Marie Curie

Experiences of Palliative and End of Life Care
in the East of England

Full Report
March 2025

NHS England
East of England

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FOREWORD

“Marie Curie believes that everyone deserves the best possible care at end of life. Sadly research shows that this is not the case. Our Better End of Life Programme, including the *2024 Time to Care* report highlighted that there is a gap in the provision of care and too often people who are approaching the end of life experience difficulties accessing the care and support they need.

Committed to working in partnership at the local level, Marie Curie was pleased to have the opportunity to conduct a study on behalf of NHS East of England to understand experiences of palliative and end of life care in the region, including: Bedfordshire, Buckinghamshire (Milton Keynes), Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk.

The study was structured around the *Ambitions for Palliative and End of Life Care 2021-2026* (Ambitions), an NHS England publication, with a focus on understanding to what extent people’s lived experience in the region aligned to the vision set out in this national framework.

Perhaps not surprisingly for a region as large and geographically diverse as the East of England, findings present a mixed and inconsistent picture, with some respondents likening experiences of care to ‘a roll of the dice’, ‘a game of snakes and ladders’ and ‘a postcode lottery’.

Indeed, the in-depth comments shared in this study through the free-text responses and interviews reveal a full spectrum of experiences. While there are uplifting accounts of positive care, many stories are deeply challenging and highlight areas where the provision of end of life care in the East of England is falling short of the Ambitions. Many themes resonated with what we learnt through the national study.

In response to our central survey question, 55% rated their overall experience of care for their terminal illness as ‘Very good’ or ‘Good’. It is encouraging that the majority rated this positively. However, we urge those who are responsible for the delivery of palliative and end of life care to reflect on whether 55% is an acceptable figure. With over a fifth of respondents rating their experience as ‘Poor’ or ‘Very Poor’ and 86% identifying challenges with their care, we suggest much more still needs to be done.

We would like to thank all the individuals who contributed to this study – patients, family carers and those recently bereaved. Their voice is at the heart of this study – not just their experiences, but also what they felt should be priority areas for improvement. We are committed to ensuring that their valuable input shared does not go unnoticed.

Our hope is that this report will provide renewed impetus for all organisations to continue to work together towards a more consistent and equitable experience of palliative and end of life care for everyone in the East of England. For it is the collective responsibility of all of us who are passionate about delivering high-quality palliative and end of life care to review, reflect and work together to take action. Only then can we fulfil the promise of the Ambitions, transforming them into reality.”

Marie Curie

Julie Quinn

Associate Director Strategic Partnerships & Services London & Home Counties

EXECUTIVE SUMMARY

The *Ambitions for Palliative and End of Life Care 2021-2026*[1] **set out a vision to improve end of life** care through partnership and collaborative action between organisations at a national and local level throughout England.

This study, which was conducted across all six integrated care systems in the region, has highlighted that with only just **over half (55%)** of people who completed our survey rating their overall experience as 'Very good' or 'Good', **more than one fifth (22%)** rating their overall experience of care as 'Poor' or 'Very poor' and a **further 21%** only rating it only as 'Fair', **we have some way to go to achieve this vision in the East of England.**

The 625 responses in the online survey from people affected by terminal illness – whether as patients, carers, or those recently bereaved – along with the experiences shared by over 50 individuals through interviews and small group discussions, reveal a complex and inconsistent picture of palliative and end of life care in the East of England.

The key findings summarised below call for continued and concerted efforts to fully realise the Ambitions and deliver a consistently high-quality palliative and end of life care experience for all in the East of England.

Key Findings

AMBITION 1:
Treated as an individual

Not everyone feels treated as an individual

- Personalised care was generally good. Just over two-thirds of respondents agreed that the person cared for was treated as an individual (68%) and treated with dignity and respect (68%).

However:

- Respondents called for more opportunities for open and honest conversations about palliative and end of life care, including with healthcare professionals.
- Only just over half (57%) said they had had the opportunity to discuss their end of life wishes and of these only just over half (53%) had discussed the important topic of their care in final weeks and days.
- Patients often felt they were not treated as a 'whole person' and their care wishes not always listened to. Family carers frequently felt they were neither respected nor supported.

AMBITION 2:
Fair access to care

Not everyone has access to good end of life care

- Geographic and financial inequities contribute to a 'postcode lottery' in accessing care, with limited services in rural areas and outside of working hours.
- Out of hours provision is not sufficient. Nearly 40% said that care was not available when needed or quickly enough and was the second most frequently identified challenge.
- GPs can be difficult to access. Nearly half of respondents (49%) said they only 'Sometimes', 'Rarely' or 'Never' had access to specialist advice from a doctor or healthcare professional.
- Provision of support and advice on money and benefits relating to their illness and care is limited. Almost half (47%) said they were 'Rarely' or 'Never' able to access this.

AMBITION 3:
Maximising comfort and wellbeing

More could be done to maximise physical and emotional comfort and wellbeing

- Pain management for those receiving end of life care at home can be a challenge, particularly for those in rural areas.
- There is poor recognition of when people are nearing the end of life, often leading to unnecessary interventions. 15% reported receiving care they felt was unnecessary, with many sharing distressing accounts of their experiences.
- Counselling and emotional support for those diagnosed with a terminal illness and their carers is lacking. Over a quarter (27%) said that support to discuss thoughts and feelings was 'Rarely' or 'Never' provided.

AMBITION 4:
Care is coordinated

Care is often poorly coordinated

- Once triggered, palliative care is generally good, with services working together to deliver care.

However:

- Patient care is not regarded as joined up. Over forty percent (43%) disagreed that different healthcare professionals knew their medical history and talked to one another.
- Delays are a significant challenge. Ranking first in a list of challenges, nearly half (49%) had experienced delays in their care, treatment or transfer between services.
- Patient and families find it difficult to navigate the system. At least a third were unsure of what care options were available (38%) or who to contact (33%).
- Many patients and families felt they had to figure things out on their own with a reliance on family members to advocate and champion for the care needed.

AMBITION 5:
All staff are prepared to care

Not all staff are skilled or experienced in end of life care

- Specialist palliative care teams including hospice and community nursing teams were generally praised for their readiness to provide expert, compassionate care.

However:

- Respondents felt that generalist healthcare professionals, including consultants and GPs, were often not proactive or knowledgeable enough about end of life care.
- Under two-thirds (64%) agreed those who provided care were knowledgeable, confident and compassionate, whilst a fifth (20%) disagreed.
- Identification of terminal diagnosis was often delayed and respondents indicated that communication was often insensitively delivered.

AMBITION 6:
Each community is prepared to help

There is not enough community support

- There are limited community resources, especially for carers who feel isolated or overwhelmed.
- Only just over one third (36%) said they 'Always' or 'Usually' received emotional and practical support from groups in the community.
- There is a need for better public awareness of palliative care, improved volunteer networks and stronger local community engagement.

ABOUT THIS STUDY

Why This Study

Marie Curie and partners in the **East of England Palliative and End of Life Strategic Clinical Network**[2] are committed to improving end of life care for all.

Acutely aware of the challenges around palliative and end of life care – not least the increasing demand and limited resources – there is a shared aspiration to enable everyone to have a good end of life experience. (*See Marie Curie description*)

The **Ambitions for Palliative and End of Life Care 2021-2026** is a national framework designed to guide local action and establish a collaborative vision for improving care in this vital area. This framework, which has been incorporated into statutory guidance for Integrated Care Boards, has played a key role in shaping service developments since its introduction in 2015.[3] Structured around six core Ambitions (*Figure 1*), it encourages professionals and local leaders across health and social care to work together, regularly assess their performance against these Ambitions, and hold themselves accountable for achieving these standards.

With limited data on personal perspectives across the region, NHS East of England commissioned Marie Curie to conduct a study to understand to what extent the Ambitions were being achieved in terms of people's lived experience of palliative and end of life care in the East of England.

By inviting local people affected by terminal illness – whether as a patient, carer or someone recently bereaved – to share their experiences, we were looking to identify what was working well as well as priority areas for improvement, at both a regional and local integrated care system level.

Figure 1:
Ambitions for Palliative and End of Life Care 2021-2026

01 **Each person is seen as an individual**
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02 **Each person gets fair access to care**
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03 **Maximising comfort and wellbeing**
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04 **Care is coordinated**
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05 **All staff are prepared to care**
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06 **Each community is prepared to help**
I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

How Marie Curie describes a 'good end of life experience' to patients[4]

A 'good' end of life experience means having the right care, support and systems in place, so you feel protected and safe, and your carers, family and friends understand what support is available. It's different for everyone, as it depends on what matters to you. It means the right pain and symptom management and medical care to help you live as well as you can, in line with your wishes. It means emotional and spiritual care to help you feel safe and supported. And it means a smooth and joined up experience of the health and social care system, so you can focus on the important things at the hardest of times. When you get to live well right up until you die, and what matters most to you has been listened to and respected, that's what a 'good' end of life looks like.

Background

Marie Curie conducted the study on behalf of NHS East of England between 5 July and 7 October 2024.

This was not a study of Marie Curie services, but a review of the experience of care across the whole system, whatever location or setting.

The key purpose was to understand to what extent the experiences of people affected by terminal illness in the East of England were aligned to the *Ambitions for Palliative and End of Life Care 2021-2026*, with a focus on identifying what is working well as well as priority areas for improvement.

As such the findings are intended to inform those who are responsible for shaping and delivering palliative and end of life care for people in the East of England so that as a system, we can work together for a better end of life for all.

Geographical scope

The East of England is currently made up of six Integrated Care Systems (ICS) as detailed in the map in *Figure 2*. The study was conducted across all these ICS' and Marie Curie partnered proactively across the region to promote and engage people in the study.

The East of England Context

With a growing population of an estimated 6.3 million[5] and a mix of urban centres, rural areas and coastal regions, the East of England is a vast and diverse region geographically and demographically. Economic prosperity in some areas contrasts with deprivation in others and whilst the region is predominantly White British, there is notable ethnic diversity in certain urban areas with significant South Asian, Black, and Eastern European communities. About 20% of the population is over the age of 65, which is slightly higher than the national average and reflects its popularity as a retirement destination, especially in rural and coastal areas. This aging population results in a higher demand for palliative and end of life care services – a trend that is set to continue.

Figure 2:
6 Integrated Care Systems (ICS) in East of England

1. Bedfordshire, Luton & Milton Keynes ICS
2. Cambridgeshire & Peterborough ICS
3. Hertfordshire & West Essex ICS
4. Mid & South Essex ICS
5. Norfolk & Waveney ICS
6. Suffolk & North East Essex ICS

Target audience

The target audience for this study were self-selecting **members of the public affected by terminal illness in the East of England**. This included adults who were:

- currently **living with a terminal illness** who may or may not have been receiving palliative or end of life care (patients)
- **supporting and/or caring for someone** living with a terminal illness – whether family, friends, volunteers or health or social care professionals* (carers)
- **bereaved family or friends** of someone who had died from a terminal illness in the last 2 years (ie post Covid period) (bereaved)

**All participants were invited to respond in their personal rather than professional capacity.*

Methodology

Approach

The study included the following approaches to data collection:

1. An **online survey** to collect primarily quantitative data but also some qualitative data via free text responses.
2. Semi-structured **virtual interviews** and semi-structured **in-person small group discussions** to gather qualitative information and to hear more detail about people's experiences.

The online survey was live from **Friday 5 July to Monday 7 October 2024** with interviews and small group discussions conducted within this same period.

Survey development

The survey was developed by a **Steering Group** comprising representatives from NHS East of England and Marie Curie.

The survey went through a number of iterations and stages of review between February and June 2024, including review by members of Marie Curie's Research Voices Group.[6]

In developing the questions for the survey, the guiding principles included:

- **Align to the six Ambitions** so that we can seek to understand the extent to which this vision is being met.
- Develop the same **set of core questions for all perspectives** (patient, carer, bereaved) – but adjust the voice accordingly.
- **Make it easy to complete** – provide mainly selection questions, rather than open text boxes and use simple language.
- **Make selection questions mandatory** but include the option 'Prefer not to say'. Make open text response questions optional.
- **Make the survey anonymous** but allow for identification of responses by ICS so that data could be filtered and reported back to local system leads and providers.
- Provide the opportunity for **further sharing of experiences by including an 'Opt-In' question** to allow participants to express an interest in taking part in an interview of small group discussion (with a separate contact form to protect anonymity of survey respondents).

Survey structure

The survey was built and hosted online on MS Forms.[7] All participants were asked to read a Participant Information Sheet[8] and check a box to give their consent to participating in the survey.

The survey comprised approximately 30 questions, with 15 core questions:

- Consent and Profile (3 questions)
- Details of Patient/Person Caring For/Person who Died (5 Questions)
- Experience of Care (10 Questions)
- Opt-In Question (1 Question)
- Demographic Profile of Respondent (8-10 Questions)

The online survey took on average 17 mins and 36 seconds to complete.

Interviews

Respondents to the survey were invited to share more information about their experiences by taking part in a virtual interview by telephone or Microsoft Teams. These interviews lasted on average 45 minutes and were conducted by Kate Vernon and Tracey Allan in the Marie Curie East of England Team.

Small group discussions

Marie Curie also held three small group discussions in person in collaboration with Rennie Grove Peace Hospice in Hertfordshire, Arthur Rank Hospice in Cambridgeshire and Havens Hospice in Essex.

Partnership and promotion

Marie Curie proactively marketed the study, working closely in partnership with the following organisations in the East of England:

- ICS System Leads
- Healthwatch Organisations
- Hospices
- Patient Support Groups

The following Healthwatch organisations were commissioned by Marie Curie to help secure a target of 100 responses (achieved in 3 out of 6 ICS') in their ICS with regular check in calls with the Marie Curie team to see how they were tracking:

- Healthwatch Cambridgeshire
- Healthwatch Central Bedfordshire
- Healthwatch Hertfordshire
- Healthwatch Norfolk

To support marketing efforts and promote the study as widely as possible across the East of England, Marie Curie put together a Communications Pack with a range of marketing assets which was shared with all partners. This included:

- Promotional flyer
- Poster
- Copy for website, newsletters, targeted emails
- Social Media imagery and posts

In addition, Marie Curie promoted the survey leveraging the following channels:

- Marie Curie East of England website
- Marie Curie East England Facebook page
- Advertorial in targeted media

Emotional support

It was recognised that completing the survey or taking part in the interviews and group discussions required people to reflect on their own experiences of living with terminal illness and accessing care – or in the case that they were sharing experiences of someone who had died, a bereavement.

It was highlighted that this may bring up experiences that participants may find upsetting. Participants were advised that if they needed any support after taking part in the study, they could contact **Marie Curie's Support Line on 0800 0902309** which is open from Monday to Friday 8am-6pm, and Saturday 11am-5pm. Our trained team of professionals and volunteers would be there to listen and signpost them in the right direction.

In addition, the Marie Curie interviewers sent a follow up email to all interviewees to thank them for their time and signpost them to relevant Marie Curie resources.

Data Analysis

Analysis of quantitative survey data was conducted using statistical software Stata 18, to allow data checking, cleaning and categorising responses, followed by analysis. Frequency and percentages for each question were calculated for the East of England region and for each ICS, to provide profiles of respondents and patients; and the pattern of responses. For the East of England region, differences in response patterns were assessed by ICS, respondent perspective, religion, being cared for in a hospice and in a hospital and whether living alone. Differences by ethnicity and postcode were attempted but small sample sizes of non-white respondents and within each postcode area hampered analysis.

Limitations of data

As with many surveys, respondents with more positive or negative experiences of care may be more likely to participate. The sample for the survey was identified using purposive sampling[9] and the organisations involved in marketing the survey aimed to reach as wide a range of people with experience of, or living with, a terminal illness. Approaches to engaging participants differed by ICS and some groups may have been less accessible or faced barriers to participation. As a result, the responses may not reflect or fully capture all perspectives of care in the region.

Participants in the Study

Response rate

There was strong engagement with the study with a total of 625 valid survey responses. This included:

- 492 free text responses to the ‘Further comments’ question (79% people left a comment)
- 154 free text responses to a question about the needs of carers (70% of carers left a comment)

In addition, over 50 individuals participated in a virtual interview or in-person group discussion.

625 valid responses to survey

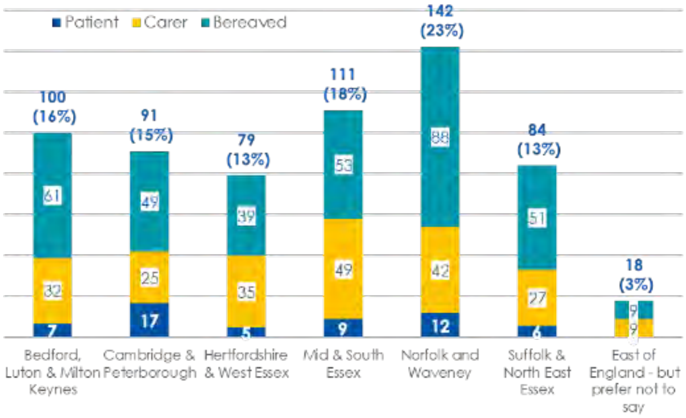
There were 664 initial responses to the survey. However, 4 did not provide consent to the study and therefore were immediately directed out of the survey.

Participants were required to specify which area in the East of England they/the person they were caring for/the person who had died was based and asked to select from the list of six ICS supported by a map. They also had the option to select ‘East of England but prefer not to say’ or ‘None of the above’. If the latter, and therefore not within the geographical scope of this study, respondents were immediately directed to the end of the survey with no opportunity to complete. This applied to 35 respondents, leaving 625 (94%) valid responses. Of these, 18 individuals (3%) preferred not to give their ICS. The sample size was therefore 625 individuals for analysis at the regional level and 607 for analysis by ICS.

By area

The breakdown by area as defined by the ICS selected, is shown in *Chart 1*. The average number of responses per ICS was 104 and ranged from 79 in Hertfordshire & West Essex to 142 in Norfolk & Waveney.

Chart 1:
Responses by area in the East of England (ICS)



By perspective

Recognising that people may have multiple experiences of terminal illness, participants in the survey were initially asked to tick all statements that applied to them:

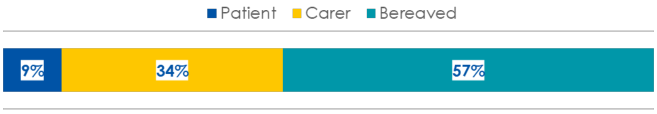
1. I’m living in the East of England with a terminal illness
2. I’m a family member or friend supporting and/or caring for someone living in the East of England with a terminal illness
3. I’m a volunteer or community member supporting and/or caring for someone living in the East of England with a terminal illness
4. I’m a health, social or other care sector professional but also supporting and/or caring for someone living in the East of England with a terminal illness in my personal capacity
5. I’m a bereaved family member or friend of someone who has died from a terminal illness in the last 2 years

Respondents were then asked to choose one perspective from which to answer the survey. For the purpose of this analysis, we have combined responses from 2, 3 and 4 to provide a single ‘carer’ perspective. However, the breakdown by type of carer was:

- Family member or friend (62%)
- Health, social or other care professional supporting in personal capacity (23%)
- Volunteer or community member (15%)

The breakdown by perspective is shown in *Chart 2* and shows that 9% of responses were from patients themselves, just over a third (34%) from carers and just over a half (57%) from recently bereaved family and friends.

Chart 2:
Responses by perspective



Multiple perspectives

- 59 people (9%) ticked more than one perspective
- 57 people had two perspectives; two had experience of terminal illness, being a carer and being bereaved
- Most people with multiple experiences (53 people) had been a carer and bereaved

About the respondents

Demographic questions were asked of the person completing the survey (rather than the patient). For the 9% of patients completing the survey, the demographic data they provided related to themselves. The demographic profile of respondents is shown in the following tables and charts. About three-quarters of respondents were women (78%) and in the age range of 45 to 74 years (73%). They identified as predominantly White British (92%) and Christian (48%).

Table 1:
Respondents by gender identity

Gender identity	No. of responses	% of total (625)
Male	93	**15%**
Female	488	**78%**
Non-binary/ other	1	**0%**
Prefer not to say	43	**7%**

Chart 3:
Respondents by age group

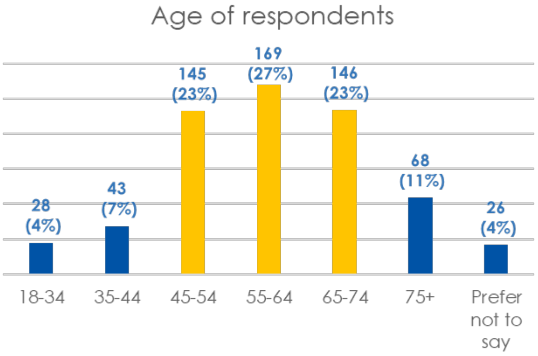


Chart 4:
Respondents by ethnicity

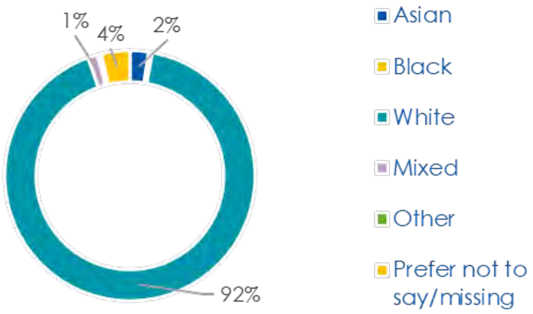
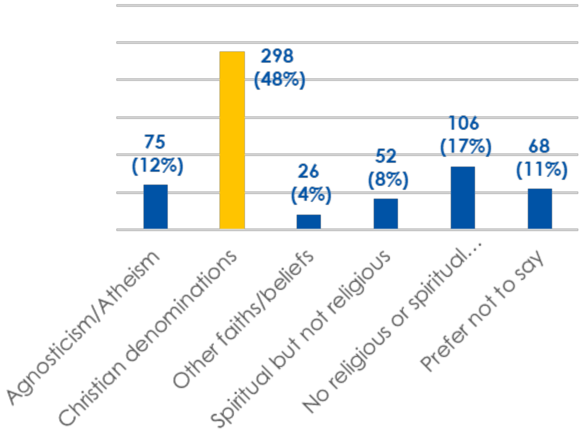


Chart 5:
Respondents by religion



Whilst efforts were made to remove barriers to participation in the survey (eg language support, different formats, etc), at just 8% the number of people from non-White groups who responded to the survey is low (but in line with national statistics on ethnicity of the general population in this region of the UK). It has therefore not been possible to explore responses by ethnicity. As highlighted in Marie Curie's *Better End of Life Report*, research to understand experiences and outcomes of care for minoritised ethnic groups is needed.

How representative of the East of England was this sample?

Compared to the general population in the East of England, survey respondents were more likely to be mid-life women with a disability. This is consistent with sample respondents being predominantly carers or bereaved family members.

About the patients

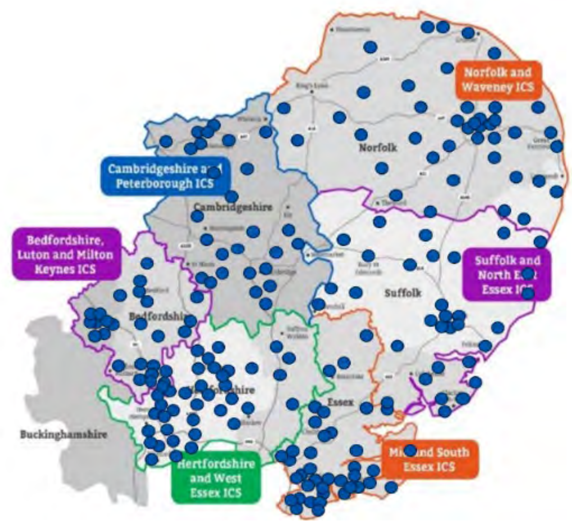
In this section we use the term ‘patients’ to refer to those currently living with a terminal illness, as well as to refer to those people being cared for or who had died.

Location

Respondents were asked to include their postcode district (three or four digit) or the postcode district of the person they care/d for. This was a non-mandatory question, however 579 respondents (93%) provided a valid postcode district. (Interestingly, this also included 11 individuals who did not want to give their ICS.)

The blue dots on the map in *Figure 3* represent one or more response for a postcode district (location approximate). There were less than ten responses for each postcode location except Huntingdon (10 responses) and Chelmsford (12 responses, CM1 and 11 responses, CM2).

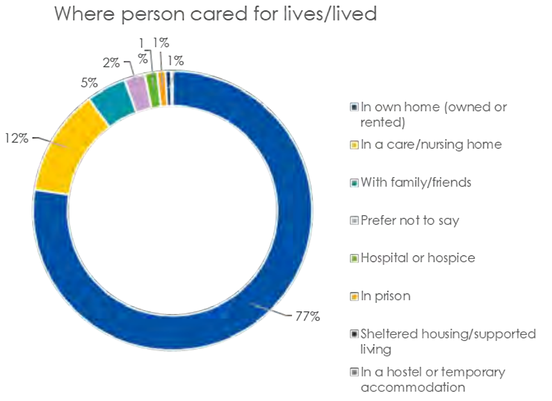
Figure 3:
Location of patients by postcode



Setting

Over three-quarters (77%) of patients lived at home (owned or rented) and of these nearly a third (32%) lived on their own, at least sometimes. 12% said they lived in a care or nursing home. (*Chart 6*)

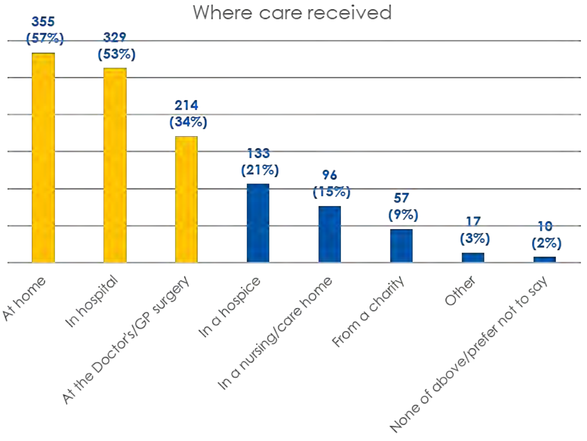
Chart 6:
Where patient/person cared for lives/d



Where care received

Care was mostly received at home (57%), in hospital (53%) and/or the GP surgery (34%). Only one fifth (21%) had received care in a hospice. (*Chart 7*)

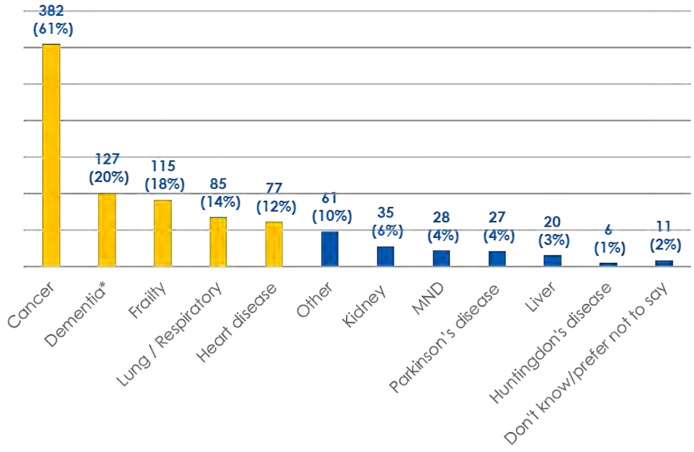
Chart 7:
Where care received



By condition

The majority of patients had cancer (61%). The other most prevalent conditions were dementia (including Alzheimer's) (20%), frailty (18%), lung or respiratory disease (14%) and heart disease (12%). (*Chart 8*)

Chart 8:
Patient Condition[10]



179 people (29%) selected more than one condition, indicating just under one third of patients had comorbidities.

FINDINGS

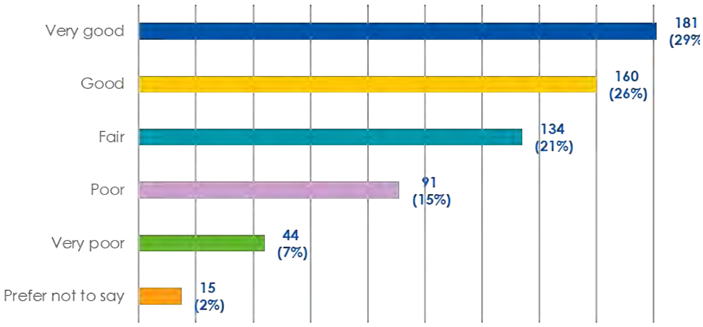
In this report, we present the findings from the East of England as a region. Individual Data Packs presenting the data at the individual ICS level have been shared with local system leads and are available on request. Please note that due to rounding of all percentages, totals may not necessarily equal 100%.

Overall experience

At the beginning of the survey, respondents were asked to rate their overall experience of care in relation to their terminal illness.

Over half (55%) rated the overall experience of care as 'Very good' or 'Good'. However, more than one fifth (22%) rated their overall experience of care as 'Poor' or 'Very poor' with a further 21% rating it only as 'Fair'.

Chart 9:
Overall, how would you rate the experience of care you've received for your terminal illness?



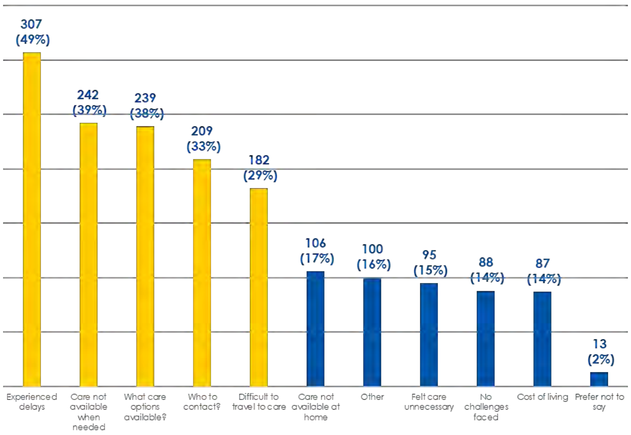
Some respondents noted that it was difficult to give an overall rating as experience of care was not consistent, depended on the setting and individuals involved and often changed over time. This was powerfully illustrated in the experiences people shared in the free text responses and interviews. Also strongly evidenced in the quantitative data was that those who had received hospice care reported a significantly better overall experience, with 74% rating this as 'Very good' or 'Good'.

Notes on Variation in Data	
By ICS	- Patterns were similar by ICS.
By Perspective	- Those who had been bereaved were more likely to rate their overall experience as 'Poor' or 'Very poor' (27%).
By Care Location	- Good or better responses were higher for hospice care (74%) than for hospital care (49%). Only 11% of hospice care was rated poor or very poor overall compared to over a quarter (27%) of hospital care.
Living alone	- Pattern similar among those living alone and those living with others.

Challenges

Towards the end of the survey, we asked respondents to indicate whether they had experienced any challenges with their care and to select from a range of options. *Chart 10* shows the frequency and ranking of the challenges identified.

Chart 10:
Challenges most frequently cited



In evaluating people's overall experience of care, it is noteworthy that **only 14%** of respondents reported no challenges, while the **vast majority (86%)** selected at least one challenge and **nearly two-thirds (62%)** identified multiple challenges.

BY AMBITION

In this section we look at the findings by Ambition, presenting quantitative data from the survey questions as well as qualitative insights gained from the free text responses, interviews and small group discussions.

Quotes attributed with an * indicate a perspective shared by a participant in an interview or small group discussion. All others are taken from the free text responses in the online survey.

It should be noted that the interviews and small group discussions were not structured directly around the Ambitions but allowed for more open responses in terms of respondents' experience of care including what was good, what was not so good and what they thought needed to be improved. As a result, mapping their responses to the Ambitions was not always straightforward, and in some cases, their input pertained to multiple Ambitions. Given their interconnected nature, there was also an inherent level of subjectivity in aligning responses with a particular Ambition.

In presenting the data for each Ambition we have also included a table to summarise any significant variations in data, including by ICS, perspective, demographic, care location and those living alone.

AMBITION 1: Each person is seen as an individual

> *I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.*

Ambition 1 focuses on treating each person – whether patient or carer – as an individual. This includes ensuring that patients and their families have opportunities to discuss their care with healthcare professionals and receive care that is personalised and aligned to their wishes.

Quantitative Findings

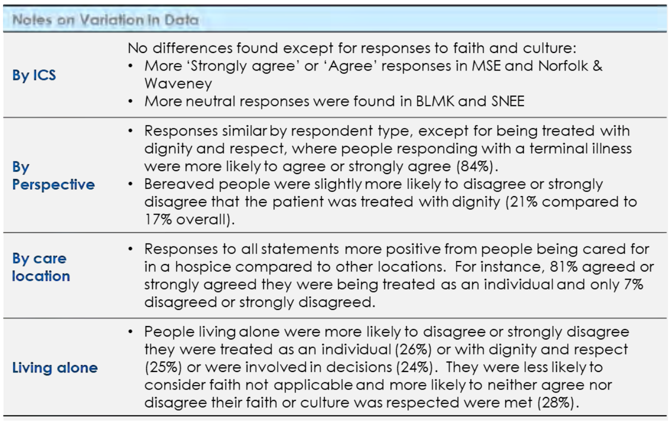
How the patient was treated

To assess people's experience against this Ambition, we asked respondents to reflect on how they were treated with regards to their care and to say to what extent they agreed or disagreed with a number of key statements. (*Table 2*)

- Just **over two-thirds** 'Strongly agreed' or 'Agreed' that the person cared for was 'treated as an individual' **(68%)** and **'**treated with dignity and respect' **(68%).**
- **Slightly fewer** 'Strongly agreed' or 'Agreed' that the person cared for was 'involved in decisions about their care as much as they wanted to be' **(61%)** and 'their wishes were listened to and considered' **(60%)**.
- **Nearly a fifth** 'Disagreed' or 'Strongly disagreed' with each of those four statements.
- With regards to whether the care recipient's 'faith and culture were respected and supported', interestingly **over a quarter (28%)** selected 'Not applicable' or 'Don't know'. When these responses were excluded, just under two thirds **(64%)** 'Strongly agreed' or 'Agreed' that their faith and culture were respected, **29%** 'Neither agreed nor disagreed' and **7%** 'Disagreed' or 'Strongly disagreed'.

Table 2:
How patient was treated

	Treated as an individual	Treated with dignity and respect	Involved in decisions about care	Wishes listened to and considered	Faith and culture respected
Strongly agree	33%	34%	28%	29%	22%
Agree	35%	34%	34%	31%	25%
Neither agree nor disagree	14%	13%	16%	16%	19%
Disagree	11%	11%	11%	12%	3%
Strongly disagree	6%	6%	6%	7%	3%
Not applicable/ Don't know	1%	1%	5%	4%	28%



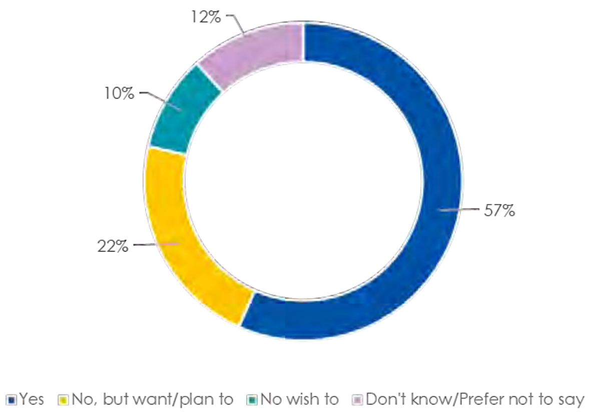
Notes on Variation in Data	
By ICS	No differences found except for responses to faith and culture: • More 'Strongly agree' or 'Agree' responses in MSE and Norfolk & Waveney • More neutral responses were found in BLMK and SNEE
By Perspective	• Responses similar by respondent type, except for being treated with dignity and respect, where people responding with a terminal illness were more likely to agree or strongly agree (84%). • Bereaved people were slightly more likely to disagree or strongly disagree that the patient was treated with dignity (21% compared to 17% overall).
By care location	• Responses to all statements more positive from people being cared for in a hospice compared to other locations. For instance, 81% agreed or strongly agreed they were being treated as an individual and only 7% disagreed or strongly disagreed.
Living alone	• People living alone were more likely to disagree or strongly disagree they were treated as an individual (26%) or with dignity and respect (25%) or were involved in decisions (24%). They were less likely to consider faith not applicable and more likely to neither agree nor disagree their faith or culture was respected were met (28%).

Opportunity to discuss end of life wishes

In line with Ambition 1, we also asked specifically whether those receiving care had had the opportunity to discuss their end of life wishes, and if yes, what they had discussed.

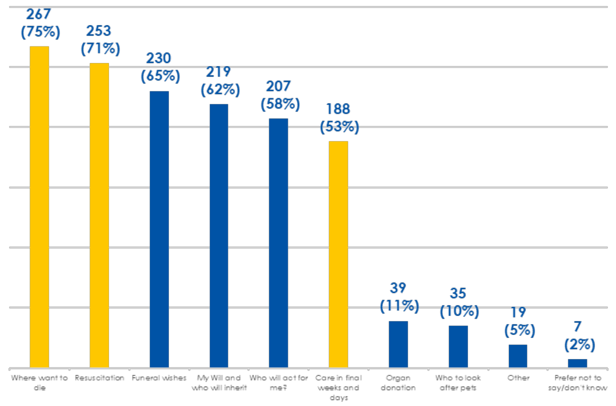
Just over half (57%) said they had had the opportunity to discuss their end of life wishes with a further **22%** saying they had not, but wished to.

Chart 11:
Opportunity to discuss end of life wishes



Of the 354 people who had discussed their end of life wishes, **about three-quarters** had talked about 'where they wanted to die' **(75%)** and 'whether they wished to be resuscitated if their heart stopped' **(71%)** but **only just over half (53%)** had discussed the important topic of 'their care in final weeks and days'. (*Chart 12*)

Chart 12:
End of life wishes - topics discussed



Qualitative Findings

Meeting Ambition

The free text responses and interviews provided plenty of evidence to demonstrate progress towards achieving the vision of personalised care outlined in Ambition 1.

Treated as an individual

In all areas of the East of England, there were examples of people praising the care they had received, highlighting how they were seen as an individual, treated with dignity and respect, involved in decisions about their care and had their wishes listened to and considered:

> *"The consultants have been very good at explaining the positives and negatives around not having Chemo so my Mum could make her own decision. Mum has been supported with dignity and compassion throughout."*
>
> Carer (Mid & South Essex)*

> *"The [hospice] care they received was incredible. They listened to his needs. They asked him what he wanted most. They made sure those wishes were fulfilled to the absolute best of their abilities and gave him dignity."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)

> *"Community care (washing dressing etc) fantastic team very supportive always involved patient when able to. Asked questions if didn't know! Empathetic and respectful."*
>
> Bereaved (Norfolk & Waveney)

There were examples of where this individualised and respectful care was extended to family carers too:

> *"We all received the best care, compassion and respect - both for our relative having palliative care, and us, as a family."*
>
> Carer (Bedfordshire (Luton & Milton Keynes)

One carer praised the way they had been treated, highlighting how healthcare professionals actively consulted and involved her:

> *"The care my husband received was outstanding. They arrived and asked me what kind of evening he had had any problems through the night and would be a support to me and my husband. They listened to me but then spoke with my husband and asked him to make decisions for himself."*
>
> Bereaved (Hertfordshire & West Essex)

Some respondents spoke about how such care allowed the person to have the end of life experience they hoped for:

> *"My wife's palliative care was excellent and was provided by the hospice at home team who were able to give her the safe and calm ending that she wanted."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)

Personalised care involved not only recognising the patient's unique needs and wishes, but also involving family members and supporting them through the process too:

> *"The last 3 weeks of my mother-in-law's care were very good. She was in her own home with support around her. The District Nurses acted like a UN peace keeping team and helped to negotiate family issues. They supported family members to understand patient decisions were the at the forefront. It was refreshing to have people involved who understood what a good death meant."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)*

Opportunities to discuss end of life wishes

There were examples of people having had the opportunity to proactively discuss their end of life wishes:

> *"My husband used the Living Well sessions to discuss his wishes and they ensured he had the peaceful death at home that he wanted."*
>
> Bereaved (Cambridgeshire & Peterborough)

These thoughtful conversations provided peace of mind and allowed for meaningful preparation:

> *"The GP explained the death, what would happen and so on, so it wasn't a shock. This gave us time to talk about things. We had time to plan his wake and funeral which was so important to him."*
>
> Bereaved (Norfolk & Waveney)*

Such overall positive reports of personalised care were most frequently cited within the hospice and community care setting. As one patient starkly put it:

> *"Part of the reason I am terminal is because of GP and hospital failings. On the other side I had amazing support from the hospice when I contacted them. ... I felt listened to, heard and respected - completely opposite to my experience under the gastro cancer team at the hospital."*
>
> Patient (Suffolk & North East Essex)

Not Meeting Ambition

Unfortunately, the free-text responses and interviews also provided plenty of evidence that Ambition 1 is not being consistently met. Several distressing experiences were shared, showing that patients often felt they were not treated as individuals, were poorly informed, or were not treated with dignity and respect.

Not treated as a whole person

A common theme was patients feeling they were treated as their condition rather than as a whole person. Many felt their wishes were not considered, with medical professionals focusing on symptoms and curative treatments, rather than adopting a person-centred approach.

> *"Medical professionals are looking at the symptoms and the condition in front of them, not the whole person.... I was not in a position to choose. I should have been given time and chance. And the respect of discussing things properly with me before any decision was made."*
>
> Patient (Bedfordshire, Luton & Milton Keynes)

One respondent went so far as to say:

> *"We were like a scientific experiment, no-one was listening to us."*
>
> Bereaved (Hertfordshire & West Essex)

Another raised some challenging questions about the overly clinical approach of some medical professionals:

> *"Do they engage with you as a human being? Do they address illness as a collaborative effort or see as a problem to solve, categorise, allocate to the right slot?"*
>
> Patient (Cambridgeshire & Peterborough)*

The perceived focus on treatment rather than the individual was described by some right up until the end. As one interviewee shared:

> *"The last night of his life – the On Call team in particular did not listen. In their minds they were trying to treat - not look at the whole patient. They just needed to listen. To their patient, to their family."*
>
> Bereaved (Cambridgeshire & Peterborough)*

Patient wishes not considered

Some respondents expressed frustration and distress at patients having their wishes overlooked or disregarded, leaving them feeling ignored:

> *"My consultant took a few meetings to understand my wishes and reasons for refusing treatment, which was traumatic. I wasn't truly listened to. The consultant handed my care to the GP, who hasn't contacted me since. I don't want treatment but expected help with an end of life plan—alas, nothing."*
>
> Patient (Norfolk & Waveney)

Carers not respected or valued

From a carer's perspective, several expressed concern at not being consulted or listened to regarding their loved one's care. They shared stories of feeling unheard and dismissed by healthcare professionals. As one carer shared:

> *"I had a chat with the Consultant as I thought we needed to make decisions about next steps. I could see that my aunt was end of life. I felt not listened to the whole time. The Consultant came in and said "you need to encourage your aunt to eat" oblivious to the fact that we had been trying to do that for the last month."*
>
> Bereaved (Norfolk & Waveney)*

Another carer criticised healthcare professionals for:

> *"Not listening enough to the family regarding the real needs of the patient especially when they are so vulnerable."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)

Family members of patients who were not able to communicate for themselves, for example those with dementia and motor neurone disease (MND), expressed concern that their views and understanding of the patient were often not taken into account:

> *"When someone has Alzheimer's or dementia their day-to-day carers know them best and must be considered. This is not always the case, even with Power of Attorney. More needs to be done."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)

Lack of honest, informed and timely conversations

A key issue highlighted by many respondents was the absence of open and honest communication regarding terminal diagnoses. In numerous cases, patients and their families felt in the dark about the condition, the likely progression and the care options available. This lack of transparency made it difficult for families to prepare emotionally and practically, creating unnecessary distress during an already challenging time.

One family carer shared their frustration at the lack of explanation regarding their family member's condition and the absence of end of life planning:

> *"Things about the conditions have not been explained, like, what they are, what can be done to help him with the symptoms. No one has talked to him about end of life apart from telling him that they did not advise resuscitation when he was last in hospital."*
>
> Family carer (Cambridgeshire & Peterborough)

Another shared how the lack of open communication significantly affected their relative's end of life experience and left the family grappling with complex grief:

> *"Lack of support, and open and honest conversation with family about end of life, what to expect and how family could support patient. Lack of information resulted in patient being on their own when they died and this has been difficult for the family to reconcile."*
>
> Bereaved (Mid & South Essex)

The absence of advance care planning (ACP) and proactive discussion about care wishes at the end of life, was also reported.

> *"There has been no ACP discussion no discussion of palliative care no follow up since diagnosis."*
>
> Carer (Norfolk & Waveney)

One family member highlighted how the lack of communication about the patient's prognosis and needs left them struggling to access adequate care:

> *"I am appalled by the lack of communication and no advance care plan*

being put in place and the fact that it was not communicated to the patient or family, that they were close to dying, and we had to literally fight for every bit of care, intervention and pain relief constantly!"

Bereaved (Bedford, Luton & Milton Keynes)

Reluctance to acknowledge end of life

Some respondents observed a distinct reluctance among healthcare professionals to actively engage in discussions about palliative care even when the patient's condition deteriorated or the prognosis was very poor. A bereaved wife explained how her husband was completely unaware of the severity of his condition, with doctors hesitant to be realistic about his prognosis:

"Right up to the end, my husband thought he had another 5 years to go. Doctors wouldn't have those conversations with him. They were so focused on fixing things, talking about trials, leaving doors open. It baffles me that this happens when 95% of patients die within a year, and they still find it difficult to talk about. If this is their job, I don't understand why they are still nervous."

Bereaved (Hertfordshire & West Essex)*

Some reported that initiating conversations about palliative care was an uphill struggle. One carer recalled having to take the lead in asking for palliative support after doctors failed to do so, despite it being clear that treatment was no longer effective:

"At no point did anyone mention any palliative care. In the last 2 years we spent a lot of time contacting doctors to say the medications were not making my mother-in-law feel better. I basically had to ask for palliative support before the GP even suggested it. The GP just wanted to change her medications again but even my mother-in-law was aware that this wasn't what she needed."

Carer (Suffolk & North East Essex)

Some respondents expressed resentment towards healthcare professionals for deferring such difficult conversations to patients or their families, adding to their emotional burden:

"It very much felt like the medical teams were not 'brave enough' to have these conversations, and they were left for the family and patient to initiate."

Bereaved (Suffolk & North East Essex)

Lack of compassionate communication

For many patients and their families, receiving a terminal diagnosis was not only an emotional shock but also an experience marked by a lack of compassion and support. Several respondents described how the conversation was blunt, with little consideration for the emotional impact or practical guidance on what to do next.

One patient shared their experience of being given their diagnosis in a way that left them both overwhelmed and traumatised:

"I was told outright in a respiratory clinic, 'You have inoperable and incurable lung cancer, and it's spread to your brain.' Before that, I knew nothing—just a bit of breathlessness and a cough. The way it was delivered frustrated me—the shock was so overwhelming it gave me PTSD."

Patient (Norfolk & Waveney)*

Another carer recounted the brutal manner in which their partner's diagnosis was shared, with no additional support or resources offered afterwards:

"The appointment at the hospital was the most harrowing we've ever had. The consultant said, 'You have a glioblastoma, you have 3 months to live, and we would not recommend treatment.' We were stunned. We drove home in silence. It was brutal. No additional support was provided—no talk of counselling or signposting. We were left to figure out what to do next on our own. The follow-up visit from the GP was equally brutal. He was only focused on getting the ReSPECT form completed."

Bereaved (Norfolk & Waveney)*

A further account echoed this experience, demonstrating a lack of clear guidance after a terminal diagnosis:

"The doctors basically said there is nothing more we can do. There was zero signposting to know what to do."

Carer (Hertfordshire & West Essex)*

Some were made aware that such experiences were an outcome of an overstretched system. As one family member shared:

> *"My father was receiving treatment for cancer, and we were led to believe it was having an impact, to then out of the blue be told he was on end of life care and sent home. He was told on a busy ward and sent home. I contacted the ward to express my concern at his treatment and was told this happened regularly as they didn't have space to have 1-1 discussions."*
>
> Bereaved (Norfolk & Waveney)

However, some also observed a lack of confidence and skills of healthcare professionals, particularly consultants and GPs, in having compassionate end of life conversations. *(Covered further under Ambition 5: Staff prepared to care.)*

End of life wishes not respected

Some shared distressing accounts of their wishes being ignored even when such plans were in place and clearly documented:

> *"He had a thorough ReSPECT form created with me, his daughter, and the Consultant. It stated he didn't want to lose his dignity or be in pain. Yet, the day he was sent home, he lost all of his dignity. When he woke up agitated and in pain, the On-Call team wanted to escalate care with a catheter and chest x-ray. I had to fight for two hours, reminding them of his wishes. He died four hours later after finally receiving sedation – finally peacefully."*
>
> Bereaved (Cambridgeshire & Peterborough)*

> *"In the last 48 hours of his life his DNR was completely ignored. No one contacted me to discuss, even though I had Power of Attorney. He was very upset, confused and the nurses were ignored when they pointed out that he had a DNR. That just meant my poor old Dad hung on for another two days of pain and sadness."*
>
> Bereaved (Norfolk & Waveney

In Summary ...

While there is evidence of progress towards achieving Ambition 1- ensuring that patients and carers are treated as individuals with personalised, respectful care - significant gaps remain. Many respondents shared positive experiences where care was empathetic, their wishes were respected and they were supported to achieve a dignified end of life. However, these experiences were inconsistent, with frequent reports of patients and carers feeling unheard, disrespected, or excluded from critical decisions. The reluctance of some healthcare professionals to engage in honest, timely and compassionate conversations about end of life care often left patients and families unprepared and unsupported. This underscores the importance of enhancing the knowledge and expertise of all healthcare professionals in supporting patients with palliative and end of life care needs.

Priority Areas for Improvement

Participants in the study identified several priority areas for improvement relating to Ambition 1 and ensuring each person is seen as an individual.

➢ **Treat the 'whole person':** Focus on treating individuals as humans with families and loved ones, not just as patients.	*"Treat people more holistically, as humans, with families and loved ones."* Carer (Norfolk & Waveney)* *"Sit down with families and understand a bit more about the situation, their background, the person they are treating. So they can understand the bigger picture and situation and not make assumptions."* Bereaved (Mid & South Essex)*
➢ **Respect patient choices:** Provide early and ongoing information about disease progression, and act promptly to changes in the patient's condition, respecting their wishes and providing necessary information.	*"Adequate information given from point of diagnosis; ongoing involvement in discussions re. disease progression would be helpful."* Carer (Mid & South Essex) *"Act when a person starts to deteriorate. Respect the person's wishes but discuss the choices and the fors and against. Give them Information to allow them to make the best choice."* Bereaved (Suffolk & North East Essex)
➢ **Promote honest and timely communication:** Acknowledge end of life situations openly and communicate sensitively and clearly with patients and families.	*"… nursing staff should not be afraid to acknowledge when someone is dying as it is better to be honest with patients and their families."* Bereaved (Bedfordshire, Luton & Milton Keynes)* *"We would have benefitted from a frank discussion at diagnosis about caring for Dad, the dying process, and hospice as an option. …Preferences vary, but everyone should have the option to understand."* Bereaved (Suffolk & North East Essex)
➢ **Enhance professional training:** Equip all healthcare professionals to have discussions about diagnosis, treatment options, and end of life care, ensuring patients and families are well-informed.	*"All health professionals should be well trained in talking to patients and families about end of life and discuss options rather than focus on prolonging life. Patients should be aware of the pros and cons of all treatment against palliative care."* Bereaved (Cambridgeshire & Peterborough)
➢ **Involve and inform carers:** Ensure carers are informed, involved in decisions, and respected for their knowledge of the patient.	*"Medical profession should keep carers and kin fully informed of implications and prognoses and processes and protocols."* Carer (Norfolk & Waveney) *"As a daughter and carer to be listened to as often close relatives know the ill person best."* Carer (Norfolk & Waveney) *"In relation to provision of necessary helpful equipment, the professionals making the decisions should discuss and take into consideration the opinions of the carers actually caring for the patient as they actually are experiencing what is actually helping and what is not."* Bereaved (Norfolk & Waveney)

AMBITION 2: Each person gets fair access to care

> *I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*

Recognising the challenges posed by health inequalities and the impact of structural and social barriers on individuals' experiences of palliative and end of life care, Ambition 2 strives for equitable access to care for all.[11]

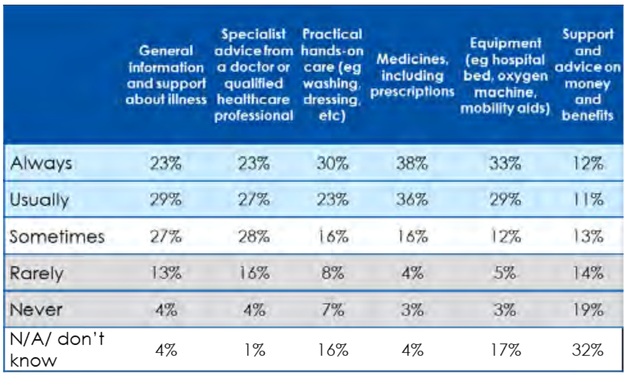
Quantitative Findings

Accessing care

In assessing people's experiences in relation to Ambition 2 and fair access to care, we asked respondents whether they were able to get fundamental aspects of care, when they needed it.

- **Nearly three-quarters (74%)** felt they or the person cared for 'Always' or 'Usually' had access to 'medicines, including prescriptions'.
- **Less than two-thirds (62%)** 'Always' or 'Usually' had access to 'equipment (eg hospital beds, oxygen machines, mobility aids)'.
- And only **about half** 'Always' or 'Usually' had access to the following when needed:
  - 'practical hands-on care (eg washing, dressing, etc)'. (**53%**)
  - 'general information and support about their illness'. (**52%**)
  - 'specialist advice from a doctor or other qualified healthcare professional'. (**50%**)
- **Nearly a third (32%)** said they were 'Rarely' or 'Never' able to 'access support and advice on money and benefits'. When 'Not applicable/Don't know' responses were excluded (32% of the sample), this increased to **almost half (47%)** who said were 'Rarely' or 'Never' able to access this advice.
- **A fifth (21%)** said they 'Rarely' or 'Never' had access to specialist advice from a doctor or healthcare professional, with a further (**28%**) saying only 'Sometimes'.

Table 3:
Access to key aspects of care when needed



	General information and support about illness	Specialist advice from a doctor or qualified healthcare professional	Practical hands-on care (eg washing, dressing, etc)	Medicines, including prescriptions	Equipment (eg hospital bed, oxygen machine, mobility aids)	Support and advice on money and benefits
Always	23%	23%	30%	38%	33%	12%
Usually	29%	27%	23%	36%	29%	11%
Sometimes	27%	28%	16%	16%	12%	13%
Rarely	13%	16%	8%	4%	5%	14%
Never	4%	4%	7%	3%	3%	19%
N/A/ don't know	4%	1%	16%	4%	17%	32%

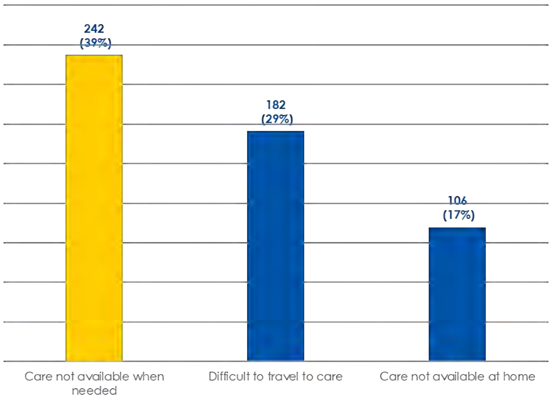
Variation in Data	
By ICS	• Hertfordshire respondents were less likely to always or usually receive specialist advice (41%) and Cambridge respondents more likely (62%). • More Bedford (25%) and Suffolk (25%) and fewer Cambridge (12.1%) respondents rarely or never received specialist advice.
By Care Location	• People cared for in a hospice were more likely to report usually or always receiving general information, specialist advice, hands on care, emotional and practical support and money and benefits. For instance, 34% of people in hospice reported usually or always receiving support with money and benefits compared to 23% in other care locations; 68% for specialist advice compared to 50% in other locations. No differences were found for medicines and equipment. • People cared for in hospital were less likely to report always or usually receiving practical support and equipment (55%), though they also were less likely to need equipment (22%). No difference for general information, specialist advice or medicines.
Living alone	People living alone were more likely to report only rarely or never having access to equipment needed (13%) and only sometimes, rarely or never receiving practical hands-on care (40%) and specialist advice (56%)
By Demographic	Non-white British respondents were more likely to need benefits and money advice than white British respondents. They were: • more likely to say advice was available only 'Sometimes' (27%) compared to white British respondents (11%) • less likely to have received advice 'Aways' and 'Usually' (18% compared to 24% among white British respondents).

A number of challenges relating to fair access to care emerged as significant issues (*Chart 13*).

- **More than one in three (39%)** said that 'care was not available when needed or quickly enough (eg at night)' and was the second most identified challenge overall.

- Challenges with location of care were experienced due to ‘difficulty travelling to where care was provided’ (29%) and ‘care not being available at home’ (17%).

Chart 13:
Challenges relating to accessing care

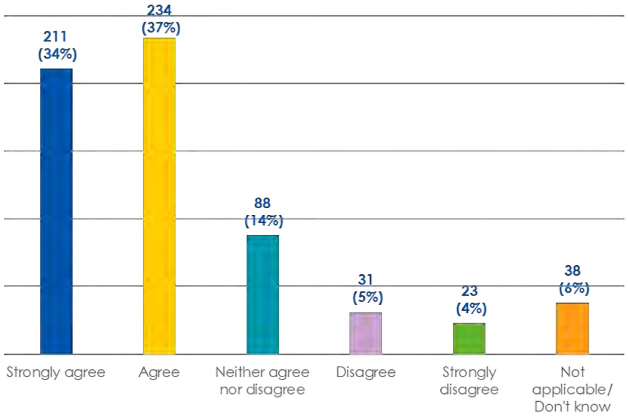


Being treated fairly

In relation to Ambition 2, we also asked respondents to what extent they agreed with the statement that they were treated fairly, regardless of their background.

- **Nearly three-quarters (71%)** ‘Strongly agreed’ or ‘Agreed’ with this statement.
- However **nearly a quarter (23%)** ‘Strongly disagreed’, ‘Disagreed’ or were neutral about this statement.

Chart 14:
Treated fairly regardless of background



As the number of people from non-White groups who responded to the survey was low. It was not possible to analyse responses by ethnicity.

Qualitative Findings

Meeting Ambition

There was some evidence in the free-text responses and interviews to suggest that the vision of equitable access to care outlined in Ambition 2 is being realised.

Several respondents shared positive experiences, highlighting the ready availability and responsiveness of key services. The accessibility of support, particularly from palliative care teams, was valued:

> *"In our case, the service by the palliative team was fantastic. We had a 24-hour helpline... it was truly remarkable."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)

> *“The Hospice at Home team were absolute heroes. A hospice bed became available for my Dad … and he spent his last 48hrs there. It was a real blessing for us all to be under their care and support.”*
>
> Bereaved (Norfolk & Waveney)

Not Meeting Ambition

However, not all respondents had such positive experiences, with many highlighting significant challenges with regards to accessing care.

Challenge in accessing medication

In contrast to the quantitative data which revealed that 74% ‘Always’ or ‘Usually’ had access to medicines, several respondents highlighted the challenges of accessing medication, particularly in rural areas:

> *“Prescriptions could not be fulfilled resulting in family members having to drive miles round Norfolk to find medication.”*
>
> Bereaved (Norfolk & Waveney)

Provision of anticipatory medicines for patients being cared for at home was identified as a particular issue:

> *"We visited five different pharmacies before finding the right medications, as many were closed or out of stock. There were not enough pharmacies open late or with enough end of life medications, and we*

could only get enough for one 24-hour period."

Bereaved (Suffolk & North East Essex)

Family carers described challenges in accessing both basic and specialist equipment to support loved ones at home, for a range of items from incontinence pads to hoists. Family members described errors in the equipment that was supplied and the negative impact that this had for both the patient and their family members:

“The most upsetting factor was the supply of equipment… Over a period of two weeks we were provided with 3 different pieces of equipment supposedly to assist my wife in standing, moving around, getting out of her chair. NONE of the equipment assisted the carers in preventing her pain and discomfort.”

Bereaved (Norfolk & Waveney)

Lack of Information and support

In line with the quantitative data, respondents highlighted the lack of access to general information and support about their illness, particularly at the point of receiving a terminal diagnosis:

"When my husband was diagnosed with his terminal illness, there wasn't much help and support - for my husband, myself and young children."

Bereaved (Bedford, Luton & Milton Keynes)

Many felt unprepared for what was to come, not having enough guidance about the illness progression or available options:

"We didn’t know what the development of pancreatic cancer without treatment was going to look like. We needed a lot more education."

Bereaved (Cambridgeshire & Peterborough)*

Lack of access to healthcare professionals

As with the quantitative data, many family members described difficulties in accessing healthcare professionals for specialist information about their condition. One respondent recounted:

“In the hospital I had easy access to doctors and nurses to help with questions. In [another hospital] the doctors were invisible and unavailable. My father didn't understand what was being discussed on the rounds and I couldn't find out.”

Bereaved (Norfolk & Waveney)

Another referenced the challenge of speaking with medical professionals, particularly with regards to discussing their relative’s needs without the patient present:

“Throughout everything there was not an opportunity to speak to a professional without Dad being there. I had so many questions that I found it difficult to get answers to. We didn’t have a chance to have private consultations to ask the questions that Dad didn’t want to ask or know the answers to.”

Bereaved (Cambridgeshire & Peterborough)*

Delays in care

Consistent with the quantitative data, many respondents reported incidences of care not being available when needed or quickly enough. In the community setting, delays were sometimes attributed to staff shortages and a lack of availability of specialist support:

"Lack of specialist support and staff shortages, with charity nurses off sick or on courses, meant symptom management fell to community nurses who couldn’t prescribe, causing delays in anticipatory medications and errors in their administration.

"Bereaved (Hertfordshire & West Essex)

Some found the escalation process and response times in the community to be inadequate – particularly out of hours:

“The escalation process for symptom control advice was unclear and the DNs attending did not have the knowledge on when or how to seek specialist advice, particularly out of hours. The response times were inadequate and visits were brief and not long enough to ensure interventions were effective.”

Bereaved (Bedfordshire, Luton & Milton Keynes)

Limited access to care outside regular hours

In line with the quantitative data, many respondents highlighted challenges in accessing care outside of regular hours.

“If it looks like you are going to die soon and this happens on a Friday there is not much

chance of getting any help till after the weekend which is ridiculous.”

Bereaved (Cambridgeshire & Peterborough)

This emerged as a particular challenge for carers looking after family members at home:

“As the carer/spouse I had to fight the whole time to get timely treatment for my partner, such as consistent district nurse visits. I often spent hours on the phone with problems arranging correct equipment or getting/finding repeat or newly prescribed drugs especially around weekends/bank holidays.”

Bereaved (Bedfordshire, Luton & Milton Keynes)

Unpredictability of care

The unpredictability of care was a recurring theme among respondents, several of whom likened their experiences to a game of chance. One respondent described the situation as feeling like a ‘roll of the dice’, emphasising the random nature and uncertainty in accessing necessary care:

“At every stage it felt like a roll of the dice that the necessary care would be available.”

Carer (Cambridgeshire & Peterborough)

Another respondent compared their experience to a game of ‘snakes and ladders’:

“We have found our overall experience to be like a game of snakes and ladders. Your experience is completely reliant on what square of the game you land on.”

Patient (Cambridgeshire & Peterborough)

This illustrates the ups and downs faced by individuals, where moments of advancement can be abruptly followed by setbacks, mirroring the inconsistent nature of care access. Both analogies reflect the frustration and helplessness often felt by those navigating the healthcare system, illustrating how the journey can be fraught with unexpected challenges and variable outcomes.

Geographical variations in availability of services

The quantitative data showed that location could be a factor in accessing care, and this was echoed in the qualitative findings.

Several respondents noted that access to hospice or home care services varied by region. As one respondent shared:

“There is no overnight hospice advice in our area for patients or staff. That makes things very difficult. … All services are limited,”

Carer (Mid & South Essex)

Some were acutely aware of this variation in access to palliative and end of life care across the East of England:

"We were incredibly fortunate that hospice at home care was available where my parents live... but in Suffolk, the same support was not available."

Bereaved (Norfolk & Waveney)

This disparity was noted not just in the availability of services in different areas, but also the level of service that different providers offered. One patient noted:

"Hospices across the East of England offer very different levels of service... some patients get early access, others only in the last days of life."

Patient (Cambridgeshire & Peterborough)

The disparities in service availability based on location suggest a ‘postcode lottery’ in accessing palliative care. Indeed, stories shared highlighted that limited access to hospice care was associated with poorer end of life experiences:

"My husband wished to die in the hospice, but there were no beds. When one became available, the ambulance couldn't transfer him due to his oxygen needs. He died in an inappropriate area of the hospital, not even in a side room. As a nurse, I feel the NHS let us Tdown."

Bereaved (Norfolk & Waveney)

This also applied to the availability of care for people in their own homes. Limited resources meant that care was not always felt to be well planned and families were well aware of the restrictions within and limited capacity of services:

“The 2 night sits we were allocated were extremely helpful as my relative had very restless nights and family exhausted. However allocation of this was very last minute and the

way we were informed highlighted how 'lucky' we were!"

Bereaved (Bedfordshire, Luton & Milton Keynes)

The variation in the provision of services meant that some respondents had to travel considerable distances to access care. For people that were unable to drive, the inequity fuelled by geographic variation in services was perpetuated:

"Of all the things that cancer has done, the worst thing it has done is taken away my driving licence as we are really isolated where we live. Being isolated is a big challenge as there are limited transport facilities available."

Patient (Norfolk & Waveney)*

The lack of availability of care in public nursing homes in East of England was also observed, raising the issue of financial inequities:

"End of life care appears to be a lottery if someone does not have a family to support them and act as their advocate. ... The hospital clearly want people out who are bed blocking, fortunately in our case money is not a problem but there seem to be insufficient nursing homes for people who cannot afford to go privately."

Carer (Mid & South Essex)

Financial inequities

Indeed, access to financial support and the ability to afford care was another theme that emerged. Some respondents expressed frustration at how difficult it was to find information about benefits and financial assistance for terminal care:

"It is impossible to find out about the financial aspects of care... even government websites don't help."

Carer (Hertfordshire & West Essex)

Others were grateful that they had access to funding to support their care, but recognised that others did not:

"We were lucky enough to have CHC [Continuing Healthcare] funding... but I feel desperately sorry for those who do not."

Bereaved (Hertfordshire & West Essex)

One respondent, who paid for private care, was acutely aware of financial inequities in terms of access to care:

"I continue to feel the weight of the decision to seek private nursing care, the guilt that not all can access this for their loved one."

Bereaved (Bedfordshire, Luton & Milton Keynes)

Reliance on advocacy of family/friends

Another key issue raised was the reliance on family members or friends to advocate for proper care. Many respondents were aware that without an advocate, patients would not have received the attention or treatment they needed:

"What concerns me is that we were able to be with my aunt 24 hours a day and advocate for her. What about the people who have no one?"

Bereaved (Norfolk & Waveney)*

There was concern for vulnerable patients who may not have the support of a family member or friend to advocate for them:

"It terrifies me how patients without advocates may be treated... it felt like a roll of the dice whether care would be available."

Bereaved (Cambridgeshire & Peterborough)

Digital exclusion

Digital exclusion was identified as another barrier to accessing essential care services:

"The GP surgery was inaccessible to the person, despite being geographically close by. Appointments had to be made by telephone and using the automated system, which the person has been unable to cope with due to early stages of dementia and lack of confidence with technology. This meant this aspect of independence was removed from her."

Bereaved (Suffolk & North East Essex)

Variation by diagnosis

Access to support was also felt to be influenced by the patient's diagnosis. For people with diagnoses other than cancer, such as dementia, motor neurone disease or Huntingdon's, access to care was thought to be especially challenging and specialist knowledge was felt to be less available:

> *"Just getting someone who understands and accepts Huntington disease"*
>
> Patient (Norfolk & Waveney)

Variation by age

Reference was also made to discrimination in the treatment of elderly patients, with some suggesting that they were often overlooked or viewed as a burden on the system:

> *"Care for the elderly is forgotten about. They are treated with no dignity no advice and are just left in the system. They're not given the same opportunity as younger people and treated as "bed blocking" in the hospital."*
>
> Carer (Bedfordshire, Luton & Milton Keynes)

In Summary ...

The findings for Ambition 2 highlight positive experiences regarding fair access to care, alongside persistent disparities and challenges. While some respondents shared accounts of accessible, compassionate care - especially from palliative care teams – it is clear many gaps remain in accessing essential services, particularly in rural areas, outside regular hours, and for non-cancer diagnoses. Geographical and financial inequities contribute to a "postcode lottery," where care quality and availability vary greatly by location and income. Structural barriers, including digital exclusion and reliance on advocacy from friends or family, disproportionately impact vulnerable individuals, highlighting systemic shortcomings. Greater investment and a more targeted effort are needed to ensure fairer and more inclusive access to palliative and end of life care services for everyone in the East of England.

Priority Areas for Improvement

Participants in the study identified several priority areas for improvement relating to Ambition 2 and ensuring each person has fair access to care.

- **Improve home-based care:** Ensure better access to palliative care at home, reducing unnecessary hospital visits.

"Patients who wish to remain at and die at home need ready access to generalist and specialist palliative care in their home. Telephone support is insufficient and leads to ambulance call outs and unnecessary attendances at accident and emergency."
Bereaved (Norfolk & Waveney)

- **Ensure equitable 24/7 palliative care support:** Set up a telephone helpline for round-the-clock advice for families caring for terminally ill patients at home, regardless of where people live.

"Access to 24/7 palliative care at home on the telephone for advice would be amazing. My relative does not want hospital treatment and if I need advice I do not want to call an ambulance or the 111 service and wait hours for a call back or visit, a telephone support line would be incredible for reassurance."
Carer (Mid & South Essex)

- **Provide information to patients and those close to them:** Ensure wrap around support is available to newly diagnosed patients and their carers, with appropriate signposting to available resources.

"More information should be shared with all family members about care and treatment so they can make an informed decision about end of life care, and the options available to them. Helpline numbers should be provided and left in the home, if loved ones caring for dying relative at home, so they know who to call for advice."
Bereaved (Bedfordshire, Luton & Milton Keynes)

"Signposting for people so understand what's available to them and how to access it. … It's like starting a new job – there's lots of unfamiliar vocabulary. It would be useful to have a cheat sheet: the DN will deal with this, just call this number, or make it really clear who all these people are. If pain becomes unmanageable who do I call? During day this number, at night this number. When you are in a panic, you're not thinking straight. Just one number or training course of all different things that are there to support."
Bereaved (Norfolk & Waveney)*

- **Increase hospice capacity:** Advocate for government funding to expand hospice care availability.

"Hospice care needs to be more widely available and funded by government rather than charity."
Carer (Mid & South Essex)

"Hospices need more support from government to carry on the work so more people with life limiting illnesses can receive their care and support."
Carer (Hertfordshire& West Essex)

- **Enhance hospital-based palliative care:** Expand the availability and scope of palliative care services within hospitals.

"Is it possible for the NHS service to have a better palliative care team within the hospital setting, not just in community? The palliative care team inside the hospital is tiny."
Carer (Mid & South Essex)*

AMBITION 3: Maximising comfort and wellbeing

> *My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.*

Ambition 3 recognises that whilst dying and death are inevitable, ensuring people are as comfortable and free from distress as possible is paramount. This means the right pain, symptom management and medical care are available to help people live as well as they can, as well as emotional care to help them feel safe and supported.

Quantitative Findings

In the survey, we had a dedicated question, aligned to this Ambition, asking to what extent respondents felt various aspects of the patient's comfort and wellbeing had been looked after.

- **Under two thirds (62%)** said that they were 'Always' or 'Usually' 'made comfortable and as free from pain as possible', whilst **35%** felt they only 'Sometimes', 'Rarely' or 'Never' were.
- Similarly, **60%** said they 'Always' or 'Usually' had 'help to manage their symptoms', but **38%** felt they only 'Sometimes', 'Rarely' or 'Never' did.
- **Just over half (52%)** felt they 'Always' or 'Usually' had their 'needs regularly reviewed', but **46%** felt they only 'Sometimes', 'Rarely' or 'Never' did.
- **Over a quarter (27%)** considered support was provided 'Rarely' or 'Never' for the patient to 'talk about their thoughts and feelings'.

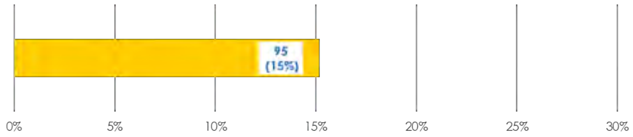
Table 4:
Comfort and wellbeing

	Needs regularly reviewed	Help to manage symptoms	Made comfortable and as free from pain as possible	Support to talk about thoughts and feelings
Always	27%	29%	30%	21%
Usually	25%	31%	32%	18%
Sometimes	28%	27%	23%	18%
Rarely	15%	8%	8%	17%
Never	3%	3%	4%	11%
Not applicable/ Don't know	2%	2%	3%	15%

Variation in Data	
By ICS	Patterns similar except for a couple of slight differences: • Fewer Cambridge respondents (10.1%) and more Hertford respondents (26.6%) rarely or never had their needs regularly reviewed. • For support in talking about feelings responses more positive than average in Cambridge and support more often rarely or never provided in Mid and South Essex and Norfolk.
By Perspective	People with a terminal illness were more likely to respond positively to each question except for being made as comfortable as possible. For instance, 69% considered their needs were usually or always regularly reviewed compared to carers and bereaved people (49% and 50%).
By Care Location	Significantly more people responded positively to these questions when cared for in a hospice (68%, 76% and 73% respectively). Only 17% of people cared for in a hospice thought there was rarely or never support to talk about feelings.
Living alone	More people living alone indicated that they rarely or never had their needs regularly reviewed (24%) and rarely or never received support to talk about their feelings (36%).

In addition, in selecting from a list of challenges, 95 people **(15%)** said the person cared for had 'received care or treatment that they felt was unnecessary or not beneficial'. (*Chart 15*) With the national *Better End of Life Report* highlighting that emergency service use in the final three months of life was high, with 61% of people who died using an ambulance and 53% visiting A&E at least once,[12] we expected this datapoint to be higher. However, the qualitative findings suggested that this was more of an issue than this quantitative data indicated.

Chart 15:
Care or treatment felt to be unnecessary



Qualitative Findings

Many respondents recounted experiences that demonstrated that steps were taken to ensure the comfort and wellbeing of patients, in line with Ambition 3.

Meeting Ambition

Comfort and wellbeing a priority

There were many examples of good care in terms of the provision of effective pain and symptom management and emotional support. This was the case across a number of settings, including hospices, community and care homes:

> *"The hospice were amazing and gave them different drugs that reduced their symptoms and stopped the pain."*
>
> Bereaved (Cambridgeshire & Peterborough)

> *"I can't say enough on behalf of my family how much the hospice from home team allowed us to be Mum's daughter, husband, son etc. whilst they dealt with the care side for Mum. They were there for my Dad as well as Mum and really provided him comfort in the worse time of his life."*
>
> Bereaved (Hertfordshire West Essex)

In some cases this focus on patient comfort extended beyond medical care, involving thoughtful gestures that acknowledged the individual preferences of those receiving care:

> *"I am grateful the home took into consideration their favourite music and continued to play it for them in their last days. I was not there for the passing but I hope that they passed listening to it."*
>
> Bereaved (Norfolk & Waveney)

Holistic approach and emotional wellbeing

Beyond physical symptoms, there were some good examples of a more holistic approach to the wellbeing of patients. One patient expressed the gratitude for the emotional support they were receiving:

> *"My local hospice provides much appreciated regular Zoom meetings which are NOT health related - talks on various subjects, quizzes and targeted poetry themes. It is so nice to escape for 1-2 hours from my health problems. They also provide information/treatment for the side-effects of previous treatments and medications. I feel very lucky to have these services, and everyone I deal with is kind, considerate and helpful."*
>
> Patient (Cambridgeshire & Peterborough)

Hospices, in particular, stood out as models of excellence, addressing not just the physical needs but the emotional and social dimensions of care:

> *"The hospice has been excellent. What they have done for me is immeasurable, priceless. ... They get it, like no one else gets it. Their wellbeing in nature/arts and crafts/breathlessness events are a lifeline to get me out of the house and take me to people who understand. Complimentary therapies also help me de-stress and relax. I have created new friendship groups and the peer support is very helpful."*
>
> Patient (Norfolk & Waveney)

This level of compassion and wrap around care was often contrasted with the lack of care offered by other healthcare providers or settings:

> *"I had amazing support from the Hospice when I contacted them. Arranged support instantly when I had been getting nowhere with GP / oncologist for months. I was able to access relaxation support and counselling and had some home visits. I felt listened to, heard and respected."*
>
> Patient (Suffolk & North East Essex)

Carer support

This holistic approach sometimes extended beyond the patient to include emotional support for carers. One carer shared how access to counselling has helped them cope:

> *"The emotional roller coaster has been extremely hard but again I am lucky and have been able to access specific counselling through a local hospice for anticipatory grief."*
>
> Carer (Mid & South Essex)

Not Meeting Ambition

However, on the whole the experiences shared indicated that respondents felt much more could be done to prioritise the comfort and wellbeing of patients and their carers.

Inadequate pain management

The issue of pain management emerged as a major concern, with many respondents describing their family member's end of life experiences as distressing due to insufficient pain relief:

> *"My husband was in a lot of pain at the end. If he was more comfortable, his death could have been better."*
>
> Bereaved (Norfolk & Waveney)

This failure to alleviate suffering often left families feeling distraught and angry:

> *"The whole experience of end of life care was traumatic, stressful and heartbreaking. I still feel angry and upset about the way my family member died. Her final days were long and drawn out with her struggling to breathe. It was definitely not a peaceful or dignified experience."*
>
> Bereaved (Suffolk & North East Essex)

Inadequate pain management was referenced particularly in the hospital setting. As one family described:

> *"I fought to get him pain medication and had to continually ask why he wasn't getting any help with his pain. In the last 48 hours of his life his DNR was completely ignored. No one contacted me to discuss, even though I had Power of Attorney. ... That just meant my poor old Dad hung on for another two days of pain and sadness."*
>
> Bereaved (Norfolk & Waveney)

However, poor pain management was referenced in the community setting too. As noted in Ambition 2, ensuring adequate pain relief for patients at home could be challenging due to limited access to and administration of the necessary medication:

> *"They wanted to die at home but at the last few days, there were issues with different community staff not acting to alleviate their pain. When there was break through pain there was often no who could come to give medication leaving them hours and hours in pain. This resulted in a request to be admitted to the hospice as it was distressing for them and us to see then in so much pain."*
>
> Bereaved (Cambridgeshire & Peterborough)

Unnecessary treatment

Although just 15% of respondents identified 'unnecessary treatment' as a challenge in the survey, this does not seem to fully reflect the experiences shared by many in the free text responses and interviews.

The administration of invasive treatments for patients nearing the end of life was a recurrent theme. Families often felt these interventions disregarded the dignity and wishes of the dying person, exacerbating their distress:

> *"We had an issue with treatment in the hospital with treatment that was considered inappropriate, invasive and unnecessary by the family and would not have been wanted by the patient. The family were not listened to and actively sidelined."*
>
> Bereaved (Suffolk & North East Essex)

One distressing account came from the daughter of a patient who described the lengths she had to go to ensure her father's comfort:

> *"My Dad only wanted to die with dignity and pain-free, and I had to fight for both of those. It was clear he was in the last hours of life, yet I had to argue with the medical team to stop trying to catheterise, cannulate, send him for x-rays, and just give him analgesia."*
>
> Bereaved (Norfolk & Waveney)

Others echoed similar concerns about the lack of sensitivity in hospital settings:

> *"The doctors in the hospital gave my mother false hope and carried on treatment and hospital admissions even though it was not achieving anything apart from distressing her*

more. Only when I became involved and started advocating for her did they listen."

Bereaved (Bedfordshire, Luton & Milton Keynes)

Such accounts highlight a need for some healthcare professionals to better recognise and respect the goals of care for terminally ill patients, focusing on comfort and dignity rather than interventions which do not focus on comfort.

Experiences of discomfort, in particular unmanaged pain, are also linked to poor access to poor coordination of care (*Covered in Ambition 4*).

In Summary ...

Findings for Ambition 3 - which recognises that while dying is inevitable, distress and discomfort should not be - highlight both positive examples of care, particularly in hospices, and significant gaps in achieving this goal consistently. Many respondents shared stories of personalised care that addressed physical, emotional, and social needs, such as thoughtful gestures, holistic therapies, and emotional support for patients and carers. However, others reported inadequate pain relief, lack of emotional support, and unnecessary treatments, particularly in hospital and community settings, leading to distress for both patients and those close to them. Continued efforts need to be made to ensure consistent and comprehensive comfort and wellbeing for individuals at the end of life across all care settings, with a particular focus on improving pain management, addressing emotional support needs, and reducing unnecessary treatments.

Priority Areas for Improvement

Participants in the study identified several priority areas for improvement relating to Ambition 3 and maximising comfort and wellbeing.

➢ **Provide immediate support:** Offer early access to counsellors and benefit coordinators for both patients and their support network.	*"Access to counsellors and benefit coordinators as soon as diagnosis confirmed."* Carer (Bedfordshire, Luton & Milton Keynes) *"Put psychological support in place for people as a matter of course, for both those with the terminal illness and their support network."* Bereaved (Norfolk & Waveney)
➢ **Adopt a holistic approach to patient care:** Focus on the overall needs of the patient, rather than just treating specific conditions, and avoid unnecessary invasive treatments.	*"Holistic approaches on all wards in a hospital. Recognition that a person is nearing end of life and for treatment to focus on the person and their needs rather than treating just a specific condition and carrying out unnecessary and sometime painful and invasive tests."* Carer (Norfolk & Waveney)
➢ **Respect patient wishes:** Ensure doctors respect the wishes of terminally ill patients, focusing on a peaceful and dignified death.	*"Doctors need to respect the wishes of their terminally ill patients and not foist a "life at all costs" mentality on them. Some people do not want a long drawn out traumatising battle that will inevitably end in their death anyway. They want to go peacefully and on their own terms. More resources should be directed to palliative care."* Volunteer/community carer Cambridgeshire & Peterborough)
➢ **Increase emotional and practical support:** Provide clear guidance, 24/7 support, and access to advice, particularly during nighttime or early hours when help is often difficult to obtain.	*"Support emotionally."* Carer (Suffolk & North East Essex) *"It would have been very helpful for the family to have had access to support / advice on what to expect, how to deal with certain situations. We felt very anxious at times and it was difficult to get help."* Bereaved (Hertfordshire & West Essex) *"If you could provide better care and support at night this would really help."* Bereaved (Mid & South Essex) *"Someone to go to in times of need and grief. A phone number to get some help early hours of the morning. When my husband died the live in carer left straight away I was on my own at 3am till doctor from hospital came a pronounced he had gone."* Bereaved (Suffolk & North East Essex)
➢ **Support terminally ill patients in living well while planning for end of life:** Ensure patients have support to live well while planning for end of life care, including discussing preferences and making informed decisions.	*"When someone has a terminal illness they should have access to a service that enables them to focus on living whilst also being able to make plans for end of life. The two should run parallel, hand in hand. Make plans and talk about eol … how we die, what we want/what we don't want … if we can do that well, I think it means you can live for each day."* Interviewee C&P"

AMBITION 4: Care is coordinated

> *I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night*

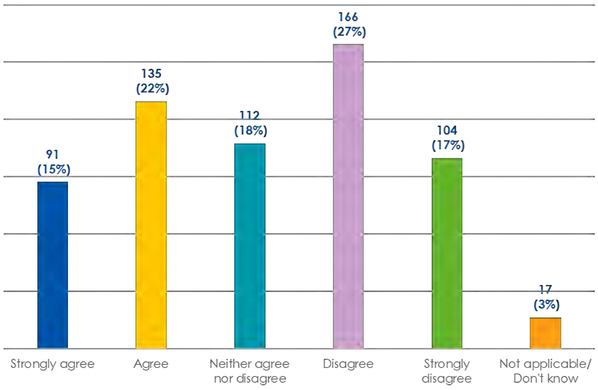
Ambition 4 recognises that many healthcare professionals and organisations may be involved in the care of a patient with terminal illness and that to ensure a person-centred approach it is critical to ensure that palliative and end of life care services are coordinated.

Quantitative Findings

To understand whether people felt their care was coordinated as set out in Ambition 4, we asked them to what extent they felt the '*different healthcare professionals knew their medical history and talked to one another*'. (*Chart 16*)

- **Only just over a third (36%)** 'Strongly agreed' or 'Agreed' that they did, whilst **over forty percent (43%)** 'Disagreed' or 'Strongly disagreed' with this statement.

Chart 16:
Different healthcare professionals know medical history and talk to one other



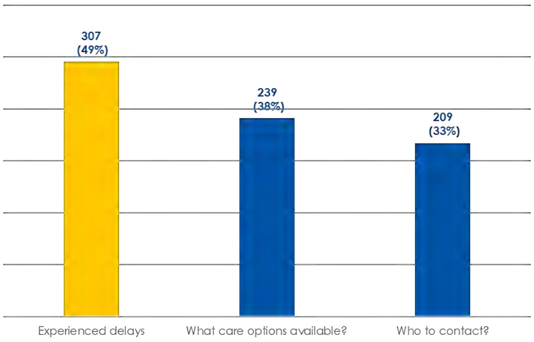
This data shows that knowledge and coordination of patient medical history among healthcare professionals was deemed to be one of the most negative experiences of care.

Variation in Data	
By ICS	Fewer Cambridge and Mid and South Essex respondents (33% and 35% respectively) and more Bedford and Norfolk respondents (47% and 51% respectively) disagreed or strongly disagreed that different professionals knew their medical history.
By Perspective	As with other aspects of care, people with a terminal illness answered more positively than other categories of respondent, but a quarter of them disagreed or strongly disagreed that professionals talked to one another.
By Care Location	• 50% of people cared for in hospital disagreed or strongly disagreed that different health professionals knew their medical history. • People cared for in a hospice were less likely to disagree or strongly disagree the different professionals knew their medical history (32%) compared to the sample overall and were more likely to agree or strongly agree (53%).
Living alone	No differences in response pattern among those living alone compared to those living with others

Challenges relating to lack of coordination of care emerged as the most commonly identified issues that people faced. (*Chart 17*)

- **Nearly half (49%)** had '*experienced delays in their care, treatment or transfer between services*'.
- **At least a third** also lacked understanding of the care system, including being unsure of '*what care options were available*' **(38%)** or '*who to contact*' **(33%).**

Chart 17:
Challenges relating to coordination of care



Qualitative Findings

Like the quantitative data from the survey, the free text responses and interviews showed that Ambition 4 was the most poorly performing area, with very few positive examples of when good coordination of care had been achieved.

Meeting Ambition

While most feedback was negative, a few respondents shared positive experiences where care coordination was delivered effectively. For example, one participant in a small group discussion remarked:

> *"Everything put in place by the GP has been excellent, and this morning the District Nurse has been on to me. Everything she said to me is being put in place."*
>
> Patient (Hertfordshire & West Essex)**

One respondent described the hospice's proactive efforts to ensure continuous care from a number of different healthcare professionals:

> *"[The hospice] were fantastic. Despite being severely underfunded and not having enough staff, they reached out to community nurses, my family member's private carers, and other groups to provide care and solutions when they couldn't get a nurse out quickly enough."*
>
> Bereaved (Mid & South Essex)

Similarly, another shared how her husband received timely and comprehensive care from a range of different healthcare providers and services:

> *"My husband was very lucky with GP support, kind and experienced carers, night support, and hospice at home."*
>
> Bereaved (Suffolk & North East Essex)

One respondent also highlighted the wrap around care and proactive support they received from their occupational and physiotherapy teams:

> *"Therapy Team (OT and PT) very very good. Listened to patients wishes, pushed for GP to listen and write Respect form following conversations. Ordered equipment quickly and supported use of this equipment, referred for help in regards to washing and dressing."*
>
> Bereaved (Norfolk & Waveney))

Seamless coordination of services once palliative care triggered

Although many reported challenges with initial access to palliative care, there was praise for the seamless coordination of services once the pathway was triggered:

> *"At the beginning it was horrific, but from when we were hooked into the Palliative Care Team, it was excellent. Care ran like clockwork once all in place. I don't think anyone could have done anything more."*
>
> Bereaved, (Norfolk & Waveney)*

Not Meeting Ambition

However, the majority of respondents bemoaned the overall lack of coordination, describing it as a major barrier to high-quality and timely care.

Lack of communication

As in the quantitative data, lack of communication emerged as a fundamental issue. This included different healthcare professionals not talking to each other or sharing information:

> *"Communication between two departments appears to be non-existent. The patient is forgotten."*
>
> Carer (Mid & South Essex)

It also included lack of communication with patients themselves, as one shared:

> *"Navigating between different departments to renew treatment is stressful and challenging because there appears to be minimal coherent communication between them and between them and myself."*
>
> Patient (Mid & South Essex)

Patients and families reported being poorly informed and confused about what was happening. One respondent recounted their experience of inadequate updates during a relative's care:

> *"We weren't kept involved in his care. We didn't know which ward he was on, and he was moved from A&E to 3 to 4 other wards. No care updates were given, and we were*

told too late about his end of life diagnosis to consider other options."

Bereaved (Mid & South Essex)

Another respondent emphasised how poor communication and a lack of collaboration between services left patients and carers feeling endlessly passed around, with no-one taking responsibility:

"So many mixed messages and a total lack of joined-up care/interventions. Patients and carers are passed on to other services. It always seems to be another service's responsibility, and we all just go around in circles, which is time-consuming, frustrating, and breaks down trust."

Volunteer carer (Norfolk & Waveney)

This experience was echoed by others who highlighted the proactive effort it took to get the care they needed:

"No one talked to each other. The GP never checked how she was, and it took a lot to get any care."

Bereaved (need to check location)

Delays in treatment and transitions between services

Consistent with the quantitative data in the survey, the delay in treatment and transitions between different services was frequently cited too. As a direct result of poor coordination and communication, patients and families reported facing long waits for tests, diagnoses, treatments, and consultations:

"Serious delays in getting test results and accessing treatments. Constantly having to follow up on appointments, medication, results. Possible options for enhanced diagnostic tests to inform treatment were not offered at the right time."

Bereaved (Cambridgeshire *& Peterborough)*

Delays in these critical stages of care often had significant consequences for patients:

"Delays in diagnosis mean my illness progressed quickly."

Patient (Cambridgeshire *& Peterborough)*

"It seemed to take too long to get a scan, then results, then meeting the consultant. Had it been quicker, there may have been a chance the cancer could have been contained."

Bereaved (Bedfordshire, Luton & Milton Keynes)

A carer described a similar experience, but highlighted disagreement, rather than lack of communication, between medical professionals as contributing to their challenges:

"Too much delay between diagnosis and treatment. Not always agreement between Consultant and the Chemo unit on what should be happening or what has been requested."

Carer (Mid & South Essex)

Delays in transfers between services were referenced, particularly in terms of transition to palliative care. One carer recalled the distressing length of time it took from consultant referral to hospice contact:

"Walking out of the consultancy room, the consultant said, 'we'll hand you over to palliative care.' That period until we made contact with the hospice felt like a long time. It took 3-4 weeks."

Carer (Cambridgeshire & Peterborough)*

Lack of joined up arrangements

Many specifically mentioned the lack of integration between different services. This was particularly highlighted in terms of discharge from hospital and the lack of arrangements in place to provide the care they needed at home:

"Lack of joined up arrangements between NHS & Social care - sent home from hospital as arranged but no special bed had been ordered."

Bereaved (Bedfordshire, Luton & Milton Keynes)

As a recurring theme, these accounts highlighted poor communication between different organisations, leading to critical delays in providing necessary equipment and support:

"There was no communication between different agencies. We had to wait 10 days after discharge from hospital to get a hospital bed delivered to home ... We were told someone would be with my mum (a medical professional at the end) - but nobody came."

Bereaved (Hertfordshire & West Essex)

Others recounted similar challenges where care that had been promised was either delayed or absent altogether. A carer described the stark difference between expectations set at discharge and the reality faced at home:

"When discharged from the hospital we were told that dad would have 24/7 palliative care available. This was not the case. He was discharged with no community nursing in place, there was little or no assistance when we needed help. And when they did arrive, sometimes it was 5 hours later."

Carer (Norfolk & Waveney)

Lack of continuity of care

Others highlighted a lack of continuity of care, noting how inconsistency in care providers often reduced the quality of care:

"She never saw the same person twice, until her very last meetings, so no consistency of care, communications lacked compassion. We had to chase scan results and appointments."

Bereaved (Mid & South Essex)

The number of different healthcare professionals involved in care was also seen to put an extra burden on patients and their families who had to fill in the gaps in the provision of patient history:

"The surgery input has been disjointed and the different visiting professionals often have to have things explained or repeated to them, meaning a significant amount of time off work to be present for home visits, (with no appointment time given)."

Carer (Suffolk & North East Essex)

Navigating the complex care system

Consistent with quantitative findings from the survey, many respondents reported struggling to navigate the care system and identify available support. This was highlighted particularly in relation to the early stages of palliative care:

"I have seen that people find it difficult to access palliative care. I'm part of my local PPG, and I've had lots of people ask questions about it—they don't know where to find information."

Volunteer carer (Mid & South Essex)

Another shared:

"Palliative care is working well once people have accessed it, but it takes some time to actually find the right place to go."

Carer (Mid & South Essex)*

Many individuals were unsure of which services were available or how to access the support they needed, leading to confusion and frustration. One carer described the overwhelming number of services and the difficulty in knowing where to turn for help:

"It is very, very confusing as a carer to know who to call. There are so many services (district nurses, rapid response care, planned care, hospice, charity night), and we had no idea where to turn to just to get a commode!"

Bereaved (Hertfordshire & West Essex)

Another family member supporting someone with dementia shared their experience of feeling unsupported:

"It was very confusing for the family to understand what would be in Dad's best interests. We had little support from overstretched staff. I had to ask the hospital chaplain for help, as I found it difficult to navigate the NHS system."

Bereaved (Cambridgeshire & Peterborough)

There were examples of people struggling to get the information they needed and knowing how to access specific services:

"We were not given any information about benefits and only found out very late on that he could have claimed Attendance Allowance. We struggled to know where to get help and eventually manged to get a hospital bed and help from [the hospice] in the last week of his life. Social Services were useless and gave incorrect information to us which delayed us getting help."

Bereaved (Norfolk & Waveney)

The overall experience with regards to coordination of care is summed up in this quote:

"There were challenges with coordination or care between different departments in the hospital and then between hospital and community (GP and community teams)

leaving family members confused as to what was done/put in place/ who to go to etc.... It required family members to be on the ball and follow up everything with the relevant health professionals."

Bereaved (Mid & South Essex)

The role of family carers and the burden of advocacy

Indeed, the emotional and physical burden put on family carers as a result of poorly coordinated services was also a prominent theme. Many respondents expressed the exhaustion of managing care logistics, following up with multiple service providers, and handling various administrative tasks. As one respondent shared:

"It is such a hard thing for everyone to go through. Having to be on top of the paperwork, copies of letters for different people, and chasing up appointments or doctors when they said they'd be in touch and weren't. It was stressful on top of the pain of seeing my mum so ill..... It was so exhausting trying to keep advocating for my mum and her care. ...It makes me feel anxious now at the prospect of getting unwell some day and receiving that same treatment."

Bereaved (Hertfordshire & West Essex)

Carers described feeling isolated and overwhelmed while trying to navigate the complexities of medical care for their loved ones. Without clear guidance or consistent support, many were left to manage difficult decisions and logistical challenges on their own. One bereaved individual reflected on the emotional and practical struggles they faced:

"I felt lost and alone in caring for the person at the beginning. There was so much worry about what to do/not to do, what to accept, what to ask for. There were medicine complications by the GP and district nurses and little to no guidance there."

Bereaved (Bedfordshire, Luton & Milton Keynes)

Several expressed concern for those without strong advocacy or professional support, recognising that the system could feel fragmented and daunting:

"I dread to think how people cope if they haven't got an advocate or someone who is constantly calling health professionals."

Bereaved

As one end of life doula shared:

"If my client wouldn't have had me as an EOL Doula, she would have been totally incapable of navigating the system on her own. ...."

Volunteer carer (Suffolk & North East Essex)

In Summary ...

Findings for Ambition 4 highlight significant challenges in coordinating care for patients with terminal illness, with many individuals and families reporting negative experiences of fragmented services, delays and poor communication between healthcare professionals. While there are some positive examples of well-coordinated care, particularly in hospice settings, these are the exception rather than the norm. The lack of coordination often leads to delays in treatment and transitions, confusion about available care options, and additional stress for patients and their families. It raises important concerns for those who do not have people to advocate on their behalf. To fully achieve Ambition 4, there is a critical need for better integration of services, improved communication between healthcare teams, and clearer guidance for patients and carers navigating the system.

Priority Areas for Improvement

Participants in the study identified several priority areas for improvement relating to Ambition 4 and ensuring care is coordinated.

➢ **Improve communication and coordination:** Strengthen communication between hospitals, GPs, district nurses, hospices and other care providers. Ensure timely responses and coordination across all departments involved in end of life care.	*"Communication needs to be improved. No one gets back to you."* Carer (Mid & South Essex) *“More communication between Hospital, district nurses and hospice and GP surgeries. Regular visits by GP to monitor end of life patients. Less time waiting for visits and continence assessments.”* Carer (Suffolk & North East Essex)
➢ **Build a centralised source of information:** Provide a directory of care services with clear contact details and process maps. Implement a seamless, shared care record system accessible to all relevant healthcare professionals.	*“One stop shop to get help and to be listened too. For all medical records to be linked to stop going over the same information and stop me having to get permission to talk on his behalf although have LPA not documented.”* Carer (Hertfordshire & West Essex) *“It would be helpful to have] a directory of care services and how to access them as well as contact details. It would be useful to have a process map in there so that you know at what point contact with these services should be made."* Carer (Bedfordshire, Luton & Milton Keynes) *“The single most important improvement would be a seamless shared care record accessible to all those appropriate.”* Carer (Cambridgeshire & Peterborough) *"It would be better if the data/info of each type of care e.g. carers/DN etc was joined up to show a better picture of the situation as and when it changes."* Carer (Suffolk & North East Essex)
➢ **Establish a single point of contact:** Appoint a designated case officer or single point of contact for all health and social care, ensuring continuity of care and minimising the need for patients and families to repeat information.	*“Each case should have a case officer to oversee everything and ensure agencies talk to each other.”* Bereaved (Hertfordshire & West Essex) *“Need a single point of contact and relationship for all health and social care.”* Volunteer carer (Mid & South Essex) *“There needs to be more collaborative working, with a single point of contact at home or in a care home for the next of kin.”* Bereaved (Norfolk & Waveney)
➢ **Enhance continuity of care with GPs**: Build stronger relationships and make It easier to book appointments.	*“I think more continuity with the GP would also make a big difference, more of a sense of personal contact and relationship.”* Volunteer carer (Cambridgeshire & Peterborough) *“Support from the GP and an easier system to navigate in terms of appointment making throughout the healthcare system.”* Carer (Mid & South Essex)

AMBITION 5: All staff are prepared to care

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

Ambition 5 relates to the empathy, skills, expertise, competence, confidence and compassion displayed by health and social care professionals supporting people with palliative care needs and those close to them. It emphasises a consistent level of professional care, no matter the setting.

Quantitative Findings

To assess people's experience in relation to Ambition 5, in the survey we asked about the qualities and behaviour of staff providing care.

- **About two-thirds (64%)** 'Strongly agreed' or 'Agreed' that those who provided care were 'knowledgeable, confident and compassionate', whilst **a fifth (20%)** 'Disagreed' or 'Strongly disagreed' with this.
- **Just over a half (51%)** 'Strongly agreed' or 'Agreed' that staff 'gave enough information so that the patient/carer knew what to expect and could make choices about care' whilst **over a quarter (28%)** 'Disagreed' or 'Strongly disagreed' with this.
- **Similarly, just over a half (52%)** 'Strongly agreed' or 'Agreed' that staff 'understood what mattered most to the patient and worked with them to do what was possible' whilst **over a quarter (26%)** 'Disagreed' or 'Strongly disagreed' with this.

Table 5:
Staff prepared to care

The people who provide care …	Are knowledgeable, confident and compassionate	Give enough Information so know what to expect	Understand what matters most and work with me to do what's possible
Strongly agree	31%	23%	25%
Agree	33%	29%	27%
Neither agree nor disagree	15%	19%	20%
Disagree	13%	17%	17%
Strongly disagree	6%	11%	9%
Not applicable/ Don't know	1%	2%	2%

Variation in Data	
By ICS	• Higher proportion of respondents in Cambridge and Peterborough agreeing or strongly agreeing that staff were knowledgeable (76% compared to 64% for the region) • Norfolk respondents were more likely to disagree or strongly disagree (28% compared to 20% for the region)
By Perspective	People with a terminal illness were more likely to agree or strongly agree staff were knowledgeable and gave enough information compared to other groups.
By Care Location	Responses for people cared for in hospice were more positive than in other care locations. Hospice care respondents answered agree or strongly agree for knowledgeable (77%), gave enough information (64%) and knew what mattered most (68%).
Living alone	No differences in response patterns among those living alone compared to those living with others

Qualitative Findings

Meeting Ambition

Throughout the free text responses and interviews there was plenty of evidence demonstrating good progress towards this Ambition.

Positive examples across all roles

Across the region and in a range of settings, respondents gave examples of staff providing competent, confident and compassionate care. This included a wide range of roles.

> *"Blessed with people who have gone out of the way to show empathy, humanity – making our whole experience more manageable."*

Carer (Mid & South Essex)*

"Every person that we saw at the Consultant level (we had been seeing a number of services: psychology, neurology and cancer) each of the professionals were outstanding. The way they dealt with my wife, the way they dealt with me. They explained what was going on."

Carer (Hertfordshire & West Essex)*

"We were supported by the hospice at home team. The nurse was fantastic in providing time, care, compassion, support and practical help. She organised care when needed and arranged for the OT to come in and provide equipment and advice at the right time."

Bereaved (Bedfordshire, Luton & Milton Keynes)

"My hospital oncology team and hospice team are excellent and connect me to lots of support including [charity groups]. My consultant speaks to me every month to see how I'm doing and my LCNS is always helpful if I need anything. The hospice are outstanding. Without them I'd have given up by now."

Patient (Norfolk & Waveney)

"Care in the nursing home was person focused and delivered by kind staff who knew their service users well."

Bereaved (Bedfordshire, Luton & Milton Keynes)

Praise for specialist palliative care teams

Specialist palliative care teams in particular were called out for praise. They were lauded for their responsiveness, professionalism and willingness to take the time to provide care:

"The empathy of the palliative care team is amazing. I can't believe the number of patients they have to look after. But we can get hold of them at the weekend. We know that if there is an emergency we know how to contact the ambulance, 111 and leave a message for the palliative care team. They are very, very dutiful and will always return our call. They are never cross, always listen and never give the sense that we are wasting their time."

Carer (Mid and South Essex)*

Some highlighted their compassion and ability to draw alongside patients at the most difficult of times:

"2 weeks later after a referral by the community palliative care team, the hospice got in touch and invited my Mum down. We had an introductory interview. The lady talked to my Mum like no-one has ever talked to my Mum. She was the kindest, loveliest person and explained that the hospice was there for all sorts of things, not just nursing and end of life care. They normalised it."

Carer (Mid & South Essex)*

The transformative experience of such personalised care was often cited:

"The CNS called and offered to refer us to the palliative care team, though we weren't sure what to expect. From that moment, everything changed. The team was amazing—empathetic, professional, and spent time with Mum at home, explaining what they could do and making it easy for her to understand."

Carer (Mid & South Essex)*

Paramedics and pharmacists also acknowledged

Paramedics were also called out as providing knowledgeable and compassionate support. One interviewee described the invaluable contributions of paramedics who were not only responsive in emergencies but played a pivotal role in their experience of care by guiding them through the healthcare system and connecting with essential resources:

"The paramedics turned up about 20 mins later and were amazing, ... It was only at that point that we were given a whole host of resources by the paramedics and told about the option on 111 that takes you directly to the palliative care team. They put us onto [charity]. They told us we could get a hospital bed at home which had no idea about and a commode chair. They explained how carers could be set up. They put in a call for a visit for the out of hours GP whilst with us on our behalf. They explained about the RESPECT form and organised for that to happen. They also told us about the Just In Case medicines and how that could be organised by the GP."

Bereaved (Cambridge & Peterborough)*

The dedication of pharmacists and the critical part they have to play in extending care to patients was also acknowledged:

> *"The local pharmacist was so kind. He said if my husband needed anything he would deliver medications. It felt like he cared."*
>
> (Hertfordshire & West Essex)**

Not Meeting Ambition

Variation among staff and settings

However, the experiences shared also revealed significant variation in people's perception of the preparedness of staff to provide care, and this was particularly apparent across different settings. One respondent summed up their experience in this way:

> *"The experience of care in hospital and in the hospice was vastly different. In hospital it was busy and noisy, nurses seemed indifferent to emotional needs, just doing their job, as they were so busy. Hospital doctors were slightly better - explained things quite well. In contrast the hospice was a sea of calm and peace. Nurses and doctors were all very attentive, respectful, gentle and caring."*
>
> Bereaved (Hertfordshire & West Essex)

The general praise for specialist palliative care teams was often starkly contrasted with the sentiments respondents expressed about generalist healthcare professionals:

> *"So grateful for that time at home. She seemed much more at peace at home. The way the community staff treated her - like a person, rather than just another on the list. To sum up the difference; they treated her as a person and recognised that every moment of her life was precious, whereas in hospital, because she had cancer and a stroke, they'd given up on her."*
>
> Bereaved, Mid & South Essex*

A similar experience was echoed by another family member:

> *"The Palliative Care Nurses that were part of the District Nursing Team were fantastic, as were the carers organised by [the Hospice] who helped us twice a day with toileting and bathing. The GP service however was poor."*
>
> Bereaved (Mid & South Essex)

Not enough support from General Practitioners

Respondents shared varied experiences regarding support received from GPs, often highlighting areas that were lacking. Many noted that a more proactive and personalised approach could enhance outcomes for both patients and their families. One bereaved family member reflected:

> *"GP support could have been better; they were kind but did not offer any home visits to understand how unwell or in pain my husband was, just kept upping the morphine patches by phone appointments."*
>
> Bereaved (Norfolk & Waveney)

Similarly, another respondent emphasised the importance of deeper understanding and prioritisation for palliative care patients:

> *"A challenge has been the GP not always knowing what mum's situation is. They need a better understanding and to give some more priority to palliative patients to make things a bit smoother."*
>
> Carer (Mid & South Essex)*

Compassion in care

Compassionate interactions with healthcare providers were deeply valued by families, yet some respondents noted that these were not always experienced. Instances where GP surgeries lacked empathy or sensitivity in their approach added to the stress of navigating a loved one's palliative care journey.

One family member shared:

> *"I would like the person I care for to be better supported by our GP Surgery. More compassion from the staff there. This would make my life less stressful. Better staff training on diversity and how to respond compassionately would improve the end of life experience we are currently going through."*
>
> Carer (Hertfordshire & West Essex)

Knowledge gaps

Concerns about gaps in knowledge and expertise were also raised. Some cited incidents where symptoms had been missed or wrongly diagnosed, leading to delayed treatment plans being put in place:

"The GP Practice have been terrible. There were missed opportunities to pick the illness up sooner, and since diagnosis have provided very little support."

Carer (Mid & South Essex)

Lack of end of life expertise

Certainly, many felt that not all professionals had the necessary end of life expertise. This included gaps in both communication skills and how staff talked to patients about their situation as well as their knowledge of end of life care and the dying process.

One bereaved family member shared:

"The carers were not trained to be nurses—they were ok when the patient was ambulant. There is a need for dedicated and trained carers who understand what is happening."

Bereaved (Norfolk & Waveney)

Concerns about a lack of specialist palliative care knowledge were raised, especially in hospitals and GP practices. For example, some families felt that hospital staff struggled with managing symptoms effectively:

"It was a shame the hospice consultant could not have reviewed him in hospital to address the pain management issue as the hospital staff did not have the required expertise."

Bereaved (Bedfordshire, Luton & Milton Keynes)

Similarly, GPs were sometimes seen as unprepared to handle the complexities of end of life, leaving families to push for more support:

"The [charity] carers were brilliant... cannot thank them enough. Doctors could use end of life training and found telephone consultation not good enough. Had to insist on face-to-face via triage form."

Bereaved (Bedfordshire, Luton & Milton Keynes)

In addition, some respondents noted that some staff lacked knowledge about important end of life services and support, including community care and financial assistance:

"The hospital professionals do not seem to know what's available in the community to help and support the patient ie charities, hospice at home or the role of District Nurses today."

Volunteer carer (Cambridgeshire & Peterborough)

"The lack of GPs' knowledge and timely response re Fast Track applications is a huge and significant barrier."

Carer (Norfolk & Waveney)

There were also concerns about staff's depth of knowledge and expertise to support patients with specific terminal illnesses like dementia, MND and Huntington's. This left patients and family members feeling frustrated and not well understood:

"My loved one had a respiratory disease that no one at the hospice and few at the hospital understood. The GP didn't know either. It was left to us each time to educate them. This should not be the case! In my opinion, access to appropriate care and the minimisation of suffering was inadequate."

Bereaved (Hertfordshire & West Essex)

Overstretched staff impacting ability to care

Many respondents recognised that the healthcare system was overstretched and acknowledged the strain staff were under. Some praised their performance:

"Community services are stretched but the teams on the ground respond appropriately and with timeliness and professionalism."

Bereaved family member (Norfolk & Waveney)

Others voiced the concern that such demands on the system were directly impacting the quality of compassionate care staff were able to provide. For some this helped to explain the variation in care between generalist and specialist settings:

"Due to demand and capacity, the lack of respect and dignity for the patient and families is so apparent; not because staff are rude, they just do not have the time or staff to cope with demand. Hospice care is very different - from the minute you arrive respect and dignity is a given and they have time to listen."

Carer (Mid & South Essex)

Another respondent described the situation more bluntly:

"Uncaring burnt-out staff trying to respond to their specialist needs with very little services or support."
Carer (Bedfordshire, Luton & Milton Keynes)

In Summary ...

Findings related to Ambition 5 highlight both positive and mixed experiences in the delivery of palliative care. While many respondents praised the professionalism, empathy and expertise of specialist palliative care teams, such as those in hospices and community nursing, there were notable concerns regarding the care provided by general healthcare professionals, particularly GPs and hospital staff. Variations in care quality were often attributed to differences in staff competence, the level of training in palliative care and the pressures of overstretched healthcare systems. To improve consistency in care, it is recommended that all healthcare professionals receive enhanced training to ensure a compassionate and skilled approach across all settings.

Priority Areas for Improvement

Participants in the study identified several priority areas for improvement relating to Ambition 5 and ensuring all staff are prepared to care.

- **Improve training for all staff involved in health and social care:** Enhance training for doctors, care home staff, and the community workforce, focusing on palliative and end of life care, empathy, and understanding, particularly for those with dementia and frailty.

"GPs need to have a better understanding of palliative pathways and need to actively see their patients."
Bereaved (Suffolk & North East Essex)*

"Please improve the training that some doctors appear to need in caring and supporting death."
Bereaved (Norfolk & Waveney)

"Much more focussed training for the staff of Care Homes."
Carer (Suffolk & North East Essex)

"Dedicated dementia training should be available to upskill community workforce who deliver end of life care. Observational tools are used via care home staff for assessing pain in people living with dementia."
Carer (Bedfordshire, Luton & Milton Keynes)

"Make sure the caring staff in general are trained to handle someone with end of life care. Be understanding and make this an experience with empathy for the person."
Carer (Hertfordshire & West Essex)

"Anybody contemplating being a doctor/nurse should read John Dunne's No Man is an Island. Ther's a lot in the British system about keeping a distance and being emotionally aloof. The best doctors are not. I accept that the Consultant I have now knows more than I do on certain subjects, but something else may be my speciality. Doctors and consultants should treat every patient as if they know just as much as you and are equal human beings."
Carer (Cambridgeshire & Peterborough)*

- **Increase GP support:** Ensure easier access to GPs and healthcare professionals for advice and support throughout the end of life care process.

"More help from GP surgery."
Carer (Mid & South Essex)

"GPs need more time to speak to palliative patients to understand the bigger picture for the patient. I understand GPs are stressed and overworked, but when I am ill I'd like them to give me more time, so I can understand and ask questions. I need you to give me attention when I'm telling you I have a problem."
Patient (Norfolk & Waveney)*

AMBITION 6: Each community is prepared to help

> *I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways*

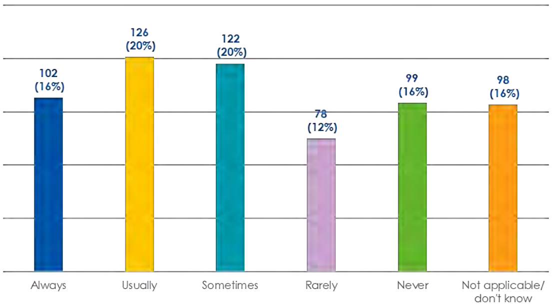
Ambition 6 recognises that death is not solely a medical event and advocates for a public health approach to palliative care, where communities are equipped with the tools and resources necessary to support one another through dying, death and bereavement.

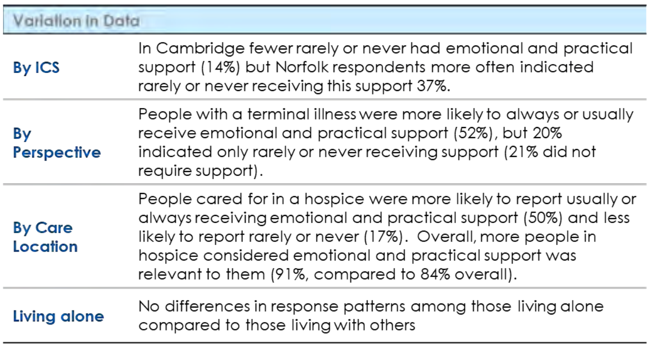
Quantitative Findings

To assess people's experience in line with this Ambition, the survey asked whether respondents felt they were able to get emotional and practical support from people and groups in their community when they needed it. (*Chart 18*)

- **Only just over one third (36%)** said they 'Always' or 'Usually' could get this support, whilst almost **one third (28%)** 'Rarely' or 'Never' had this support and a further **20%** only 'Sometimes'.

Chart 18:
Emotional and practical support from people and groups in your community





Variation in Data	
By ICS	In Cambridge fewer rarely or never had emotional and practical support (14%) but Norfolk respondents more often indicated rarely or never receiving this support 37%.
By Perspective	People with a terminal illness were more likely to always or usually receive emotional and practical support (52%), but 20% indicated only rarely or never receiving support (21% did not require support).
By Care Location	People cared for in a hospice were more likely to report usually or always receiving emotional and practical support (50%) and less likely to report rarely or never (17%). Overall, more people in hospice considered emotional and practical support was relevant to them (91%, compared to 84% overall).
Living alone	No differences in response patterns among those living alone compared to those living with others

Qualitative Findings

Meeting Ambition

Comments related to community support in the free text responses and interviews were limited. However, those that were shared reinforced the importance of this Ambition and highlighted the crucial role everyone plays in ensuring that people approaching end of life receive the care and support they need.

Support from the community

A few respondents highlighted the importance of community support during times of bereavement or caregiving. From neighbours and churches to community support workers and volunteers, these connections were described as meaningful where they existed.

For one bereaved husband, the support of a compassionate neighbour was a lifeline during his grief:

> *"Luckily the 'Community' provided care in the form of a neighbour who noticed I needed help, fed me and eventually got me up and out."*
>
> Bereaved (Bedfordshire, Luton & Milton Keynes)

Another shared their experience with community support workers and the value of informal chats with a chaplain:

> *"We are under the Community Support Workers (social worker role). They are absolutely wonderful. We are under the Chaplain and Spiritual Lead. Neither of us are religious, but she comes along and has a chat. It's like counselling—we can talk religion or not talk religion."*
>
> Carer (Mid & South Essex)

One patient talked positively about the support he was receiving from his church community, highlighting too the importance of availability of spiritual support in formal care settings:

> *"I am also part of a caring supportive church community, and have seen other members well-supported. ... I think it's very important for there to be suitable chaplains available in both hospital and hospice for those who wish to talk."*
>
> Patient (Cambridgeshire & Peterborough)

Community as a key source of care

Interestingly, some respondents shared that in their experience the community provided more reliable support than formal healthcare services:

> *"Most support came via community and charities at end of life, not within healthcare."*
>
> Bereaved (Norfolk & Waveney)

Another echoed this:

> *"The greatest support in my caring role, understanding his illness and sorting out financial matters, I received not from NHS but from charities which were invaluable in our situation. I could even call to specialist nurse (who worked for the charity) to give me advice at difficult times. They also helped my husband with transport to and from the hospital. None of this was available from the NHS."*
>
> Bereaved (Hertfordshire & West Essex)

Not Meeting Ambition

Limited community support and isolation

However, concern was expressed about the lack of community support, especially by those who were the sole caregiver. These challenges left them feeling isolated and overburdened:

> *"The majority of day-to-day care is provided by me alone. Recognition of just what full-time carers actually do would be good, and something put in place to allow them breaks. People keep saying we need to look after ourselves, but the obstacles in our way are often insurmountable."*
>
> Carer (Cambridgeshire & Peterborough)

One carer described the fear of leaving the person they were looking after on their own, highlighting the absence of a robust community network:

> *"Social isolation and fear of leaving the patient unattended to run errands or attend therapy classes or outings."*
>
> Carer (Mid & South Essex)

Reflecting on their own challenges of supporting family members approaching end of life, one respondent expressed concern for patients with no support network:

> *"How someone copes who does not have any family/friends support is beyond me. They are left to fend for themselves."*
>
> Carer (Norfolk & Waveney)

Public awareness of palliative and end of life care

To foster a community prepared to care, some respondents emphasised the need for greater public awareness about palliative and end of life care. One bereaved family member spoke about their lack of preparation for the physical and emotional realities of dying:

> *"It would be really helpful to be told about the 'process of dying' and all the different stages. My family and I weren't prepared for the changes/deterioration/reactions/the ways that a body shuts down. There were lots of occasions towards the final stages that were horrific and harrowing, and we just weren't prepared."*
>
> Bereaved (Norfolk & Waveney)

Another suggested that better education for communities could alleviate the burden on unpaid caregivers:

> *"[What would help] understanding of their condition by the general public, more importantly their family and friends. Training in social/listening skills of those who provide support other than the unpaid carer, living it 24/7."*
>
> Carer (Mid & South Essex)

The need for volunteers in the community

Volunteers were also identified as a critical resource for improving community support.

Respondents called for more trained individuals to assist patients and their families:

"More availability to access voluntary workers for one-to-one during end of life periods."

Carer (Norfolk & Waveney)

In Summary ...

Ambition 6 emphasises the importance of community involvement in providing emotional, practical, and spiritual support during dying, death, and bereavement. While some respondents highlighted the value of compassionate community members, such as neighbours, spiritual leaders and support workers, many noted the limited community resources, especially for carers who felt isolated or overwhelmed. The need for better public awareness of palliative care, improved volunteer networks, and stronger local community engagement was evident throughout the feedback. To enhance community support, further initiatives are required to increase public education about palliative care and to develop accessible networks of volunteers for those in need.

Priority Areas for Improvement

Participants in the study identified several priority areas for improvement relating to Ambition 6 and ensuring each community is prepared to help.

- **Enhance community support networks:** Provide more consistent and accessible support for carers, particularly in offering respite care and reducing isolation.
- **Promote public awareness of end of life care:** Increase education around the process of dying, death, and bereavement to better prepare families and communities for the challenges of end of life care.
- **Expand and evaluate volunteer programmes:** Increase the availability of volunteers to support patients and families, particularly for one-on-one assistance during end of life care.
- **Increase support for carers:** Recognise and address the challenges faced by informal carers, ensuring they have access to the necessary resources, recognition, and breaks.
- **Establish central community hubs:** Provide individuals facing difficult situations easy access to a range of services, allowing them to seek help and support tailored to their specific needs.

"A network of trustworthy people who provide regular respite would have been a real bonus."

Carer (Cambridgeshire & Peterborough)

"More support within the community to support families before illnesses get terminal."

Carer (Mid & South Essex)

"Encourage people to talk about death. I feel really passionately about this. I am aware that many people are scared to talk about death. No-one wants to talk about it. For a lot of people, when one or other of them is diagnosed, it is the elephant in the room. Actually, it is liberating to openly talk about death. I felt comfortable and confident that I knew what my husband would want and if he couldn't speak, I could."

Bereaved (Cambridgeshire & Peterborough)*

"More volunteers out in the community to be with clients with life-limiting illnesses."

Carer (Bedfordshire, Luton, Milton Keynes)

"More availability to access voluntary workers for one-to-one during end of life periods."

Carer (Norfolk & Waveney)

"Carers need more support – ensure more advice on support is available to them. You focus so much on the person you are caring for, you lose track of the things you need to survive."

Carer (Cambridgeshire & Peterborough)*

"A community hub of some description that ensures a broader good experience for people. Something central that brings people together, to pick and choose the services you choose to access, for example housing help. When someone is in a rubbish situation, if not technically able, then it would be nice if they could pick up the phone and say I have been diagnosed with x and need help."

Carer (Mid & South Essex)*

CARERS' PERSPECTIVES

The survey revealed that 34% of participants identified as carers currently looking after or supporting people with a terminal illness. The carers included: family members or friends (62%), health, social, or other care professionals supporting in a personal capacity (23%) and volunteers or community members (15%).

Recognising the critical role that informal carers play, the survey included a dedicated question for carers:

"Thinking specifically about your own needs in supporting and/or caring for someone, what do you or would you find most helpful?"

Carers had much to share, with 154 out of the 219 carers (70%) leaving a comment.

Need for greater respect and recognition

One of the most pressing concerns expressed by carers was the need for greater respect and recognition from healthcare professionals. Carers felt that their vital support role was often overlooked. One carer emphasised:

"More recognition from medical professionals of the vital support role I am playing and a less dismissive attitude about my input and advocacy on behalf of the person I am supporting."

(Cambridgeshire & Peterborough)

Another carer highlighted the importance of being acknowledged as an individual and an expert in their partner's care, stating:

"I am recognised as an individual, not ignored by some professional. I am an expert in my partner's care/condition."

(Mid & South Essex)

Access to healthcare professionals

Carers expressed a strong desire for more access to healthcare professionals. The reassurance of knowing there is someone to turn to in times of need can significantly alleviate the stress and burden of caregiving. One carer emphasised this need, stating:

"Knowing there is a professional at the end of a phone when needed."

(Suffolk & North East Essex)

They wanted more time to discuss their loved one's care and to plan for the future. One carer shared:

"Now that he has multiple illnesses and the start of dementia, he is relying on me to explain things. I could do with being able to talk to someone about what the future might look like for him and how we plan for this."

(Cambridgeshire & Peterborough)

Better communication and information

Effective communication with healthcare professionals was another critical need identified by carers. They sought the opportunity for confidential debriefs and the assurance of having a professional available when needed. Carers also emphasised the importance of being kept informed about their loved one's health and care needs. They expressed the need for clear expectations and guidance on what to anticipate in the caregiving journey. Knowing what to expect can significantly reduce anxiety and help carers prepare for future challenges. One carer highlighted this need, saying:

"Better advice on what to expect and how to deal. Earlier understanding of potential in-home care. It is expected you know what to ask for and when, but the situation can be overwhelming."

(Norfolk & Waveney)

Coordinated care and support

Carers called for more coordinated care with ready access to support and for medical records to be interconnected to prevent the frustration of repeating information. As one carer put it:

"One stop shop to get help and to be listened to. For all medical records to be linked to stop

going over the same information and stop me having to get permission to talk on his behalf."

(Hertfordshire & West Essex)

They also stressed the importance of having knowledgeable professionals who could provide timely and appropriate care, thereby reducing their loved one's distress and pain. Improved communication between various care providers and hospitals was another key concern.

Practical and emotional support

The need for practical and emotional support was a recurring theme among carers. They called for more care at night to give family carers a break, respite care and practical help. Emotional support was equally important, with carers expressing the need for someone to talk to and guidance on managing medication and other caregiving tasks. One carer mentioned:

"Support with taking a few hours break now and then. I am unable to go out for more than 10 minutes."

(Norfolk & Waveney)

Another carer added:

"Support in caring, i.e., how to do things. Managing the medication which is very scary. Especially controlled drugs. Given time out."

(Norfolk & Waveney)

Financial and informational support

Carers also highlighted the need for better access to advice and information, particularly regarding financial support and entitlements. One carer stated:

"Advice on financial support and the funding available. What happens when money runs out. What should I expect as mum deteriorates. What should I be putting in place."

(Bedfordshire, Luton & Milton Keynes)

Another carer emphasised the importance of having a helpline and information on home support equipment, saying:

"Someone or somewhere to access the information and support of what they are entitled to or can access. A helpline. Information where to access home support equipment."

(Cambridgeshire & Peterborough)

Conclusion

The responses to this dedicated question in the survey reveal the critical role carers play in supporting individuals with terminal illnesses and the significant challenges they face. Greater respect, better access to healthcare professionals, improved communication, coordinated care and practical and emotional support are essential to address the needs of carers. As we move towards a future of palliative and end of life care that relies more on community and home-based care, addressing these aspects is paramount to ensuring quality care for all.

REFLECTIONS & OBSERVATIONS

To what extent are we meeting the Ambitions for Palliative and End of Life Care in the East of England?

From the outset, the primary aim of this study has been to equip those responsible for shaping and delivering palliative care services in the East of England with crucial data to inform their strategies and guide their improvement plans.

Recognising the importance of understanding people's lived experiences, we chose to structure our approach around *the Ambitions for Palliative and End of Life Care 2021-2026*.

The central question was to understand to what extent we were meeting these Ambitions in the East of England, identifying what was working well as well as priority areas for improvement.

This report has highlighted that while there are many examples of good practice, the **East of England is currently only partially meeting the Ambitions for Palliative and End of Llife Care**, with a mixed picture of successes and significant gaps across the six Ambitions.

Progress

- **Hospice care as a strength**: Responses where patients were cared for in a hospice were generally more positive than responses where patients were cared for in hospital, with 74% describing their experience as "Good" or "Very Good", compared to 49% for hospital care. Hospices were identified as delivering personalised, compassionate support, aligning with Ambition 1 (treating people as individuals) and Ambition 3 (Comfort and wellbeing). These settings were often described as calm and dignified, with staff providing empathetic, tailored care.
- **Specialist palliative care teams praised**: Many respondents highlighted the dedication and professionalism of hospice and community palliative care teams. Their expertise in symptom management, emotional support and holistic care demonstrated progress in delivering fairer access to high-quality services (Ambition 2). Respondents felt particularly supported by palliative care nurses, district nursing teams and hospice care at home services.
- **Improvements in care once palliative care pathway is triggered**: Whilst early experiences of care were often difficult and even traumatic, many shared that once patients were formally identified as requiring palliative care, the quality and coordination of services improved significantly.

Gaps and challenges

- **Care is often poorly coordinated**: Ambition 4, (Coordination of care) remains a key area of concern. Only 36% of respondents felt that healthcare professionals communicated effectively or were well-informed about medical histories, while 49% reported delays in treatment or transfers. Respondents often felt abandoned during transitions between services, highlighting gaps in continuity.
- **Not everyone has access to good end of life care:** Lack of availability of services, geographic and financial inequities contribute to a ‘postcode lottery’ in accessing care, particularly affecting rural areas, out of hours services and non-cancer diagnoses. This lack of consistency hinders Ambition 2’s goal of equitable care for all.

- **Lack of open and honest conversations is undermining individualised care:** Limited opportunities - or a perceived lack of readiness by healthcare professionals - to engage in timely and meaningful discussions have left many feeling unheard and unsupported. This gap directly undermines the achievement of Ambition 1's goal of ensuring each person is seen and cared for as an individual.
- **Gaps exist in provision of pain management and emotional support**: Ambition 3 (comfort and wellbeing) showed shortfalls, with many reporting challenges with effective pain management at end of life – particularly in hospitals and for home-based care. The need for more emotional support was also identified with over a quarter (27%) of respondents reporting inadequate support for discussing their thoughts and feelings.
- **Not all staff have the necessary skills and experience in end of life care:** Contrary to Ambition 5 (All staff prepared to care) there was clear concern that some healthcare professionals were not sufficiently proactive or knowledgeable about end of life care. Additionally, there were issues with delayed identification of terminal diagnoses and the insensitive delivery of difficult news. Variations in care quality were often linked to differences in staff competence, insufficient palliative care training and the pressures of an overstretched healthcare system.

A mixed and inconsistent picture

The findings reveal that the extent to which the different Ambitions are being met varies significantly depending on the setting, with hospices and community palliative care services outperforming hospitals and generalist care providers. Respondents' experiences reflected a spectrum, from compassionate and well-coordinated care to distressing accounts of isolation and unmet needs. This variation makes it difficult to definitively assess the region's performance or rank achievement of specific Ambitions. However, issues around Ambition 2 (Fair access to care) and Ambition 4 (Coordination of care) stood out most clearly as requiring attention.

Conclusion

While there are areas of clear progress, many of the Ambitions continue to remain aspirational rather than fully realised. This study highlights the need for targeted action to address persistent gaps. Moving forward, we encourage all those responsible for shaping and delivering palliative and end of life care services in the East of England to review the data and insights from this study. We urge them to work together to develop actionable strategies that drive improvements and ensure a high-quality, consistent experience of care. It will take a collective effort, and only by doing so can we fulfil the promise of the Ambitions, ensuring that all individuals in the East of England receive compassionate and dignified care at the end of life.

Recommendations

In its framework, the *Ambitions for Palliative and End of Life Care* already embodies a set of recommendations, so there is no real merit in setting them out again here. To assist leaders to continue to realise these Ambitions, we encourage reference to the practical guide The Open University, Marie Curie and others put together designed to facilitate action: *Small Steps, Big Vision*.[13] This guide can be used for individual reflection, to facilitate team discussions, or in work with partners and across systems. In conducting this activity, leaders are encouraged to reflect on the recommendations made by the participants in this study, referring not only to their experiences, but also to the 'Priority Areas for Improvement' that they identified.

SMALL STEPS, BIG VISION

This is your Grab-and- Go Guide for the Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

1. Personalised care planning

2. Shared records

How do findings of this local study compare with Marie Curie's national *Time to Care: Better End of Life Report 2024?*

This report has presented a regional perspective of the experiences of people affected by terminal illness across the East of England. In assessing the extent to which people's experiences are aligned to the *Ambitions for Palliative and End of Life Care*, it has brought to light a number of themes common to those identified in Marie Curie's national *Time to Care* report from the Better of End of Life research programme, published in September 2024.

These include:

- **Examples of excellent care**: Some people, especially those with access to specialist palliative care, reported positive experiences of high quality care.

However:

- **Poor overall experience**: Only just over half (55%) of people who completed our survey rated their overall experience as 'Very good' or 'Good', more than a fifth (22%) rated it as 'Poor' or 'Very poor' and 86% identified challenges with their care.
- **Lack of open conversation about death and dying**: A notable reluctance, particularly among consultants and GPs, to discuss palliative care or address death and dying openly.
- **Challenges navigating the system**: People not knowing what care and support was available and how to access services – particularly out of hours.
- **Poor coordination of care:** Systems and different parts of the healthcare system not communicating or working together.
- **Insufficient GP support:** A perceived lack of willingness or capacity to engage, often attributed to time constraints and limited expertise in end of life care.
- **Delays in care:** The most frequently cited challenge in this study, including delays in treatment, care delivery or service transitions.
- **Distressing hospital experiences:** Reports of hospital staff being too busy to provide compassionate care, often compounded by a lack of knowledge about palliative care needs.
- **Lack of capacity:** Insufficient provision of palliative and end of life care in the community including limited access to hospice care.
- **Inadequate carer support:** Family carers often felt excluded, undervalued, and underappreciated despite their essential role in providing care.

Recommendations

In light of these common themes, we reiterate some of the recommendations made in the Better End of Life Policy Summary[14] and other Marie Curie policy reports, which would particularly respond to findings on patient experiences in the East of England:

Systematic identification of patients approaching the end of life

- Integrated care boards (ICBs) should commission services that offer everyone the opportunity to set out their wishes for the end of life and ensure these plans are shared and followed by health and care providers.
- Integrated care boards (ICBs) should commission services that demonstrate early identification and assessment of unmet needs and systematic initiation of advance care planning.
- Health and care professionals should be trained to use a consistent and systematic approach to identifying patients likely to be approaching the end of life and adding these patients to the supportive palliative care register.

Strengthen equitable access

- Equitable access to palliative care needs to be strengthened through increased investment in primary care and community nursing services so that people are not denied care based on where they live or their socio-economic status.

24/7 access to services

- Every part of England should have a 24/7 single point of contact palliative and end of life care telephone advice line, staffed by professionals with specialist palliative care expertise who can provide advice, guidance and support to access local services, available to all people with a terminal illness, their carers and health and care professionals, and sustainably funded by ICBs.
- Every ICS in England should have an urgent community response service operating 24/7 for people with palliative and end of life care needs that utilises provider collaboratives involving palliative providers to achieve a 2-hour maximum response time.

Access to medication

- Digital systems should be in place, and IT systems should be integrated, to allow all relevant health and care professionals involved in patient care to view and amend patient records and, for independent prescribers, to prescribe electronically.
- Community pharmacy services should be commissioned to provide a standardised set of "core" palliative care medications that are consistently available 24/7, with pharmacies with stock that are operating out-of-hours greater in number and more even in geographic distribution.

Training and workforce

- Integrated care boards (ICBs) should ensure all services across settings have sufficient workforce to meet the palliative care needs of the patients they're supporting, including adequate time to facilitate advance care planning.
- The proportion of non-medical health and care professionals, including district/community nurses and pharmacists, able to independently prescribe palliative and end of life care medicines should be increased through provision of funded clinical training and continuing professional development.

Supporting unpaid end of life carers

- Local Authorities should increase support for carers of people at the end of life through better identification, needs assessment, financial and bereavement support.

Themes align with research priorities[15]

As part of a separate project, in collaboration with the James Lind Alliance (JLA)and other partners, Marie Curie recently established a Palliative and End of Life Care Priority Setting Partnership[16] to agree on set of priorities for research, informed by people with lived and professional experience.

This included a Lived Experience Group of people affected by terminal illness – including patients, those close to them and a steering group of professionals. Through the project over 1,000 people with lived or professional experience of palliative and end of life care put forward suggestions for future research priorities.

These were ranked and prioritised by over 600 people to generate a list of 10 top priorities for palliative and end of life care research. These represent the range of issues that influence people's experiences towards the end of life. A number of the priorities were represented in the responses shared by participants in this local East of England study, including:

- How can NHS, social services and charities work more collaboratively to provide joined-up care that better meets the needs of people with a serious life-limiting illness and their carers, friends and families?
- What are the best ways to provide palliative and end of life care, support and advice at all hours (24/7 or out of hours)?
- How can the quality of palliative and end of life care in hospital be improved? What helps or hinders improvement?

The alignment between these priorities and the themes identified in this study further strengthens the need for us to address these issues, both at a local and national level.

How does this study help to inform future planning of Palliative and End of Life Care across the East of England?

Dr Eva Lew, NHS East of England reflects on how this study could help to inform planning of people at end of life care across the East of England.

The *Ambitions for Palliative and End of Life Care*, first published 10 years ago, provide a best practice national framework to spur *local* health and social care leaders to improve palliative and end of life care within *local* communities. Whilst more recently refreshed, the principles of the Ambitions have not changed, and the experiences and needs of the local communities that we serve remain central to this.

Provision of high quality, personalised, and proactive palliative and end of life care must be *"everybody's business"*: the responsibility for caring for those at the end of their lives, and their families and carers, spans across health and social care services, and into our communities themselves. Part of this also requires a societal cultural change to see dying, death and bereavement as part of normal life.

National context

Nationally, the findings of this study are extremely timely as we move towards new milestones such as the forthcoming **10 Year Health Plan**, and a renewed focus on the development of integrated neighbourhood services to deliver care closer to home. This study may also aid the newly established Palliative and End of Life Commission. Many of the key narrative themes arising out of this study reassuringly align with the direction of travel in these areas.

The **10 Year Health Plan** vision tasking statements[17] (see Box) mirror the aims of the Ambitions and reflect a focus that will hopefully help to address some of the study's findings around unmet information needs, lack of timely and honest conversations, and inequitable access to high quality, individualised, coordinated palliative and end of life care.

10 Year Health Plan Vision Statements

Tasking statements for the 10 Year Health Plan working groups - GOV.UK

- **I can stay healthy and manage my health in a way that works for me**
- **I can access the high-quality and effective care I need, when and where I need it**
- **My care is integrated around my needs and wishes, and I am listened to**
- **I am treated in a fair and inclusive way, irrespective of who I am**

Recently published guidance for neighbourhood health services[18] now specifically identifies "people of all ages with palliative care or end of life needs" as an important cohort for ensuring that the "right care is at the right time, including focus on access to GPs", "maximising community services" closer to home, and reducing unnecessary emergency admissions to hospital. This must be achieved in a collaborative fashion as outlined below:


Diagram showing the aims for all neighbourhoods over the next 5 to 10 years

Perhaps this will begin to address our participants' concerns about access to community support and not having to travel to access care. Finally, the impetus within national plans to move towards digital systems such as shared care records is recognised by our participants as a key improvement priority.

Regional and local context

Tangible positive changes in response to this study must also begin at a more local level. We foresee that this study will actively contribute to the growing call for more action and bring this vital area of care into the spotlight once again within the East of England. General priorities for improvement have been specifically identified by participants alongside individual Integrated Care System (ICS) quantitative and qualitative "performance" data. This information will help to guide local health and social care system leaders to collectively and collaboratively strive towards improving care and service provision within their own ICS, developed around the needs of their communities, rather than people adapting to the design of existing services. This should undoubtedly include working in partnership with voluntary sector organisations and local communities who are recognised as positive key contributors within this report.

Finally, and most importantly, we are indebted to those who took their time to share such deeply personal experiences as part of this study, hopefully knowing that these will serve as a powerful collective voice towards shaping a better future for palliative and end of life care across the East of England. We also thank Marie Curie for partnering with NHS East of England for this unique study, and for representing the views and experiences of participants so expertly, sensitively, and clearly.

NHS
England
East of England

Dr Eva Lew

NHS East of England Regional Palliative & End of Life Care Clinical Lead

APPENDICES

Findings-At-A-Glance: Comparing performance across the Ambitions by ICS

In this report we have presented the findings from the study at a regional East of England level. We have also been able to review the data at an individual Integrated Care System (ICS) level as respondents were asked to select where the patient (or the person they were looking after or who had died) lived. Individual Data Packs for each of the six ICS' have been created and shared with key stakeholders at the local level.

In these Appendices, we provide an 'At-a-Glance' view of key findings at the East of England regional level as well as for each ICS to allow some level of comparison between different areas. We have indicated strongest (▲) and weakest (▼) performance in the region for key datapoints.

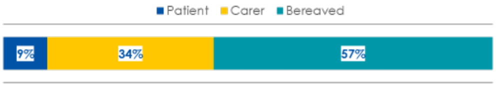
However, we are wary of making definitive comparisons of the performance between ICS' for a number of reasons:

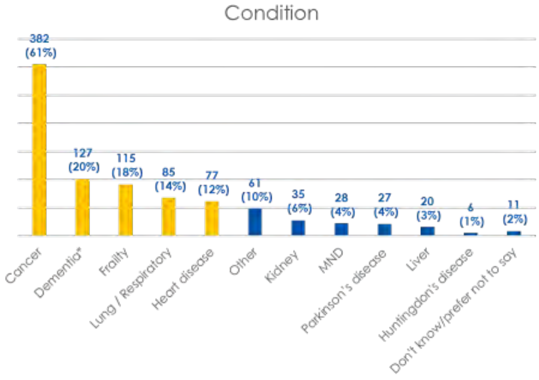
- The study was based on purposive sampling[9] rather than a random sampling method. Purposive sampling means the findings may not fully reflect the full range of care experiences in each ICS and differences between ICS will in part reflect differing success in reaching all groups of people living with or with experience of terminal illness.
- The quantitative data does not take into account the rich insights shared through the qualitative data.

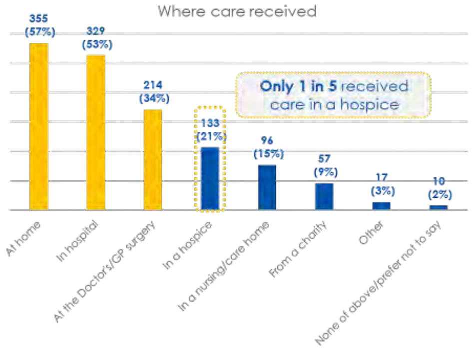
FINDINGS AT-A-GLANCE BY ICS

East of England Region

625 Valid Responses





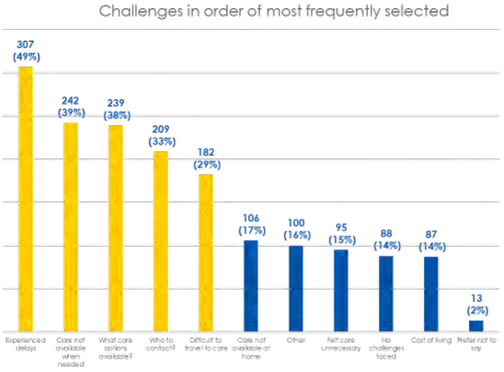


Only 1 in 5 received care in a hospice

Just over half (55%) rated their overall experience of care as 'Very good' or 'Good'

Over a fifth (22%) rated their overall experience of care as 'Poor' or 'Very poor'

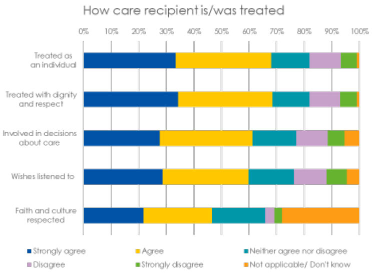
86% identified at least one challenge	Most common challenge:
62% selected multiple challenges	**Experienced delays in care, treatment or transfer between services (49%)**



AMBITION 1: Treated as an individual

Just over two-thirds felt person cared for was treated:

- as an individual (**68%**)
- with dignity and respect (**68%**)



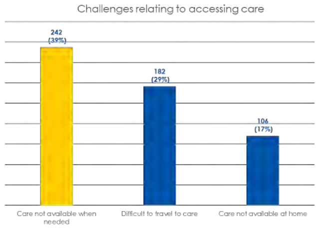
AMBITION 2: Fair access to care

About half said they had access to:

- Specialist advice (**50%**)
- General information and support (**52%**)

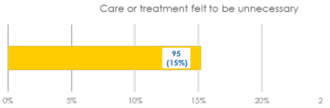
71% said they were treated fairly regardless of background

39% said care was not available when needed or quickly enough



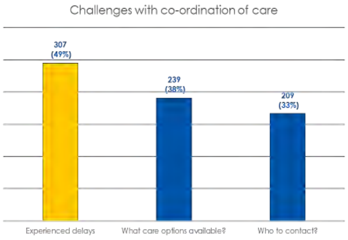
AMBITION 3: Maximising comfort and wellbeing

- **46%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed
- **27%** were 'Rarely' or 'Never' offered support to talk about thoughts and feelings



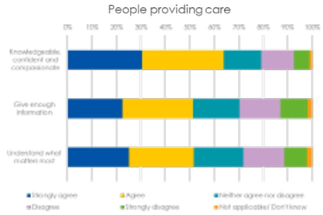
AMBITION 4: Care is co-ordinated

- **49%** experienced delays in care, treatment or transfer between services
- **43%** disagreed that different healthcare professionals knew their medical history and talked to each other



AMBITION 5: All staff are prepared to care

- **64%** felt staff were knowledgeable, confident and compassionate
- **51%** felt they gave enough information, whilst **28%** felt they did not



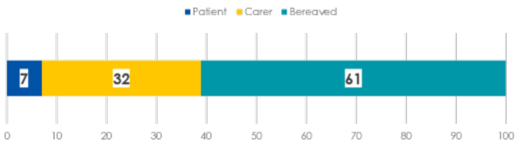
AMBITION 6: Each community is prepared to help

- **Only just over one third (36%)** said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **28%** 'Rarely' or 'Never' did

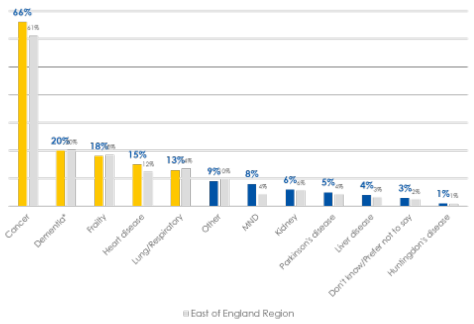
FINDINGS AT-A-GLANCE BY ICS

Bedfordshire, Luton & Milton Keynes ICS

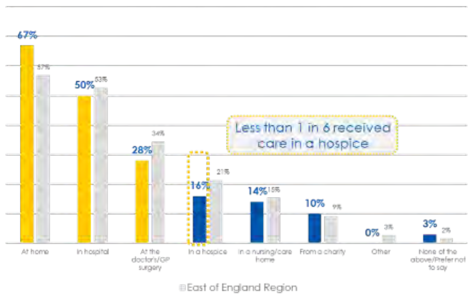
100 Valid Responses



Condition



Where care received



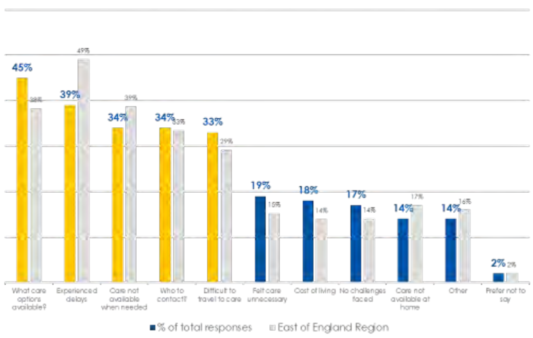
Less than 1 in 6 received care in a hospice

Just over half (54%) rated their overall experience of care as 'Very good' or 'Good'

A fifth (20%) rated their overall experience of care as 'Poor' or 'Very poor'

83% identified at least one challenge	Most common challenge:
62% selected multiple challenges	**Not sure what care options are available (45%)**

Challenges in order of most frequently selected



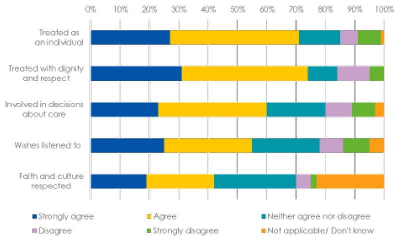
▲ *Strongest performance in region* ▼ *Weakest performance in region*

AMBITION 1: Treated as an individual

Nearly three-quarters felt person cared for was treated:

- as an individual (**71%**)
- with dignity and respect (**74%**)

How care recipient is/was treated



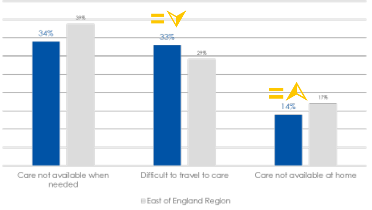
AMBITION 2: Fair access to care

Over a third (34%) said care was not available when needed or quickly enough

Less than half said they had access to:

- Specialist advice (**48%**)
- General information and support (**45%**) ▼

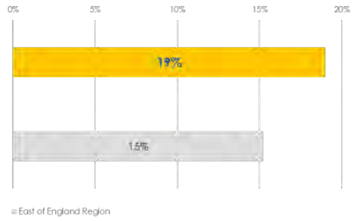
71% said they were treated fairly regardless of background



AMBITION 3: Maximising comfort and wellbeing

- **49%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed
- **28%** were 'Rarely' or 'Never' offered support to talk about thoughts and feelings

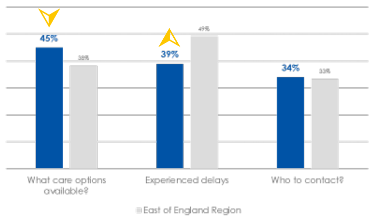
Felt care or treatment received unnecessary



AMBITION 4: Care is co-ordinated

- **39%** experienced delays in care, treatment or transfer between services ▲
- **47%** disagreed that different healthcare professionals knew their medical history and talked to each other

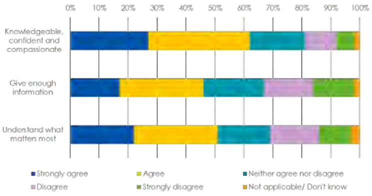
Challenges relating to co-ordination of care



AMBITION 5: All staff are prepared to care

- **62%** felt staff were knowledgeable, confident and compassionate
- **46%** felt they gave enough information, whilst **31%** felt they did not

People providing care



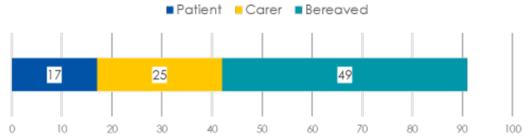
AMBITION 6: Each community is prepared to help

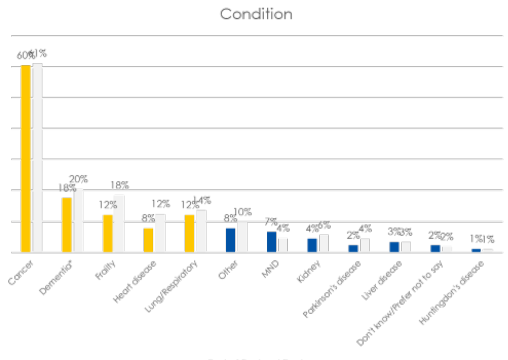
- **Nearly a half (43%)** said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **over a quarter (27%)** 'Rarely' or 'Never' did

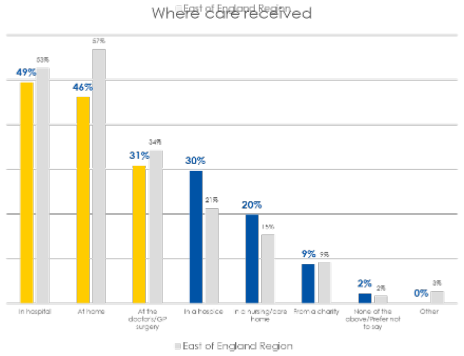
FINDINGS AT-A-GLANCE BY ICS

Cambridgeshire & Peterborough ICS

91 Valid Responses



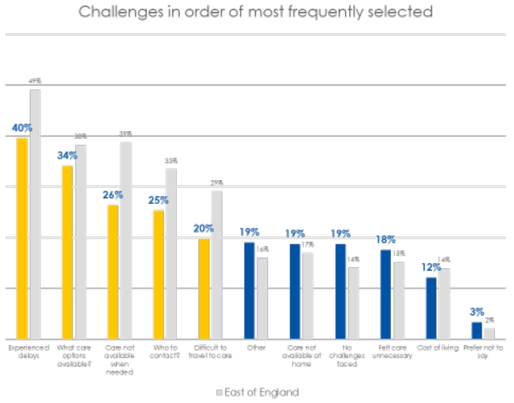




Nearly two-thirds (64%) rated their overall experience of care as 'Very good' or 'Good' ▲

14% rated their overall experience of care as 'Poor' or 'Very poor' ▲

80% identified at least one challenge ▲	Most common challenge:
54% selected multiple challenges ▲	**Experienced delays in care, treatment or transfer between services (40%)**

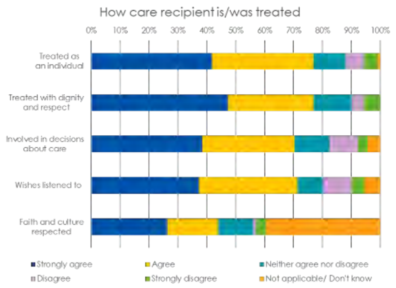


▲ *Strongest performance in region* ▼ *Weakest performance in region*

AMBITION 1:
Treated as an individual

Over three-quarters felt person cared for was treated:

- as an individual **(77%)** ▲
- with dignity and respect **(77%)** ▲



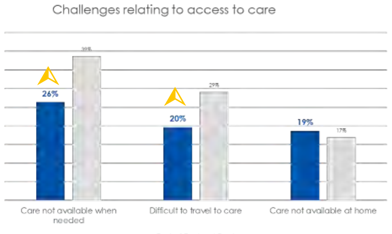
AMBITION 2:
Fair access to care

Under two-thirds said they had access to:

- Specialist advice **(63%)** ▲
- General information and support **(62%)** ▲

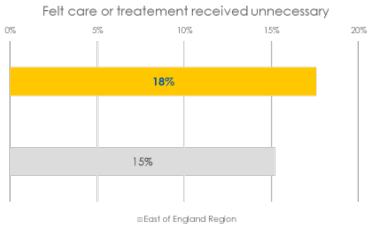
81% said they were treated fairly regardless of background ▲

Over a quarter (26%) said care was not available when needed or quickly enough



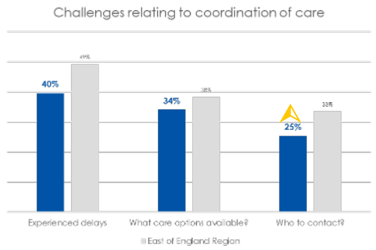
AMBITION 3:
Maximising comfort and wellbeing

- **31%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed ▲
- **15%** 'Rarely' or 'Never' offered support to talk about thoughts and feelings ▲



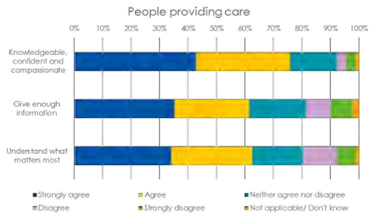
AMBITION 4:
Care is co-ordinated

- **40%** experienced delays in care, treatment or transfer between services
- **33%** disagreed that different healthcare professionals knew their medical history and talked to each other ▲



AMBITION 5:
All staff are prepared to care

- **76%** felt staff were knowledgeable, confident and compassionate ▲
- **62%** ▲ felt they gave enough information, whilst **36%** ▼ felt they did not



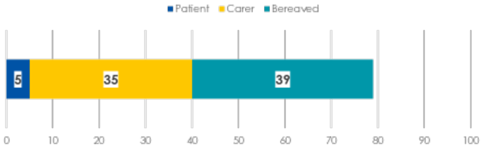
AMBITION 6:
Each community is prepared to help

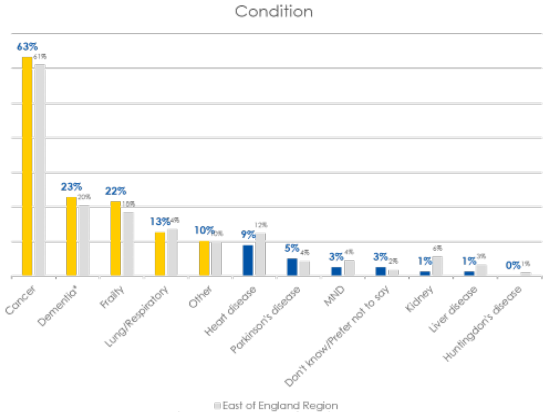
- **Just under a half (49%)** ▲ said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **14%** ▲ 'Rarely' or 'Never' did

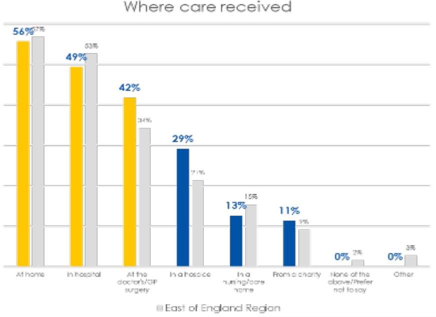
FINDINGS AT-A-GLANCE BY ICS

Hertfordshire & West Essex ICS

79 Valid Responses



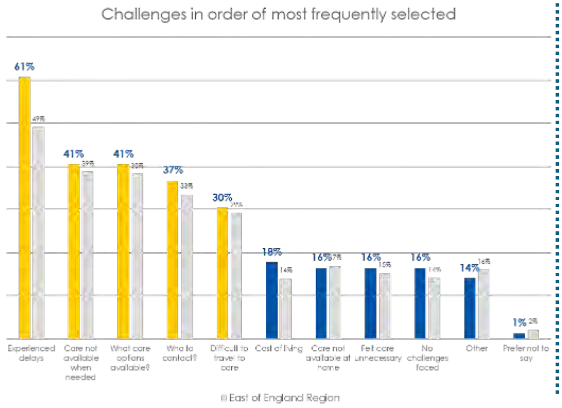




Under half (48%) rated their overall experience of care as 'Very good' or 'Good' ▽

Over a fifth (23%) rated their overall experience of care as 'Poor' or 'Very poor'

84% identified at least one challenge	Most common challenge:
63% selected multiple challenges	**Experienced delays in care, treatment or transfer between services (61%)**

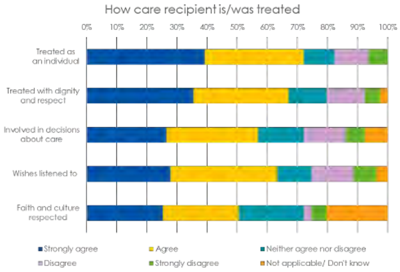


△ *Strongest performance in region* ▽ *Weakest performance in region*

AMBITION 1:
Treated as an individual

Over two-thirds felt person cared for was treated:

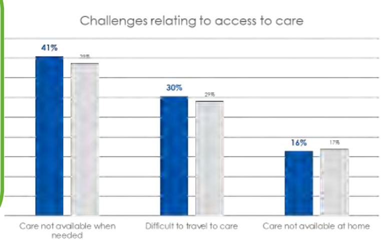
- as an individual (**72%**)
- with dignity and respect (**67%**)



AMBITION 2:
Fair access to care

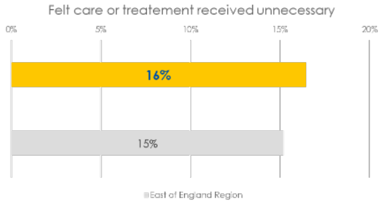
- **Less than half** said they had access to specialist advice (**41%**) ▽
- **Just over half** said they had access to general information and support (**51%**)
- **71%** said they were treated fairly regardless of background

41% said care was not available when needed or quickly enough



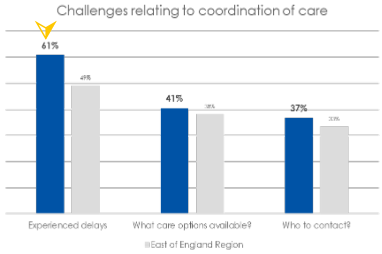
AMBITION 3:
Maximising comfort and wellbeing

- **52%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed ▽
- **25%** were 'Rarely' or 'Never' offered support to talk about thoughts and feelings



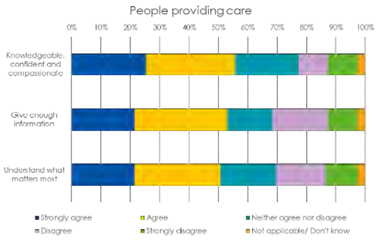
AMBITION 4:
Care is co-ordinated

- **61%** experienced delays in care, treatment or transfer between services ▽
- **46%** disagreed that different healthcare professionals knew their medical history and talked to each other



AMBITION 5:
All staff are prepared to care

- **56%** felt staff were knowledgeable, confident and compassionate ▽
- **53%** felt they gave enough information, whilst **29%** felt they did not



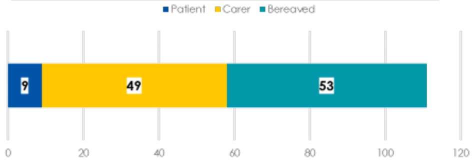
AMBITION 6:
Each community is prepared to help

- **Over a third (37%)** said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **over a quarter (27%)** 'Rarely' or 'Never' did

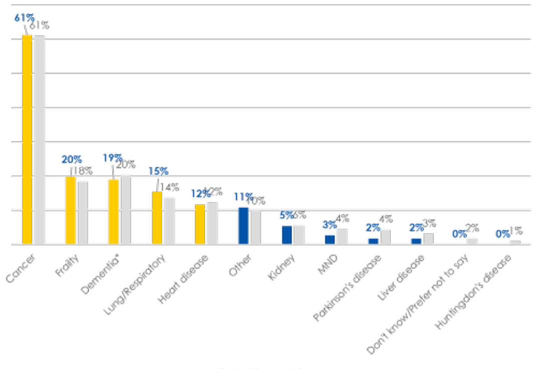
FINDINGS AT-A-GLANCE BY ICS

Mid & South Essex ICS

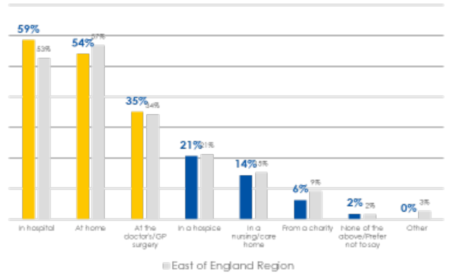
111 Valid Responses



Condition



Where care received

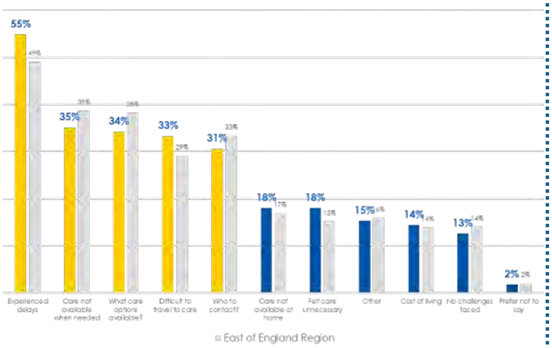


Just over half (56%) rated their overall experience of care as 'Very good' or 'Good'

A fifth (20%) rated their overall experience of care as 'Poor' or 'Very poor'

87% identified at least one challenge	Most common challenge:
60% selected multiple challenges	**Experienced delays in care, treatment or transfer between services (55%)**

Challenges in order of most frequently selected

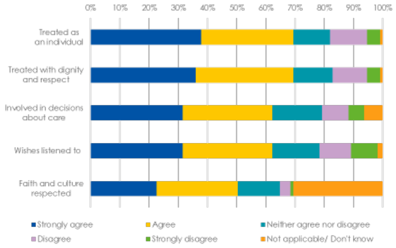


AMBITION 1:
Treated as an individual

Over two-thirds felt person cared for was treated:

- as an individual (**69%**)
- with dignity and respect (**69%**)

How care recipient is/was treated



AMBITION 2:
Fair access to care

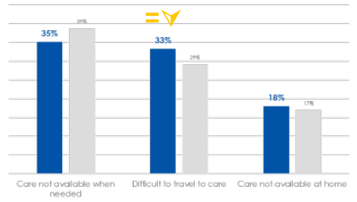
Just over half said they had access to:

- Specialist advice (**56%**)
- General information and support (**54%**)

70% said they were treated fairly regardless of background

35% said care was not available when needed or quickly enough

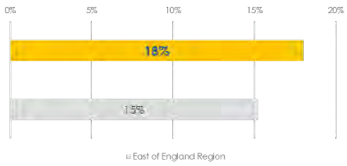
Challenges relating to access to care



AMBITION 3:
Maximising comfort and wellbeing

- **45%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed
- **32%** were 'Rarely' or 'Never' offered support to talk about thoughts and feelings

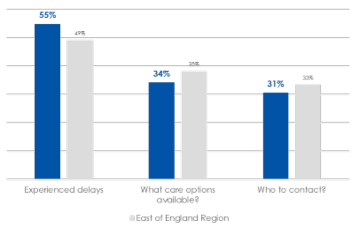
Felt care or treatment received unnecessary



AMBITION 4:
Care is co-ordinated

- **55%** experienced delays in care, treatment or transfer between services
- **35%** disagreed that different healthcare professionals knew their medical history and talked to each other

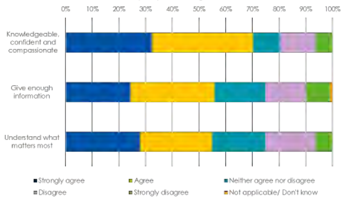
Challenges relating to coordination of care



AMBITION 5:
All staff are prepared to care

- **70%** felt staff were knowledgeable, confident and compassionate
- **56%** felt they gave enough information, whilst **24%** felt they did not

People providing care



AMBITION 6:
Each community is prepared to help

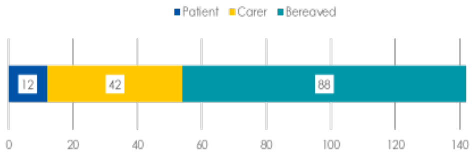
- **Just under a third (32%)** said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **over a quarter (28%)** 'Rarely' or 'Never' did

▲ *Strongest performance in region* ▼ *Weakest performance in region*

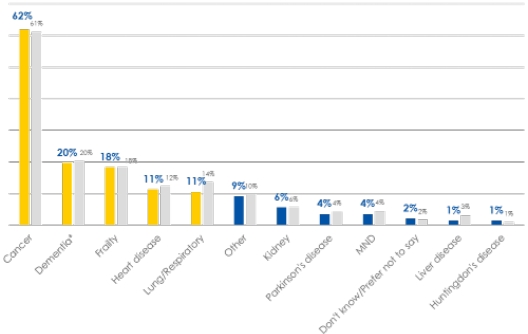
FINDINGS AT-A-GLANCE BY ICS

Norfolk & Waveney ICS

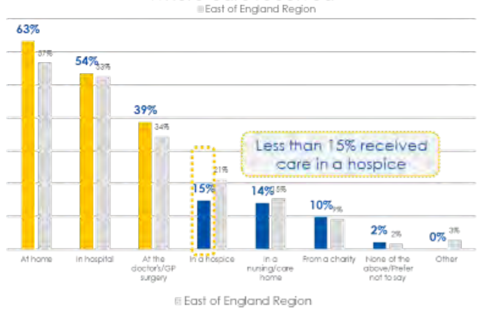
142 Valid Responses



Condition



Where care received



Just over half (54%) rated their overall experience of care as 'Very good' or 'Good'

Over a quarter (27%) rated their overall experience of care as 'Poor' or 'Very poor' ▼

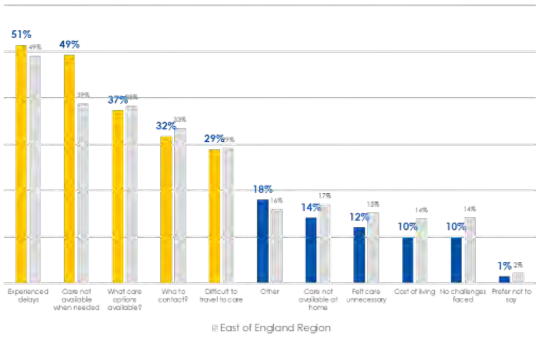
89% identified at least one challenge ▼

Most common challenge:

66% selected multiple challenges ▼

Not sure what care options are available (51%)

Challenges in order of most frequently selected

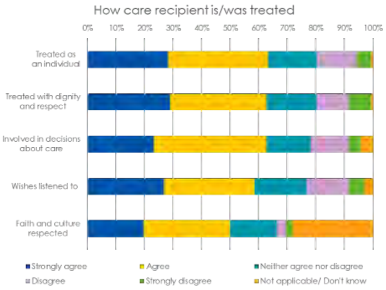


▲ *Strongest performance in region* ▼ *Weakest performance in region*

AMBITION 1:
Treated as an individual

Nearly two-thirds felt person cared for was treated:

- as an individual (**63%**)
- with dignity and respect (**63%**)



AMBITION 2:
Fair access to care

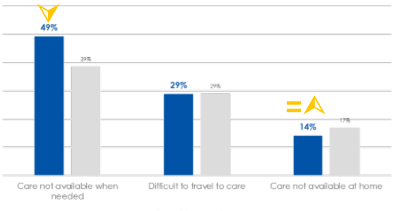
About half said they had access to:

- Specialist advice (**50%**)
- General information and support (**49%**)

69% said they were treated fairly regardless of background =▼

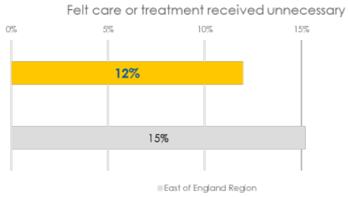
Nearly half (49%) said care was not available when needed or quickly enough

Challenges relating to access to care



AMBITION 3:
Maximising comfort and wellbeing

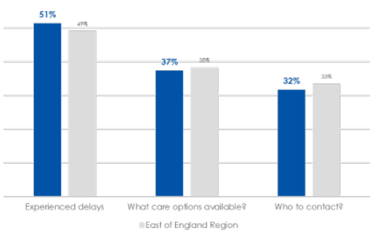
- **50%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed
- **33%** were 'Rarely' or 'Never' offered 'support to talk about thoughts and feelings' ▼



AMBITION 4:
Care is co-ordinated

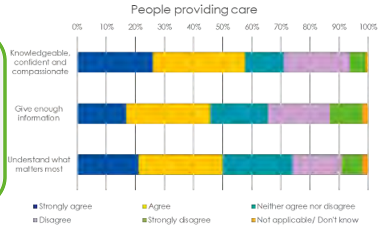
- **51%** experienced delays in care, treatment or transfer between services
- **51%** disagreed that different healthcare professionals 'knew their medical history and talked to each other' ▼

Challenges relating to coordination of care



AMBITION 5:
All staff are prepared to care

- **58%** felt staff were knowledgeable, confident and compassionate
- **46%** felt they gave enough information, whilst **32%** felt they did not

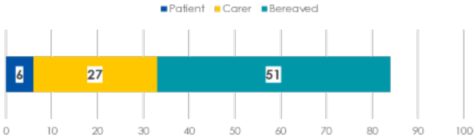


AMBITION 6:
Each community is prepared to help

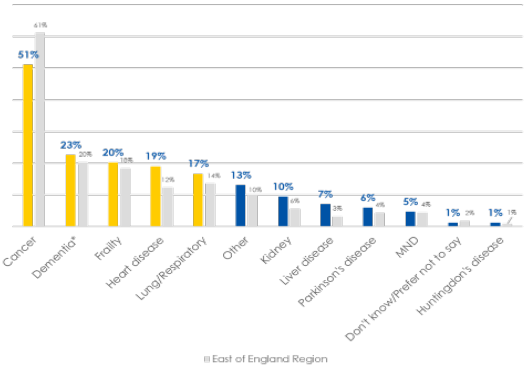
- **A quarter (25%)** ▼ said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **over a third (37%)** ▼ 'Rarely' or 'Never' did

Suffolk & North East Essex ICS

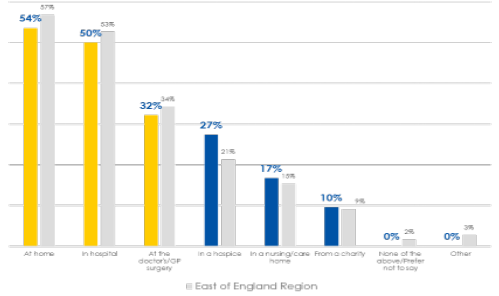
84 Valid Responses



Condition



Where care received

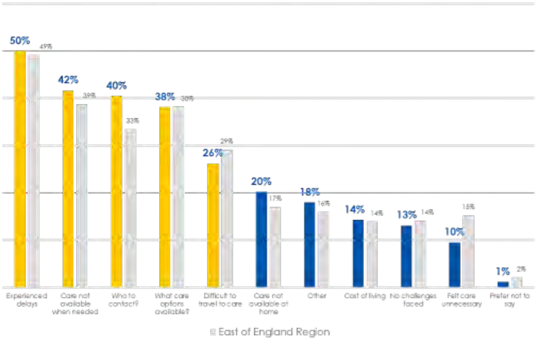


Just over half (56%) rated their overall experience of care as 'Very good' or 'Good'

A fifth (20%) rated their overall experience of care as 'Poor' or 'Very poor'

86% identified at least one challenge	Most common challenge:
61% selected multiple challenges	**Experienced delays in care, treatment or transfer between services (50%)**

Challenges in order of most frequently selected



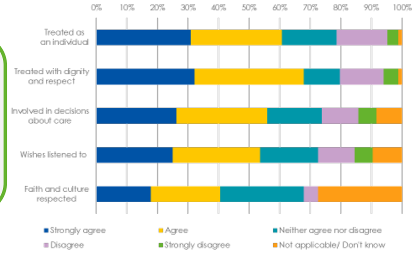
▲ *Strongest performance in region* ▼ *Weakest performance in region*

AMBITION 1:
Treated as an individual

About two-thirds felt person cared for was treated:

- as an individual (**61%**) ▼
- with dignity and respect (**68%**)

How care recipient is/was treated



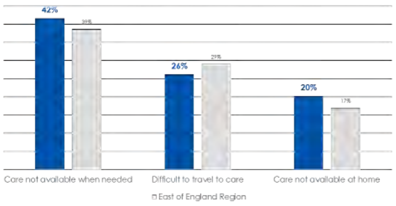
AMBITION 2:
Fair access to care

About half said they had access to:

- General information and support (**54%**)
- Specialist advice (**45%**)
- **69%** said they were treated fairly regardless of background = ▼

42% said care was not available when needed or quickly enough

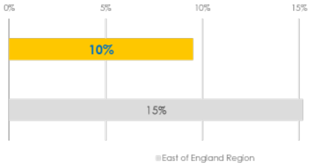
Challenges relating to access to care



AMBITION 3:
Maximising comfort and wellbeing

- **50%** only 'Sometimes', 'Rarely' or 'Never' had needs regularly reviewed
- **20%** were 'Rarely' or 'Never' offered 'support to talk about thoughts and feelings'

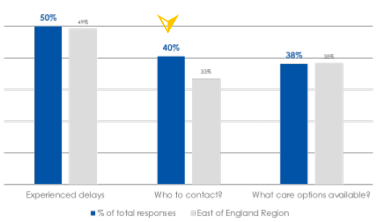
Felt care or treatment received unnecessary



AMBITION 4:
Care is co-ordinated

- **50%** experienced delays in care, treatment or transfer between services
- **45%** disagreed that different healthcare professionals 'knew their medical history and talked to each other'

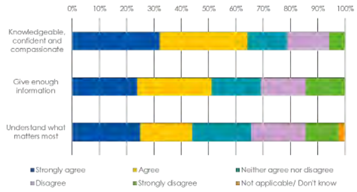
Challenges relating to co-ordination of care



AMBITION 5:
All staff are prepared to care

- **64%** felt staff were knowledgeable, confident and compassionate
- **51%** felt they gave enough information, whilst **31%** felt they did not

People providing care



AMBITION 6:
Each community is prepared to help

- **Under half (42%)** said they 'Always' or 'Usually' received emotional and practical support from groups in the community, but **nearly a third (29%)** 'Rarely' or 'Never' did

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Steering Group

NHS East of England

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- **Jo Tonkin** – Lead Nurse
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Marie Curie

- **Jonathan Clemo** – Associate Director Strategic Partnerships & Services for East of England
- **Kim Bonnar** – Head of Strategic Impact
- **Briony Hudson** – Associate Director, Internal Research Development
- **Kate Vernon** – Deputy Head of Operations
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Project Team

Initiating the Study	• Beverley Pickett • Jonathan Clemo
Designing the Survey and Advising on Overall Approach	**Steering Group** *(See above)*
Promoting the Study	Various system partners, including Health Watch organisations
Conducting the Study, including Telephone Interviews	• Kate Vernon • Tracey Allan
Collating and Analysing the Data and Producing Data Packs	• **Emma Maun** – Quantitative Research Manager, Marie Curie • Briony Hudson • Kate Vernon • Tracey Allan
Writing the Report	• Kate Vernon • Briony Hudson • Emma Maun
Reviewing	• Beverley Pickett • **Dr Eva Lew**, NHS East of England Regional Clinical Lead for Palliative and End of Life Care

REFERENCES

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[9] Purposive sampling (also called judgmental, selective, or subjective sampling) is a non-random sampling technique in which participants are selected or targeted based on specific characteristics, knowledge, or experiences relevant to the study – in this case their experience of terminal illness.

[10] Note: Since multiple conditions were selected, the total count is higher than the total sample size.

[11] NHS England » What are healthcare inequalities?

[12] Page 6: beol-2024-report-england-commentary.pdf

[13] *Realising the Ambitions: Insights from how People Understand, Interpret and Implement the Ambitions Framework for Palliative and End of Life Care*

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Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end. We bring 75 years of experience and leading research to the care we give you at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system. Marie Curie is a charity working across the UK and we need your support to do our vital work.

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