as our citizens and their families and carers.

The Reference Group has worked collaboratively, bringing together a wide range of stakeholders from across the area to co-design this strategy. Membership has included acute trusts, community providers, the ambulance service, GP representatives, hospices, voluntary organisations, Healthwatch Surrey and other third sector partners.

0.13 Our vision for end of life care across Surrey Heartlands

"Throughout their journey, we want individuals, their families and carers to receive high quality and compassionate palliative and end of life care that is person-centred and co-ordinated, with partners working together to make sure people's wishes and choices are met, wherever possible".

To achieve this vision:

- We will be responsive to changing circumstances and provide person-centred care and support, tailored to individual needs and wishes
- We will ensure people who are approaching the end of life, and their families and carers, receive dignified and compassionate care, wherever they're being cared for
- We will make sure individuals and their families and carers have the best possible experience and a 'good death' where possible
- We will address inequalities and reduce variation in palliative and end of life care
- We will provide the right care in the most appropriate place, in line with people's wishes
- We will ensure care is joined up, with services that are integrated and people only having to 'tell their story' and provide information once
- We will not over medicalise death
- We will help people prepare for death and support individuals, their families and carers every step of the way, including through bereavement support.

0.14 Research, engagement and insight

Early on, we knew that meaningful engagement with citizens, relatives and carers would provide valuable insights into people's experiences of end of life care and their aspirations for how care should be provided that would help shape this strategy and inform our collective ambitions as a system. We also wanted to ensure broader views were sought as part of our wider engagement, with feedback from partner organisations and staff also informing our work, with key themes triangulated across all groups to see if themes were shared. For example, this included looking at whether a citizen's understanding of co-ordinated and integrated care was similar to the understanding held by a member of staff and whether priorities were aligned across different engagement groups.

As part of developing this strategy our comprehensive engagement programme has included:

- Completion of a 'desktop' research review that looks at findings from previous research and insight work, both locally, nationally and globally into end of life care
- Engaging with key stakeholders to look at potential themes around end of life care and areas we may want to explore as part of our engagement work
- Conducting 25 interviews with individuals, families, carers, staff and the voluntary sector

Given the sensitivities around this subject, we worked with voluntary organisations that are involved in supporting individuals, families and carers before, during and after death to help us identify people who may be willing to speak with us as part of our engagement work. In addition, participants from third sector organisations were interviewed to not only speak about their own experience, but also to speak on behalf of the families and carers they support to help us gain as much insight into people's experiences as possible.

We are grateful to everyone who has spoken to us and contributed to the development of this strategy. The key findings from our insight work, including areas for improvement, are summarised throughout this strategy and also feed into our local ambitions to improve care.

0.15 The national ambitions for end of life care

Following the work that has been conducted nationally, this Surrey Heartlands strategy builds on the national direction of travel and priorities set out in *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*, which is still considered to be the blueprint for delivery of palliative and end of life care.

This national framework sets out six ambitions, which are essentially principles for how care for those nearing death should be delivered at local level.

These ambitions are:

1. Each person is **seen as an individual**
2. Each person gets **fair access to care**
3. **Maximising comfort** and wellbeing
4. Care is **coordinated**
5. All **staff are prepared** to care
6. **Each community is prepared** to help

The framework also identifies eight enablers that will support delivery and enable us to drive forward the improvements in care we want to see for local people and their families and carers. These are covered in chapter 7 of this strategy.

7 0.16 Plans for a national policy review

NHS England and Improvement plans to launch the Ambitions Framework for 2020-25, refreshing and reinvigorating the collective aspirations and ambitions for palliative and end of life care. This strategy will be reviewed in light of the new national framework and will be updated, where needed, to reflect any changes in national policy.

0.17 Meeting the needs of our population

Data about people living in Surrey can be found in a document called the [Joint Strategic Needs Assessment](#). It is essentially an assessment of the current and future health and social care needs of the local community that is regularly updated. It informs the Joint Health and Wellbeing Strategy (JHWS) and informs the planning and delivery of health and social care services across the county.

The document has a section about end of life care, which is [available online](#).

Key facts from the health profile that need to be taken into account as part of this strategy are summarised below.

Key facts

- The 65 years and over age group is projected to be the fastest growing age group in Surrey between now and 2039
- In Surrey there are approximately 10,000 deaths each year
- Some areas of the county have higher mortality rates than others. These areas include Reigate and Banstead, Spelthorne and Tandridge.
- The leading causes of death in Surrey are cancer (26% for females and 32% for males), diseases of the circulatory system (26% for females and 28% for males) and respiratory diseases (15% females and males) – these account for 67% of female deaths and 75% of male deaths in Surrey.
- Mental health is given as the underlying cause of death for 12% of females and 6% of males – this is predominantly dementia conditions. These figures are broadly consistent across Surrey, with very little variation.
- In Surrey 41% of the total number of deaths occur in hospital, followed by:
 - 27% in care homes
 - 20% at home
 - 10% in a hospice
- The current trend is that the percentage of deaths in hospital and in a hospice is decreasing while the percentage of deaths in care homes and at home are increasing. This may be due to a drive to support more people at home if it is their wish.

Ambition 1.

Everyone is seen as an individual, with care tailored to meet their needs and wishes



“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.”

“[Conversations about dying] can often be more emotive for the families rather than the person facing the death” (Voluntary sector representative)

“We might go in and think their three main problems are nausea, pain and constipation but actually it’s who’s going to look after my cat when I die? It’s very different so we ask them to identify [their priorities] themselves” (Nurse consultant)

“[The palliative care charity] respect you as an individual person and provide you with bespoke care” (Palliative care patient)

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What our insight work told us

Through our conversations, we have heard about the importance of identifying if someone would benefit from palliative care early on, the crucial role of advance care planning and the importance of having these conversations earlier.

We also heard about some of the challenges faced by our workforce in relation to being able to access records and information generated by another organisation, and how frontline staff can sometimes feel uncomfortable having honest conversations about end of life care with individuals, their families and carers because they are worried it will upset them.

As part of our interviews, we asked staff from primary, secondary and community care which factors are most important to people who have been planning their deaths. Whilst it was recognised that these factors will differ from one individual to another, depending on their own personal situation, we found there are some aspects of end of life care which are frequently discussed and considered to be important. Healthcare professionals reported that ‘planning ahead, pain relief and symptom control, involving families and carers, and having flexibility and choices’ all contribute to a ‘good death’.

During our interviews we heard from a palliative care nurse who talked about her recent experiences with a young lady who decided right from the start that she did not want to discuss her end of life wishes, instead wanting to focus on symptom management and her emotional needs. Sometime later when her condition had deteriorated and she was told she had just two weeks to live she was then ready to have this conversation and talk about her wishes. The nurse talked about how initiating a conversation earlier would have gone against this lady’s wishes and upset her so timing for the individual and being guided by them is really important.

Voluntary sector colleagues also told us that individuals often tell volunteers that they did not understand all of the information they were being given by health and care professionals, with many saying it would have been helpful to have had an opportunity to discuss aspects of care in more detail at a time when they felt less overwhelmed, and more able to take in information.

If we want to deliver truly person-centred care, we must listen to, and understand, the needs and wishes of individuals who may be nearing the end of their life. We must also listen to the wishes of their carers and loved ones, who will also need support during what will be a very difficult time for them.

And this is where what's known as **advance care planning** comes in.

Advance care planning helps ensure that the right questions are asked, at the right time, and that this information is stored in a record that can be accessed by health and social care professionals when they need it. It helps prevent people having to repeat key information and 'tell their story' many times. It helps individuals, their families and carers think pro-actively about their future wishes and gives them somewhere to record them. It also gives health and care staff access to important information so people's wishes can be followed wherever possible.

In an article entitled 'Don't torment me with hope' (published in The BMJ 09 September 2020), Alexandra Filby describes the last few weeks of her father's life and the importance of pre-emptive conversations about end-of-life care. Quite simply, no one said he was dying, and the family were carried away in unrealistic optimism about treatment options from clinicians. Alexandra explains "If the reality of death had been discussed at diagnosis, and access to palliative care services provided, we might have been able to seek out what we needed when it was lacking..."

Discussing end of life care early with palliative patients is not about predicting when they are going to die, but raising awareness and expectations for this inevitable outcome, no matter the timescale.

1.1 Encouraging difficult conversations

Individuals, their families and carers don't know what to expect, and when, so we need to encourage conversations much earlier and find ways to bring people together to help them achieve the best possible death for themselves and for their loved ones.

There will never be 'a right time' to approach such a sensitive issue and that's why having a conversation earlier, and giving people time to think about their wishes, is important. They may not have specific preferences but we won't know until we start the conversation. Online references and case studies of people who are going through something similar, or putting people in touch with those in similar circumstances, can sometimes help, but there is no easy answer – it will depend on the individual and their family so we need to be guided by them.

1.2 An ongoing conversation

People's views, preferences and wishes will change so we need to ensure that this is an ongoing conversation. To help achieve this we need to ensure there are mechanisms in place to ensure care plans are regularly re-visited and that plans can be updated by all of those involved in an individual's care.

1.3 Advance care planning across Surrey Heartlands

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process has now been introduced across most of the Surrey Heartlands area. This gives health and social care professionals access to information about an individual's care, treatment and wishes in an emergency situation, including their preferences in relation to end of life care. It also helps ensure clinicians have meaningful conversations with individuals, their families and carers sooner to ensure their wishes are followed throughout their future care.

Some Integrated Care Partnerships also use the Pro-active Anticipatory Care planning (PACe) approach, which is a more detailed personalised care management plan. The aim of PACe is to record preferences and decisions about care, usually as an illness progresses, but it can be completed at any time.

1.4 Our plans in this area

<p>Everyone is seen as an individual, with care tailored to meet their needs and wishes</p>	<p>What we are doing and our plans for the future</p> 
<p>Advance care planning</p>	<p>We will provide further training to educate health and care professionals on the role of advance care planning and use of the ReSPECT process.</p> <p>We will continue to actively promote engagement with families and carers in advance care planning, so they know what to expect, understand the individual's wishes and any implications on them.</p> <p>We will support 'Dying Matters Week' through a public awareness campaign that reinforces the need to have conversations about dying much earlier.</p> <p>We will continue our plans to further integrate our digital infrastructure, including continued development of the Surrey Care Record and looking at how we can make shared records accessible to all professionals involved in providing care.</p>
<p>Honest conversations</p>	<p>We will provide further training to ensure our health and care workforce has the skills needed, and confidence, to have conversations about death with individuals, their families and carers.</p>
<p>Setting out clear expectations</p>	<p>One of the themes we have seen from feedback to end of life care services is that sometimes people can feel let down if their expectations have not been met in the final days. We understand end of life care and support can be complicated to navigate, with many different services and providers.</p> <p>Looking ahead, we will do more to help individuals, their families and carers understand what to expect, the different sources of support and advice and where they can find more information. This will include promotion of the new Surrey Caring to the End support website.</p>
<p>Equal access to bereavement support</p>	<p>When a death is expected, we know that bereavement support is more likely to be offered to family members than when the death has been sudden. We also know some groups are less likely to access bereavement support.</p> <p>We want to address this and ensure there is support available to everyone who needs it. Many providers are offering additional bereavement support in response to Covid-19, and we need to ensure that such provision meets the needs of all of our population in the future. We will carry out a review of bereavement services to understand the demand for services, current provision and any gaps that need to be addressed.</p>

Ambition 2.

7

**Everyone has equal access to
palliative and end of life 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”

“...a lot of BAME people want to care for their own at home or in a certain way and they think we can't accommodate that. I think that's certainly an area that needs to develop” (Nurse)

What our insight work told us

When we asked health and care professionals about access to end of life care and any barriers that may exist, it was recognised that the ways in which patients die vary significantly due to the nature of their underlying conditions, their degree of deterioration and their environment. However, health and care professionals reported five main barriers which contribute to a patient's end of life care wishes or needs not being met. These were late referrals, overstretched resources, unpredictable or emergency situations, lack of coordinated care and health or care professionals not having the training or confidence to provide care.

There is also a correlation between late referrals into end of life care services and some cultures and faiths. In some cultural groups, it is common practice to support family members at home without any external health and social care support. However, as the families and carers may not know the full extent and implications of the patient's conditions, they may struggle to facilitate that. This can lead to them seeking help for their family member at a very late stage of their deterioration, when their condition is difficult to manage and options will be further limited.

2.1 Access to end of life care

We know access to end of life care can vary from one individual to another and we also know some groups or communities report having poorer access to care. For example, people from black and minority ethnic (BAME) communities and deprived areas report a poorer quality of end of life care. The same is true of those who are living with non-malignant illnesses, people living in more deprived areas, the homeless or imprisoned and those who are more vulnerable or less able to advocate for their own care.

There are still unacceptable inequalities in access to palliative and end of life care, particularly for people with learning disabilities, dementia and non-malignant long term conditions. Quality of end of life care can be poorer and harder to access for people who live in rural or other isolated areas. There can also be unacceptable variations in aspects of palliative and end of life care such as access to symptom control, related to different care settings.

There is a collective responsibility on all of those involved in the commissioning and provision of end of life care to put this right and this is an area we are looking to address as part of this strategy.

2.2 Our plans in this area

Everyone has equal access to palliative and end of life care	What we are doing and our plans for the future 
<p>Further understand where communities may not be accessing end of life care and any barriers that may exist</p>	<p>Following on from our insight work, we will do more to understand where communities are not accessing end of life care, any barriers that exist and how we can work with communities to overcome these.</p> <p>We will address inequalities and gaps in services, and increase access and participation, working alongside diverse lived experience groups and networks. We will aim to ensure fair and equal access to care for all.</p> <p>We will work as a system to improve data monitoring (including key demographic data, social and ethnic group and data relating to health conditions) so we can understand who is accessing care and where inequalities may exist. We can then compare this data to the population data within the Surrey Joint Strategic Needs Assessment and use it to inform future service planning.</p>
<p>Understanding place of death</p>	<p>As a system, we already have access to data on place of death, and we will monitor this to understand where people are dying and if preferences are being met.</p>
<p>Engaging with our communities and faith groups</p>	<p>To ensure equal access to end of life care, we are keen to further engage local communities, including faith groups. As a system we will work closely with Surrey Faith Links and other organisations to gain insights from these communities.</p> <p>We will also be asking our Integrated Care Partnerships to engage with their communities and faith groups at a local level.</p>
<p>Using research and insight to enhance end of life care</p>	<p>Following on from the engagement work we have undertaken in the design of this strategy, we will continue to work with stakeholders, our workforce and our citizens to gain further insight that will help inform future service planning.</p> <p>We will also continue to work with the Academic Research Collaboration, the Clinical Research Network, and other partners to identify best practice and build innovation and evidence into our programmes of work and service planning.</p>

Ambition 3.

7

People are made to feel comfortable and their wider wellbeing needs are met



“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.”

“Fear and anxiety can be so much worse overnight.” (family member)

“Focus on what we can do. We can give medication, we can support you, we can visit, we will spend more time. Sometimes there’s not much you can do but you can still visit.” (Consultant in Palliative Medicine)

What our insight work told us

One major theme that emerged from the interviews we carried out is that more education should be provided about palliative care and the holistic nature of it. We also heard that people feel a cultural shift is needed to get people talking about, and thinking about, dying much earlier as this would help people when it comes to making plans.

We spoke to one individual who was receiving palliative care who told us that from their experience there seems to be little time offered in the earlier stages of diagnosis to talk about the sudden change to their life, the realities of what treatments will involve and the possible side effects they may experience. They felt that more time to discuss their care in a non-clinical setting would be valuable. They would also like to have been offered more practical support, including how to get equipment, more information on medications and details of where they could get advice on financial issues.

Helpfully, for this individual these practical needs had been met by the voluntary sector but this does suggest more could be done to consider an individuals’ wider wellbeing needs and to signpost people to sources of information and support.

All providers of end of life care - GPs, nurses, hospital staff, social care, nursing homes, hospice staff and the voluntary and faith sector – should work closely with individuals, families and carers to make people as comfortable as possible and support their wider wellbeing, helping them make the most of their time together.

Being able to measure this is very difficult. Aside from meeting people’s medical needs, including symptom control, we don’t always know whether there is more we could have done to provide comfort and support wellbeing in the final stages of someone’s life. Looking ahead, we want to do more to measure this and find a way to have those very sensitive conversations with families and carers to understand if we achieved a ‘good death’.

We have heard, from providers, families and carers, that service availability and capacity can sometimes be an issue, with people reporting particular pressures on district nursing, and challenges during the night when families and carers are caring for loved ones at home. Whether it’s a face-to-face visit from a GP or community nurse, or being able to speak to someone over the phone who can provide reassurance and offer practical information and support, people need to have access to help and support when they need it most.

3.1 Symptom management

People nearing the end of their life often worry about being in pain and other symptoms including weakness, poor mobility, stress and fatigue. Health and care professionals aim to minimise these symptoms, while also trying to ensure individuals can maintain as much control over decision-making as possible. Symptom management plays a factor not just for patients, but for families and carers too, who are often concerned about what might happen and how best to deal with any given situation.

3.2 Our plans in this area

People are made to feel comfortable and their wider wellbeing needs are met	What we are doing and our plans for the future 
Measuring comfort and wellbeing	<p>Health and care providers monitor quality of care through a holistic approach that looks beyond the medical care people are receiving to also consider comfort and wellbeing and helping people live well for as long as possible. However, this monitoring tends to take place within individual organisations and not across all providers.</p> <p>Looking ahead, we will work with Integrated Care Partnerships to develop a series of metrics that consider areas such as physical, psychological, emotional, social, or spiritual distress at the end of life to help us understand if comfort and wellbeing needs are being met as a system.</p>
Symptom management	<p>As part of our training and education offer, we need to ensure that our workforce are skilled and competent in managing end of life care symptoms. We know that the majority of end of life care is provided by general health and care professionals (not specialist staff) so we must increase the skills and competencies of this group to further improve care.</p> <p>We will look at anticipatory prescribing for symptoms that may present at the end of life, to ensure there are consistent arrangements in place. We will also explore other opportunities, working with our medicines management and community pharmacy colleagues.</p>
Access to services and specialist support	<p>Individuals, families, carers and professionals need access to advice and support 24/7 and especially during the night when it can be more challenging for relatives providing care at home. We need this to be in place and equitable across our area.</p> <p>We also need to ensure Specialist Palliative Care assessments can be undertaken when needed.</p> <p>We will work with Integrated Care Partnerships and providers to look at these issues, and service capacity, particularly overnight and at weekends.</p>

Ambition 4.

7

Care is co-ordinated, with different services working together



"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."

"Part of the problem is that there are so many systems for information and communication and they don't all marry up" (Nurse for Supportive and Palliative Care)

"Out-of-hours is the hardest area, and quite significantly harder. If you're seeing someone who might need medication, the system is very disjointed." (Out-of-hours GP)

"It would have helped to have someone there to coordinate the services" (Voluntary sector)

"We rely a lot on the GP and I have to say the GP is quite pivotal in a lot of the care because often they've known the patients the longest and know about the complexity of any other illnesses they've got." (Consultant in Palliative Medicine)

What our insight work told us

For coordinated care to happen effectively and to ensure that more people experience good deaths, certain barriers need to be addressed. One barrier that was frequently mentioned in interviews with health and care staff was sharing patient notes with colleagues from other organisations and sectors. Often patients nearing the end of life need a multi-disciplinary approach, however currently organisations tend to have their own IT system and records.

From the perspective of health and care staff, there is a challenge to provide the right care as efficiently as possible with limited knowledge about the patient and limited resources to hand. One GP explains that they sometimes are called to treat a patient at the end of life during out-of-hours work. However, without knowing the patient well, without knowing their relatives and without easy access to their records, providing the right care can be difficult.

We also heard that the transition from child to adult services for end of life care can be difficult to navigate, with the children's hospice providing a very different service to an adult hospice. Ensuring a smoother transition to adult services was felt to be an area that could be improved. Through our conversations, we also heard that we need to do more to ensure we are meeting the individual needs of people with learning disabilities, autism and specific mental health needs.

4.1 Joining up care

Fragmented and disjointed care can cause unnecessary frustration and anxiety to someone who is dying and to those close to them. Carers often report the difficulties of multiple professionals and organisations working with little awareness of each other. This lack of coordination causes significant distress and leads to poor communication and duplication, with conversations being repeated unnecessarily.

Looking ahead we will focus on joining up services and care across the NHS, social care, hospices and the wider voluntary sector, putting the individual at the centre. The closer integration of services and the continued roll out of shared patient records (which can be accessed by everyone who is involved in an individual's care) will be key but there are also other areas we need to address, taking into account what we have learnt through managing our response to the Covid-19 pandemic and the move to more digital services.

Our experiences from our Covid-19 response

During our response to Covid-19 many providers replaced face-to-face support with virtual support, where this was needed to comply with social distancing and other measures. In many situations, we found that reaching out to families and carers, and providing support through video conferencing, was well received and effective, particularly in reaching younger age groups. However, we also found that some people did not have access to digital services and alternative solutions were needed. Looking ahead, our plans will need to be mindful of the digitally excluded and ensure that services are delivered in a way that ensures equal access to all members of our communities.

4.2 Our plans in this area

Care is coordinated, with different services working together	What we are doing and our plans for the future 
Joining up information through a shared care record	We have launched a Surrey Care Record, which gives health and care professionals access to key information to help join up care. We are currently exploring how we can use this to enhance end of life care, through a Palliative and End of Life Care Surrey Care Record user working group.
Coordinating care through GP practices	<p>General practice plays a crucial role in supporting people who are receiving end of life care. There are many benefits in having a regular forum in primary care, which brings together multi-professional teams to discuss an individual's care and holistic needs. By coming together in this way, partners can share intelligence and coordinate care.</p> <p>Currently, there are different arrangements in place across different practices, so we will work with Integrated Care Partnerships and our colleagues in primary care to look at how best to do this as a system.</p>
Improving communication	<p>When complaints are received, communication is often a key theme. Whether this is due to families and carers feeling they were not kept informed, mis-communication between different partners or the way in which health and care professionals communicated, we know communication can be an issue.</p> <p>Improvements including shared care records will help address this and we will look at staff awareness and training in this area.</p>
Clearer information	<p>During what is an emotional and stressful time for families and carers, we want to make it easier for people to know who to contact to get the help and support they need.</p> <p>Providing clearer information about services and how they work together is an area we are looking to improve. The new Surrey Caring to the End website will help provide information.</p>
Making sure care is coordinated for specific groups	We are working with partners to improve coordination of care for particular groups including children who transition into adult services, people living with dementia and people with learning disabilities, who all have specific needs that need to be considered. We will explore potential opportunities in relation to these areas with partners.

Care is coordinated, with different services working together	What we are doing and our plans for the future 
Certification of death	<p>We want to make the certification of death process as quick and simple as possible, for health and care professionals and families and carers, and we are exploring ways to do this, working with our council and digital colleagues.</p> <p>Currently the next of kin are required to liaise with a number of different professionals and organisations to receive a copy of the Medical Certificate of Cause of Death and register the death before they can make arrangements. Sometimes if information is missing or inaccurate this can lead to unnecessary delays.</p> <p>We want to make this a faster and easier process for relatives, building on our learning through the Covid-19 pandemic.</p> <p>Following the successful introduction of the Medical Examiner Service at some acute hospitals to support the certification process (where information is reviewed and checked prior to submission), we plan to introduce a similar process for deaths that happen in the community. This will help increase the quality and accuracy of medical certificates and help reduce the number of forms referred back to the GP or coroner.</p> <p>As part of this work we believe there is also an opportunity to design a digital solution that could support and help streamline the process.</p>
Opportunities to include end of life care in other digital projects	<p>There are a wide range of digital projects underway across Surrey Heartlands to improve and integrate care and we are currently exploring these to understand where these could also benefit end of life care. These include projects relating to assisted technology (such as Telecare) and remote monitoring, which we are currently using with dementia patients and their carers as part of a Technology Integrated Health Management (TIHM) project.</p>

Ambition 5.

Staff have the skills and knowledge to provide the best care



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

“Some of those softer skills about actually dealing with families [who are bereaved]. I think that could be really improved.” (Pharmacy representative)

“I think the community are... really overstretched... and I think that sometimes people at home find it a struggle.” (Nurse for Supportive and Palliative Care)

“We found people with heart failure recognised when they were less well and potentially facing death but their healthcare professionals didn't want to discuss it with them” (Hospice staff member)

7

What our insight work told us

Through our interviews with staff we heard that health and care professionals not always having the training, education or confidence to start conversations about end of life care could impact on the quality of care being provided. In particular, it was felt that training frontline staff should be prioritised so they developed the right skills and felt equipped to have these conversations. We heard that sometimes health and care professionals may be worried about upsetting an individual or getting it wrong because they haven't yet developed the skills or confidence to start conversations slowly and with empathy and understanding.

It was also recognised that other support roles would benefit from additional training and support, including pharmacists and volunteers who can play a valuable role but who may not have received any training in this area.

Caring for the dying and supporting people facing loss and grief, before and after death, is difficult and distressing. It challenges the resilience of those working in end of life care and makes for a difficult working environment. It also means making sure these staff get the support they need is essential for their own wellbeing, and the care and wellbeing of those they are looking after.

5.1 Supporting our workforce

Most health and care staff look after people who are nearing death, so if care is to improve, they must be trained in those aspects of end of life care that are appropriate to their role. Given the demands frontline staff experience every day, it's really important staff get the training and support they need, not only to do their job, but also to help them cope with stressful situations.

Staff can only provide compassionate care when they are cared for themselves and they must be supported to sustain their compassion so that they can remain resilient, and use their empathy and apply their professional values every time.

Following the Covid-19 pandemic, this has become an even greater area of focus for us. As a system, we have launched new online training packages, increased the mental health support that is available and offered counselling to those staff who would find this helpful. Following publication of the NHS People Plan, we have developed our own Surrey Heartlands Plan and through this we will ensure the health and wellbeing of our workforce remains a top priority.

5.2 Symptom management and supporting careworkers

We know that good symptom management benefits both the dying and those who spend time with them. If we are to make deaths at home more achievable, for those that want it, we know that we have to do more to ensure sufficient support for careworkers who may be vital to sustaining the viability of care at home.

5.3 Our plans in this area

Staff have the skills and knowledge to provide the best care	What we are doing and our plans for the future 
Supporting our staff	<p>We recognise that those working in end of life care are working in a challenging environment and they need to be supported, both in their job and in their wider wellbeing. Following the Covid-19 pandemic we have seen unprecedented demand for services so supporting our workforce has never been more important.</p> <p>We have already referenced our plans for further education and training in relation to some areas of palliative and end of life care, and we will be building on this, and our local People Plan, to ensure we have the right support in place.</p>
Upskilling our general workforce	<p>We know that the majority of end of life care is provided by GPs, nurses and other ‘general’ health and care professionals, and not by staff who have specialist end of life care roles. In view of this, we need to make sure our general workforce has the right training and feels equipped to provide high quality end of life care, linking in with specialist staff for advice and support when they need it.</p> <p>We will work with Integrated Care Partnerships to understand training offers available for the generalist workforce, and aim to increase the number of professionals who receive specialist training, and carers who receive relevant skills training.</p>
Developing specialist skills	<p>We are also looking at more specialist roles within end of life care and where these may be required to provide support and help coordinate care for specific groups. These roles need to be developed in partnership with local providers but could include specialist roles in end of life care for people with learning disabilities.</p>

Ambition 6.

7

Communities come together to provide help and support



“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.”

“Talking about death and dying remains the biggest taboo in our society.” (Palliative Care Clinical Nurse Specialist)

What our insight work told us

Although willingness to discuss death and dying depends on an individual, their background and their illness, talking about death isn't really seen to be the 'done' thing. This can make staff reluctant to have these conversations, even when they are needed.

We also heard from frontline staff that there is often a misconception about palliative care solely focusing on end of life. Through our conversations, both health and care professions and voluntary representatives emphasised the need for people to understand that these conversations are not simply about the end of the patient's life, but also about the *rest* of their lives. By taking this approach we can empower the individual and their families and carers and help them to enjoy a good quality of life while also preparing for death.

Dying, death and bereavement are not medical issues – they are part of life and shouldn't be over medicalised.

Dying and bereaved people often feel disconnected or isolated from their communities and networks of support. Despite some real progress, and the growing reach and impact of the Dying Matters Coalition, there remains a continued need to address and dissolve the taboo that many people feel when it comes to talking about dying, death and bereavement and facing up to their own mortality and that of the people important to them.

6.1 Normalising death

Earlier in this strategy we have talked about the need to have conversations earlier, and find a way to normalise death. We understand it is a very sensitive subject and for many talking about death may either lead to anxiety over their own immortality or it may bring back feelings of grief or sadness, thinking about loved ones they have lost.

6.2 Developing compassionate communities

There are ways to foster and support compassionate communities and to put end of life care at the heart of community health and wellbeing. Supporting and working with communities, to develop their capacity to play a significant role in supporting individuals and those important to them, at the end of life and through bereavement, can help achieve the best outcomes for those who need support. As we have seen through the Covid-19 outbreak, volunteers can play a vital role in offering practical support and this is something that could be used more in end of life care and support.

6.3 Our plans in this area

Communities come together to provide help and support	What we are doing and our plans for the future 
Building compassionate communities	<p>To change how we think about, plan for, and respond to death as a society, we need to start by building compassionate communities. Integrated Care Partnerships will need to work with partners, the voluntary sector and local communities to talk about end of life care and what needs to change to help us give better support when people need it.</p>
Helping people to talk about death and dying	<p>If we want to improve care, we need to start these conversations earlier so we can understand how people would like to die so we can make sure wishes are followed. It will also help us get communities talking about how people want to be supported at the end of life and throughout bereavement.</p> <p>As a system we will take part in national awareness campaigns such as Dying Matters Week to get people in Surrey Heartlands thinking and talking about death. Our focus will be on normalising conversations about death and dying so everyone feels more equipped to have better conversations.</p> <p>Together, we are keen to explore the concept of a ‘dying friendly’ initiative, similar to the ‘dementia friendly Surrey’ scheme, where we offer training and support to help people have these conversations. We need to think creatively about how we can get people’s attention and encourage conversations to happen, learning from other areas.</p>
Starting conversations in schools	<p>Partners feel that schools would be a good place to start, so we will be working with Surrey County Council to understand what is already covered as part of children’s Personal and Social Education, and if there is more we can do to support teachers and encourage conversations during school age children. This would help increase understanding and it may also slowly lead to a shift in attitudes towards death and dying as children grow up and become adults.</p>
Empowering local communities to provide support	<p>End of life care isn’t just about medical support so we will be working with partners to explore how we might be able to create a network of volunteers who can provide practical help to people who need it, as we have seen happening in communities during the Covid-19 pandemic. We will work closely with our voluntary, community and faith sector partners to build on the volunteer networks that already exist.</p>

7.

7

Delivering on our ambitions

7. Delivery and enablers

Delivery of this ambitious strategy will be led by Integrated Care Partnerships. These are partnerships of local organisations that are working together to plan and deliver healthcare for local communities. The partnerships include local NHS organisations (such as hospital, community, mental health and ambulance trusts), local authorities, hospice and specialist palliative care providers, the voluntary sector and other local partners. There are four partnerships in the Surrey Heartlands area – Guildford and Waverley, North West Surrey, Surrey Downs and Crawley, Horsham and East Surrey (sometimes referred to as the CRESH partnership).

It will be for these partnerships to work together with local service providers and other partners to look at how they can best meet the aims of this strategy and how they can work together to improve care for their local populations.

We recognise that the partnerships all have their own local services and practices in place, with some further ahead than others in terms of care planning and the implementation of processes such as ReSPECT. There will also be differences in terms of the provider landscape (such as the number of care homes), as well as differences in demographics (such as the number of people with learning disabilities). It will be for local partnerships to consider local services and local needs and to prioritise elements of this overarching strategy, based on local needs. Where there are opportunities to deliver improvements once at scale, across the whole of Surrey Heartlands, we will explore these as a system so that local partnerships can focus on the areas that need to be tailored to meet the needs of local communities.

It is recognised that local partnerships will need the infrastructure and resource in place to deliver this strategy and that this will vary from one area to another. This will need to be considered by the ICPs as part of next steps to ensure they have the resources in place to deliver this strategy.

7.1 The role of the Integrated Care System

The Surrey Heartlands Integrated Care System (which is responsible for setting the high level ambitions across the area and overseeing how partnerships are performing against these) will monitor progress and support local partnerships as they develop their own local plans.

7.2 Timescales for delivery

As Integrated Care Partnerships are still evolving and are still working through their own local priorities to meet local needs, as a system we are not mandating a timescale for delivering these improvements. However, we will work with local partnerships to ensure improvements are delivered as soon as possible in line with this strategy.

7.3 Enablers

Delivery of this strategy will be linked to a number of overarching enablers that will help us achieve our ambitions for end of life care (see Figure 1 below).

Figure 1 – System enablers (source: Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020)



Many of these enablers have been referenced throughout this strategy, and are central to our plans for the future. Areas such as delivering more co-ordinated care will only be possible through closer integration, better personalised care planning and the roll out of the Surrey Care Record which will give us a secure platform where we can hold and share information across partners with everyone involved in delivering an individual's care.

Moving forwards we know that leadership, and a commitment from local partnerships to deliver these ambitions, will also be key, as will the continued input from staff, partners, local people, those nearing the end of their life and their loved ones to help make sure the right services, and the right support are in place.

The changes we have seen to the local landscape, with the emergence of Integrated Care Partnerships and Primary Care Networks will help us focus on local communities and local needs and it will also further strengthen the collaboration needed across partner organisations to maximise every opportunity to improve care, in line with our shared system ambitions.

7.4 Digital

Currently information that is recorded about palliative and end of life care can be fragmented, not available in 'real time' and sometimes information cannot be accessed by everyone involved in an individual's care. For example, if someone is taken to hospital in an emergency, A&E staff may not be able to access information about the medication an individual is taking, their care plan or about their wishes. None of this makes for co-ordinated care, so bringing this information together, and connecting partners through one shared record, will be a major step forward.

The Surrey Care Record is helping to join up information and care by making sure important information can be viewed by everyone who needs to see it.

We have also heard from both clinicians and carers that they would welcome technology that could support them when providing end of life care. Remote monitoring and systems such as telecare may have a role to play and these are areas we are now exploring.

7.41 Our digital strategy for end of life care

Building on the findings from recent insight work, we are developing a digital strategy to support the realisation of our ambitions, embracing digital technology to help improve end of life care for our citizens. Our digital approach is focused on six person-centred principles, which are outlined below in Figure 2. These principles link back to the national ambitions, with digital solutions under each that will act as enablers to help us realise our plans.

Figure 2 – Digital principles and our digital solutions

<p>Principle 1 – Know me, know my needs (enabling data sharing)</p> <p>Digital solution – Sharing care records We will join up records so health and care professionals can read and update records across systems used by GPs, hospices, hospitals, emergency services, out-of-hours staff, pharmacies and community services. This will help share vital information across different partners, reducing duplication, help to reduce clinical interventions and unnecessary admissions, help the system work more efficiently and importantly, it will help ensure individuals and their families and carers only have to tell their story once. This will be achieved through the continued roll out of the Surrey Care Record and connecting existing systems directly where needed to join up care.</p> <p>Digital solution – empowering individuals, their families and carers As part of our digital solution, we want individuals, family members and carers to be able to see some parts of their record, within the Surrey Care Record. We believe this will empower them and give them more control in their care and decisions and help them navigate their journey through end of life care.</p>

Principle 2 – Initiating the difficult conversation (early identification of palliative care needs)

Digital solution – ‘Bringing death to life’

Through our insight work we heard that when people are starting their end of life journey sometimes it can be helpful to see stories from other people who are going through a similar experience. We want to explore how we can use digital technology to bring together existing materials from local hospices and other partners and share them, creating new materials where needed.

Digital solution – Identifying those at risk

We also want to look out how we can use data that is already stored in the Surrey Care Record and other systems to use Artificial Intelligence (AI) to proactively identify those who could be moving into end of life care to help make sure these individuals get the care and support they need.

Principle 3 – Do they truly know my wishes? (enabling a flexible and transparent approach to advance care planning)

Digital solution – telling stories once and sharing information

We will standardise the information that exists currently and bring it all together into one system, which can be updated by the right person at the right time. This will ensure individuals only have to tell people their wishes once and it will save time and duplication in updating records for staff.

Digital solution – conversation reminders to update people’s wishes

We will also introduce new AI generated flags within IT systems that will trigger a planning review and the need for a further conversation with an individual to understand if their wishes or preferences have changed as they have continued their journey.

Principle 4 – Allow me to safely be where I want to be (technology enabled monitoring and support)

Digital solution – remote monitoring

We plan to use the latest technology and remote monitoring systems to enhance care, give individuals more control and help them stay at home for longer. By deploying a range of sensors (including biometric and environmental sensors) we will be able to proactively monitor an individual’s condition. This will help alert us to any deterioration quickly and help reduce anxiety and stress for those caring for the individual at home.

This can be achieved by coordinating and combining existing tools and systems and synchronising these with remote monitoring tools being used in other pathways (e.g. dementia care, frail and older people’s care). We will also use the data captured to inform future planning.

Principle 5 – Help me start my end of life journey and find my way through it

Digital solution – an online portal to help people ‘navigate the system’

There are many different organisations involved in end of life care. This can make it difficult for individuals, families and carers to navigate the system and know who to contact, when. By bringing together information and resources into one place we can help share people’s experiences and signpost people to organisations and groups that may be able to provide further support, outside of the support we can provide through health and social care. The development of the new Surrey Caring to the End website is a positive first step that we will build on.

Principle 6 – Balance convenience with support and compassion (use of virtual services)

Digital solution – virtual engagement and virtual appointments

We will work with our workforce, with insight from individuals, families and carers, to design virtual services that meet the needs of individuals and their loved ones, and enable the system to continue to provide the best possible care, without the need for travel. Virtual services will not replace face-to-face care and would only be offered where it was felt to be appropriate and if individuals and their families and carers agreed this was the right option. Being mindful of access to services, and digital exclusion, face-to-face appointments will always be available.

7.5 Carers

Carers are vital in providing end of life care. They also face many challenges including difficulties in coping as the person's physical, emotional and social needs become more complex and demanding. This is whilst also trying to coordinate care on a 24/7 basis, managing symptom relief and starting to think about funeral arrangements, all while managing their own feelings of grief. With such an important role to play, it's essential we recognise that carers have their own needs and rights, which should be assessed, and that we do all we can to work together to support carers.

Nationally there are approximately half a million people caring for someone who is under end of life care. To help build resilience carers need to be able to access a range of support services that are appropriate to their needs, responsive and readily available. Whilst there is already good practice in some areas, this is not consistent across Surrey Heartlands, especially in relation to the identification, assessment and involvement of carers – and we need to change this.

The national End of Life Care Strategy recognises carers not just as care providers but also as people in need of support. The national Carers Action Plan also recognises the importance of supporting carers in end of life care. Locally, this is also an area of focus in our draft Carers Strategy 2021-24.

Through our work with carers, the voluntary sector and partner events focusing on the needs of carers during end of life care, we have identified the following themes:

- Carers want to be more involved in an individual's care and in discussions around advance care planning - they will know the individuals and be able to support this
- More training is needed to ensure everyone involved in end of life care understands the importance of engaging carers and making sure wrap-around care is provided.
- Carers are worried about managing pain relief at home – and knowing when to call for help.
- Carers want more support and information to help them manage the strain on their own finances – and their own lives
- Services can feel very fragmented so greater co-ordination, and continuity of care, would help individuals and their carers who sometimes find it hard to 'navigate the system'
- Carers want good access to support and advice, including medicines advice, out of hours.
- Dignity and respect are important and small things can make a big difference to individuals and their families and carers - so personalised and individual care is crucial.

We are very aware of the impact dying, death and bereavement can have on a carer and we want to make sure that carers are supported and fully involved in decisions related to an individual's care. Education is required to make sure health and care professionals are actively engaging in a whole family approach to end of life care. Carers are expert partners in care so it's crucial that they are fully involved in care planning. Carers that have been supported have not only helped achieve 'better deaths' through their involvement, but this sense of purpose has also potentially helped to reduce physical and mental health issues experienced by carers.

Professional staff should offer carers repeated opportunities to discuss and absorb information relating to the cared for person's end of life care. Carers also need information concerning legal and logistical issues.

Addressing some of the key issues and themes that we have heard through our engagement with carers and voluntary groups is a key focus of our work and of this strategy.

8. Key challenges

Through the development of this strategy, we have identified a number of challenges that will need to be considered in delivering this strategy. These are outlined in Figure 3 below.

Figure 3 – Risks and mitigation

Key challenge/ risk	Mitigation
<p>Advance care planning Ensuring that Advance Care Planning is promoted and facilitated effectively to enable people to express their wishes and care preferences and make them known so care can be planned and managed according to individual need</p>	<p>We will work with local partnerships on training and support for health and care professionals to increase knowledge and use of advance care planning. We will also raise awareness with the public of the need to have these conversations so wishes are known.</p>
<p>Effective partnership working Developing and maintaining effective partnership working across the public, private and third sector organisations to achieve more co-ordinated care</p>	<p>The new Integrated Care Partnerships bring together many of the organisations involved in end of life care so this will help facilitate partnership working in a much more effective way. We have seen great examples in response to the Covid-19 outbreak.</p>
<p>Workforce As a system our ability to recruit and retain clinical staff in all areas of end of life care, including in specialist roles</p>	<p>Workforce planning will need to be considered and addressed as part of local planning to ensure the right skills and the right resources are in place to achieve the ambitions of this strategy. This includes the role of community pharmacists and also needs to take into account that the majority of end of life care is provided by general health and care professionals, not specialists.</p>
<p>Training and education Ensuring adequate resources are available to support the provision of multidisciplinary training for the NHS and its partners and that resources are available to cover the cost of releasing staff to attend training courses.</p>	<p>This strategy identified education and training as a key area that needs to be addressed and local partnerships will need to ensure training needs are met, with resources allocated to support this.</p>
<p>Funding and investment Securing sustainable funding for all areas of end of life care, including the voluntary sector, to realise the ambitions within this strategy.</p>	<p>Funding and plans for investment will need to be considered by local partnerships as they take on responsibility for devolved budgets and local service planning and delivery. This should include greater investment in early intervention to join up care and reduce admissions, which is beneficial to individuals and also helps ensure value for money in use of resources.</p>

9. Measuring outcomes

To determine the success of this strategy, and the extent to which we achieve our collective system ambitions to improve palliative and end of life care, it will be essential that key outcomes with measurable indicators of success are defined and closely monitored.

Whilst it is recognised that defining outcomes in relation to end of life care is challenging, our high level outcome measures will include monitoring how local partnerships are performing against the following high level ambitions:

Desired outcome	Individual and family outcome	System outcome
<p>People die with dignity and their wishes are respected</p>	<p>Individuals can choose where they are cared for and die, and they die with dignity.</p> <p>Their wishes, and those of their loved ones, are met, wherever possible.</p> <p>Symptom control is effectively managed for the dying patient in all settings.</p>	<p>Increase in achievement of preferred place of care and death.</p>
	<p>Evaluation methods include:</p> <ul style="list-style-type: none"> - surveys for individuals who have been bereaved - feedback from individuals and families and carers - complaints and compliments 	<p>Metrics include:</p> <ul style="list-style-type: none"> - Upward trend in positive response to the question: 'Overall do you feel the person close to you died in the right place?'
<p>Care is provided in the community, wherever possible, and palliative and end of life care is available when people, families and carers need it</p>	<p>Trips to, and stays in, hospital are minimized for people at end of life, only happening when clinically necessary.</p> <p>Individuals and their families and carers have access to rapid advice and support, including out of hours or in a crisis situation, in the community.</p>	<p>More individuals are being supported in the community.</p> <p>The general workforce have access to specialist telephone advice and support when required.</p>
	<p>Evaluation methods include:</p> <ul style="list-style-type: none"> - surveys for individuals who have been bereaved - feedback from individuals and families and carers - complaints and compliments 	<p>Metrics include:</p> <ul style="list-style-type: none"> - Downward trend in unplanned admissions to hospital in the last three months of life.

Desired outcome	Individual and family outcome	System outcome
<p>Palliative care needs across all health conditions are identified early and support is provided</p>	<p>Palliative care needs are identified early on and a care offer is made from the start.</p> <p>Individuals are given the opportunity to plan ahead, and be involved in decisions about their care.</p>	<p>Timely identification of palliative care needs for all disease types, with appropriate support</p>
	<p>Evaluation methods include:</p> <ul style="list-style-type: none"> - surveys for individuals who have been bereaved - feedback from individuals and families and carers - complaints and compliments 	<p>Metrics include:</p> <ul style="list-style-type: none"> - Evidence, from general practice palliative care registers, that all disease types are represented proportionally.
<p>Palliative and end of life care is coordinated</p>	<p>Individuals and their families experience coordinated care, with clear and consistent information and different organisations coming together to seamlessly wrap care around the individual.</p>	<p>Partners are working together effectively to provide co-ordinated care.</p> <p>Continued expansion of advance care planning (ReSPECT, PACe etc) with effective solutions to share clinical records and care plans to enable the system to work efficiently.</p>
	<p>Evaluation methods include:</p> <ul style="list-style-type: none"> - ICS wide survey for individuals who have been bereaved, seeking insight on their experiences - feedback from individuals and families and carers - complaints and compliments 	<p>Metrics include:</p> <ul style="list-style-type: none"> - Increase in the number of personalised care plans created - Increase in the number of personalised care plans being reviewed and updated - Evidence that digital solutions are in place to share clinical records and personalised care plans.

Desired outcome	Individual and family outcome	System outcome
<p>After someone has died families are supported and the certification process is quick and easy so they can make arrangements swiftly if they wish to do so</p>	<p>The next of kin is offered bereavement support. They also experience a faster and easier death certification process so they can make the necessary arrangements.</p>	<p>The Medical Certificate of Cause of Death (MCCD) process is streamlined, leading to death certificates being issued more quickly.</p>
	<p>Evaluation methods include:</p> <ul style="list-style-type: none"> - surveys for individuals who have been bereaved - feedback from individuals and families and carers - complaints and compliments 	<p>Metrics include:</p> <ul style="list-style-type: none"> - increase in achievement of death certificates being issued within 5 days of death (Surrey currently at 58%) - reduction in the number of MCCDs referred to the coroner due to missing information (nationally around 50% of cases are referred to the coroner, some of which could be avoided)

Metrics have not been determined before for palliative and end of life care across the ICS. Whilst much data is collected at national or individual organisation level, baseline measurement for the ICS is not readily available. We will not duplicate any existing data collection or surveys, but will form a working group to:

- agree standardisation of measurement across all settings, where possible;
- use or adapt existing data or intelligence to understand the ICS position, and drive system improvement in the future;
- work with CCG business intelligence colleagues to develop an ICS dashboard for palliative and end of life care.

With plans for a refresh of the NHS’ Ambitions Framework for Palliative and End of Life Care for 2020-2025, NHSE/I are developing a palliative and end of life care dashboard. We will keep the above outcomes under review and update them to reflect any changes in the national dashboard.

10. Conclusion and next steps

This strategy sets out our ambitious plans to improve palliative and end of life care for people living in Surrey Heartlands. Delivery of this strategy will require the commitment of all partners and implementation will be taken forward at a local, place-based level through Integrated Care Partnerships.

Once this strategy has been approved it will be for Integrated Care Partnerships to take forward these improvements at a local level, working with partners, prioritising areas as needed, based on local health needs.

As an Integrated Care System, we will be working with our local partnerships to monitor delivery of this strategy and ensure these ambitions are realised for the benefit of our citizens.

