Palliative and End of Life Care

NHS Lincolnshire

Engagement Report

10 April 2025 – 30 September 2025

Executive Summary – Key findings – Public feedback

Introduction

It is really important that we understand the experiences of those who have sadly died in order that we can understand what has worked well and what requires improving for individuals and their families.

This was the third year that the NHS ran this survey in order to continually compare progress and improve services. The previous report was undertaken for 2022/23.

Following previous feedback received, NHS Lincolnshire implemented:-

- Additional training specifically for palliative and end of life care.
- Easier access to specialist clinicians for advice and help.
- More widely available information and up-graded the information on the Palliative and End of Life web-site.
- Strengthened the Palliative Single Point of Access (PSPA) to support people, their families and those important to them. Connected to the PSPA, Palliative Neighbourhood Huddles have also been introduced across the county, improving co-ordination and reducing duplication of work between teams.

Aims of the engagement

The aims of the engagement were to:-

- Understand experiences from those with experience of receiving palliative and end of life care and their loved ones, whether this was families, carers, neighbours or representatives gathering experiences cross the whole pathway.
- Understand if there were improvements or any further areas of learning from those identified from previous years.

Co-production in the design of the engagement

- Prior to launching the survey, we sought feedback from the Lincolnshire Palliative and End of Life Care Co-production Group. Whilst the aim of the engagement was also to compare and review feedback from the previous year, the group were able to review, amend and provide suggestions to this year's survey.

Respondent profiling

The highest level of responses were from people living in the East Lindsey area, females aged between 50 – 59 and daughter's.

Feedback has been captured across key areas of care received at home, urgent care provided out of hours, District Nurses, Community Nurses, specialist services and carers, social care, care from the GP/GP Practice Team, Care homes, last hospital admission, experience in the last 2 days of life and circumstances surrounding their death with feedback collated from the survey, telephone calls and emails.

Feedback has been analysed across sites, population and equality groups and if there are any differences, these are highlighted within the report.

Public feedback engagement overview

- A total of 222 responses were received (slightly reduced from the previous report where 254 responses were received).
- Some respondents didn't answer every question so therefore the numbers vary for some questions.
- For the purposes of this engagement, comparisons in the service and patient experience have been identified from the previous Healthwatch Voices Report undertaken during 2022/23, although it must be noted that these are obviously a different sample of respondents.
- Social media was the most popular way of viewing the engagement.

Care provided during the last 3 months of life

- Respondents stated that cancer was the most common condition that their loved ones died of. 48% (56/117) of individuals suffered with the condition for 1 -2 years before they died. Overall, the largest number of individuals receiving palliative and end of life care died within 2 – 5 years.
- 74% (99/133) of respondents stated that their loved ones spent the majority of time during their last 3 months of life at home.
- 79% (74/119) agreed that they were involved in organising support and decision making 6% (7/119) said they were rarely or never, 3% (3/119) stated that it wasn't relevant to them.
- Only 25% agreed that as a carer/family they fully received as much help from health and social services as they needed with 37% saying that they partially received help but would have preferred more.

Receiving care at home

- 79% (86/109) of respondents stated that they stayed in the place "that they call home" within the last 3 months of life. Individuals stated that their loved ones had stayed in care homes during the last 3 months of life with 18% (19/104) living in a care home as a resident and 17% (15/89) staying in a hospice for end of life care.
- 48% (42/86) of respondents thought that services worked well together.
- During the last 3 months of life, while they were at home, 65% (57/88)of respondents felt that their physical symptoms were managed fully or most of the time. 35% (31/88) of respondents felt that they were not really or not at all.

Urgent care provided out of hours

- 67% (75/113) of individuals stated that they had needed to use the out of hours service in the last 3 months of life, 27% (31/113) had not needed to use the out of hours service and 6% (7/113) did not know.
- Satisfaction was generally high across all areas. The most positive was receiving the outcome they wanted in relation to the rapid response team and lifeline pendant and the least receiving the outcome they wanted from the GP where overall, 52% 12/23 who needed to contact a GP received the outcome that they wanted and 43%% did not, 4% sometimes.
- 61% (43/71) of respondents advised that the care received when they needed urgent out of hours in the last 3 months was very good/good with 34% (24/71) advising that it was poor/very poor.

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District, Community Nurses, specialist services and carers

- 71% (81/114) did use, 20% (23/114) did not use and 9% (10/114) did not know if their loved ones had used District Nurses, Community Nurses, specialist services and carers.
- Overall, the top 3 highest rates of satisfaction were from community nurses and specialist services treating loved ones with dignity and respect and being able to discuss concerns about their condition with specialist services and the top 3 lower rates of dissatisfaction were levels of care provided in the last 3 months and being able to discuss any concerns with community nurses and carers

Care from the GP/GP Practice Team

- The largest percentage of individuals were registered at practices within East Lindsey.
- Overall, 69% had seen a GP/member of the GP practice team within the last 3 months of their life. The highest number of respondents - 32% (36/113) had seen a GP/GP practice team member once or twice within the last 3 months with being seen once or twice with cancer was the most common condition to be seen.
- 61% (46/75) were satisfied and 28% dissatisfied with their loved ones being treated with dignity and respect, 52% (35/75) were satisfied and 34% dissatisfied with being able to discuss their worries and fears they may have had about their condition, treatment or tests with the GP/GP practice team and 50% were satisfied with the level of care provided in the last 3 months and 41% dissatisfied.
- 41% said they found it difficult to arrange a home visit if it was requested by themselves and found it easier if it was required by someone else.

Care Homes

- 66% (69/104) of respondents stated that they did not live or stay in a care home during the last 3 months of life.
- However, 18% (19/104) lived in a care home as a resident, 6% (6/104) lived in a care home as respite, 8% (8/104) a palliative care bed within a community hospital, 2% (2/104) did not know.
- If they did stay in a care home, satisfaction was generally high with loved ones 71% feeling that their loved ones were treated with dignity and respect, 69% able to discuss worries, 60% holistic needs managed, 58% spiritual needs and symptoms were managed and 68% satisfied with care received from the Care Home Team.

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Last hospital admission

- 66% of respondents had stayed in hospital during their last 3 months of life, 32% (33/102) had not stayed in hospital and (2/102) did not know.
- The highest levels of satisfaction were nurses and other staff treating individuals with dignity and respect and dissatisfaction were not being able to discuss worries and fears about their condition, tests or treatment, the care received during the last 3 months of life, holistic and spiritual symptoms and needs being managed, hospital services working together with GP and other services and continuity of care.

Hospice admission

- 79% (70/89) did not stay at a hospice at any time during the last 3 months of life, 3% (3/89) stayed in a hospice for respite care, 17% (15/89) stayed in a hospice for end of life care and 1% (1/89) did not know
- When they did, levels of satisfaction were high with 100% of the 13 respondents saying that they were very satisfied or satisfied with the care received at the hospice. The only level of dissatisfaction related to 1 respondent being dissatisfied with the care received and continuity of care received during the last 3 months of life and being very dissatisfied that nurses were not treating their loved one with dignity and respect.

Experience in the last 2 days

- For the majority of the last 2 days of life, 67% stated that this was where wanted to be. 47% (46/97) were at home (previous report 27%). 100% stated that there is where they wanted to be.
- 10% (10/97) were in a care home (previous report 17%). 50% (5/10) stated that this is where they wanted to be and 50% was not where they wanted to be.
- 27% (26/97) were in hospital
- 13% (13/97) were in a hospice.
- 1% (1/97) was in a nursing home (Holbeach and East Elloe Hospital and was where they wanted to be.
- 1% Didn't know.

In the lead up to their death

- 80% (37/46) of those who were at home knew that they were going to die.
- 70% (7/10) who were in a care home knew that they were going to die.
- 65% (17/26) who were in a hospital knew that they were going to die.
- 100% (1/1) who were in a nursing home did not know that they were going to die.
- 68% of those at home felt that they broke the news in a caring manner.
- 50% were told in a caring manner within a care home.
- 19% were told in a caring manner within a hospital setting. 23% (6/26) were not told in a caring manner at all, 19% (5/26) did not get told that they were dying.
- 58% (7/12) were told in a caring manner within a hospice. 25% (3/12) did not tell them that they were dying.

Circumstances surrounding their death

- 48% died at home, 29% in hospital, 12% in a hospice, 10% in a care home and 2% in a nursing home.
- 65% (66/101) of respondents felt that they had enough choice about where they died.
- Overall, 52% felt supported with 39% feeling unsupported. Hospices received the most positive experiences. 9% did not know.
- Overall, 78% (75/96) of respondents felt that staff treated them and their family in a sensitive manner after their loved one had died.
- When looking back over the last 3 months of their life, 63% (60/95) of respondents felt that they were involved in decisions about their care, 25% (24/95) felt that they weren't and 12% (11/95) were unsure.
- 60% (58/97) of respondents stated that a ReSPECT form had been completed,16% (16/97) had not completed a form, 24% (23/97) did not know.
- 41% (40/97) of respondents stated that since their loved one had died, they had not been offered anyone to talk to from health, social services or from a bereavement support service/group about their feelings following their death. 31% (30/97) did not want to, 4% (4/97) Did not know, 1% (1/97) was not applicable, 23% (22/97) had spoken to someone.

The last few days

- What worked well in the last few days was the care provided, pain relief, staff and support and what could be improved were surroundings, waiting for pain relief, support and communication from the GP, general communication and communication regarding Do Not Resuscitate.
- What worked well when they died were staff, the support and wishes respected, the Palliative SPA 24 hour helpline and what could be improved were what was the process/what would happen next, the care/after care provided to individuals and their families/loved ones, attending the death quicker and more skilled staff.
- What worked well after death were bereavement groups, care, swift and good communication, funeral directors and what could be improved were apologies when needed when an individual had received a negative experience, after care support, collecting the body quicker, local post mortem service and if a complaint was investigated a prompt response.

Future involvement

- 28 respondents advised that they would like to be involved with the Palliative and End of Life Co-production Group going forward. All respondents have been invited to the meetings and we have already seen an increase in attendance at the meetings with valuable contributions.
- 29% (20/69) advised that they would like to hear more ways that they can get involved in shaping NHS services and completing our future survey's and have been added to our circulation list.

Recommendations and next steps

- The feedback from our engagement should be used and triangulated with other ongoing patient experience data which is collated. Where there are particular areas highlighted, further engagement should be undertaken.
- The Palliative and End of Life Care Leadership Group meeting are asked to note the feedback and discuss recommendations from the findings.
- The feedback should be used to help inform Palliative and End of Life Care Services and utilise the findings to help inform the programme of work associated with palliative and end of life care services.
- Share and discuss the findings with the Palliative and End of Life Care Co-Production Group to develop action planning for improvements.
- This report will be published on Lincolnshire Integrated Care Board and Palliative and End of Life Care web-site and complete ongoing involvement of people and communities and feedback on how on how this has influenced Palliative and End of Life Care Services.
- Consideration should be given as to how patient experience feedback can be collated on an ongoing basis.

Acknowledgements

We would like to thank:-

- All of those that shared their personal stories, experiences and insights regarding Palliative and End of Life Care services in order that we can gain feedback on all of the excellent work that is happening, as well as see where improvements are needed.
- The Palliative and End of Life Care Co-Production Group members for their ongoing commitment and dedication and attendance at meetings in order to improve Palliative and End of Life individuals and their families.

Overview of engagement activities

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As part of our engagement activities, we received the following engagement:-

Patient/public survey published

Spoke to **4** people on the telephone

2 emails received

217 Survey responses received

Social media reached
Facebook = 38,248 views
Nextdoor = 3 posts 6 reactions 16,269 impressions

20 People signed up to receive the engagement bulletin "The Contributor"

28 People would be interested in getting involved further with this work through the co-production meetings

Methods of Engagement
Survey promotion

Marketing materials

The NHS Lincolnshire ICB Marketing Team created marketing materials and social media assessments to build awareness of the survey, signpost/link people to the survey, share with stakeholders to encourage participation, promote across social media channels and encourage people to take part in conversations.

To make the survey directly accessible to a range of patients, the public and staff, we circulated it regularly via our ICB Engagement Bulletin – The Contributor - which is received in Lincolnshire. Phone number and email details were also included should people wish to request the survey in an alternative format or seek support in completing the survey from the Engagement Manager. Posters/fliers were distributed to the following individuals/groups/venues for promotion:-

- Promoted in the GP Primary Care and Primary Care Network bulletin.
- Palliative and End of Life Care Co-Production Group.
- Communication and Marketing Teams across the NHS Trusts for promotion internally and externally for promotion within bulletins and communications.
- Circulated to Patient Participation Groups in Lincolnshire.
- Lincolnshire Voluntary Executive Team for circulation.
- Community Connectors in Lincolnshire for promotion.
- Hospices in Lincolnshire.
- St Barnabas Hospice Wellbeing Centre, Grantham.
- Macmillan Cancer Team, Lincoln County Hospital.
- Macmillan Cancer Team, Pilgrim Hospital.
- Macmillan Cancer Team, Grantham Hospital.
- Community nursing teams at Boston, John Coupland Hospital, Fen House, Ravendale Health Clinic, County Hospital – Louth,
- Louth Hospital.
- Bereavement Office, United Lincolnshire Hospitals NHS Trust.
- Distributed to LINCA who promoted to care homes with a request to promote the flier.
- Promoted to Healthwatch who shared it via Healthwatch newsletter and web-site.
- Promoted at the Living Well and Aging Well event on 17 September 2025.at The Venue, Navenby.
- Boston PCN event on 18 September 2025.
- Palliative and End of Life Care web-site.
- Reader's Panel at Lincolnshire Community and Hospitals NHS Group.
- Patient Panel members at Lincolnshire Community and Hospitals NHS Group.
- Lincolnshire County Council – Communications and Engagement Team for promotion.
- Lincolnshire Recovery College.
- Fliers sent to the 12 Lincolnshire Registration Offices across Lincolnshire.
- Fliers sent to the 98 Funeral Directors across Lincolnshire.
- Promoted to Lincolnshire Integrated Care Board Cancer Team for promotion to networks.
- St Barnabas for circulation to their support groups at Boston, Grantham, Lincoln, Louth Wellbeing Group, Spalding Wellbeing Group.
- Lincolnshire Integrated Care Board web-site.
- Lincolnshire Integrated Care Board social media.
- Distributed to our extensive stakeholder database that includes groups from the following; Traveller community, LGBTQ+, BAME, Disability, Carers, Young people, Older people, Faith and Religious and various community groups across Lincolnshire.
- Promoted every 2 weeks between via Lincolnshire ICB Engagement Team's newsletter between 10 April 2025 – 30 September 2025.
- Promoted on the Nextdoor App across Lincolnshire.

Social media/web-site engagement during the engagement period

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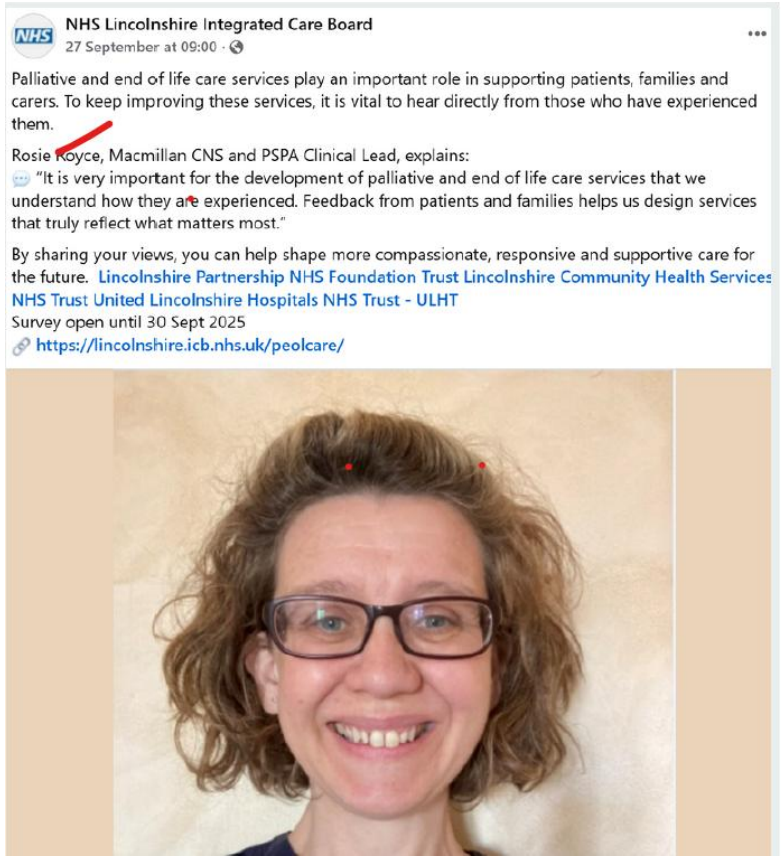
Lincolnshire ICB facebook:-

- **Posts - 14 posts**
- **Reactions and shares – 180**
- **Post reach –26,334 reach**
- **Link/post clicks - 791**



The best performing post was from Rosie Royce, Macmillan Community Nurse Specialist and PSPA Lead with 18,252 views, 102 reactions (likes, shares, comments) and 522 clicks.

Lincolnshire ICB web-page

Views - 1,144

Active users – 455

Nextdoor

3 posts

6 reactions

16,269 impressions

Review of the draft survey by the Palliative and End of Life Co-production Group

Suggestions and improvements provided and amendments made

Engagement activities
Engagement with patients, public, families, carer and representatives via:-

Public survey to gather experiences of what is working and what requires improvement.
Feedback to help improve Palliative and End of Life Care Services.

Public survey to understand help inform the Palliative and End of Life Care programme of work

Detailed feedback from engagement

Discussed at Palliative and End of Life Care Management Group Palliative and End of Life Care Co-Production Group

This report

Feedback will then help improvements for palliative and end of life care services in Lincolnshire

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Geographical locations, where specified, of 221 respondents are shown below including, where stated, the villages they live. The highest number of respondents (23%) (52/221) lived within the East Lindsey district

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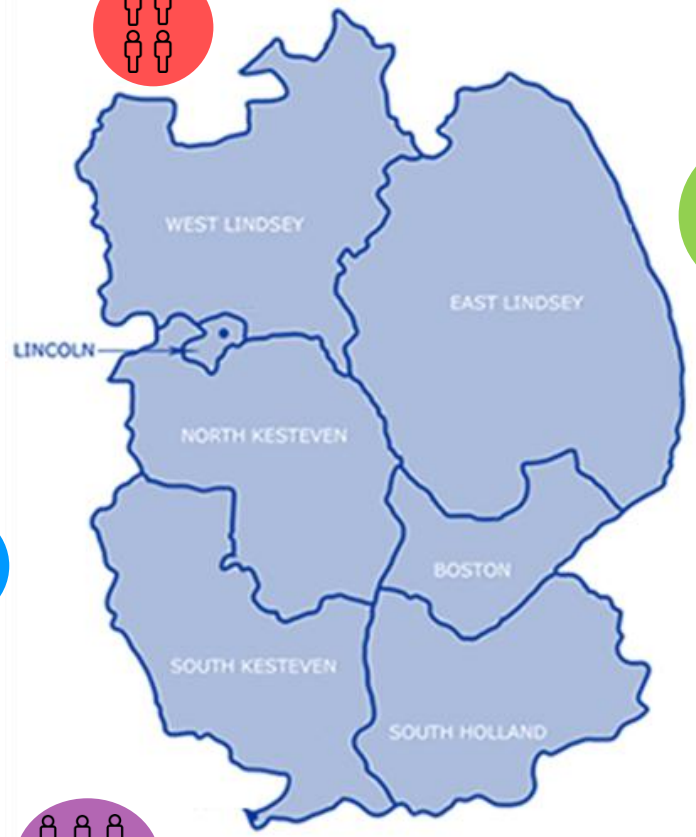
11% (25) West Lindsey
Gainsborough (7)
Market Rasen (7)
Nettleham (7)
Saxilby (2)
Caistor (1)

18% (39) Lincoln

13% (28) North Kesteven
Sleaford (6)
Metheringham (3)
North Hykeham (2)
Ruskington (2)
Bracebridge Heath (1)
Heckington (1)

19% (42) South Kesteven
Grantham (9)
Bourne (8)
Stamford (5)
Corby Glen (1)



23% (52) East Lindsey
Skegness (16)
Horncastle (10)
Louth (11)
Mablethorpe (6)
Woodhall Spa (5)
Alford (3)
Wragby (1)

7% (16) Boston
Boston (5)

9% (19) South Holland
Spalding (7)
Holbeach (4)
Long Sutton (1)
Sutton Bridge (1)

Section 1

Results and Findings from the Public Engagement

Respondent profiling

From 222 responses, the highest number of responses were from daughter's

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Are you completing as?				%	Count
Family member (of those that stated their relationship, these are listed below):-				**65%**	**142**
Daughter	(60)	Son in law	(2)		
Wife	(19)	Myself	(2)		
Husband	(11)	Grandson	(2)		
Son	(6)	Cousin	(1)		
Daughter in law	(5)	Great Granddaughter	(1)		
Not stated	(2)	Grandparent	(1)		
Sister	(5)	Mother in Law	(1)		
Granddaughter	(3)	Brother	(1)		
Widow	(3)	Father in law	(1)		
Mother	(2)	Partner	(1)		
Sister in law	(2)	Spouse	(1)		
		Father	(2)		
Parent, Carer or representative (of those that stated these are listed below)				**12%**	**27**
Carer	(11)	Unpaid carer	(1)		
Representative	(2)	Employee	(1)		
Friend				**6%**	**14**
Neighbour				**0%**	**1**
Other (of those that stated, these are listed below)				**15%**	**31**
Healthcare professional	(5)	Funeral Director	(1)		
Professional	(6)	Hospital Chaplain	(1)		
Nurse	(5)	Registered Manager	(1)		
Care Home Manager	(3)	Deputy Manager	(1)		
Concerned citizen	(1)	Care worker	(1)		
Not stated	(1)	Nursing Home	(1)		
Mental Health Nurse	(1)	Ex Marie Curie Nurse	(1)		

Of 198 responses, the most popular way of viewing the engagement was via social media, where 37% (73/198) of respondents stated that they saw it promoted via this route.
Recognising that not everyone uses virtual methods, we also promoted the engagement via promotion through A5 fliers which promoted the Engagement Lead's telephone number, e-mail address and also the survey link and QR code

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Where respondents saw the engagement (where stated)	Number of responses
Social media (Facebook (58) Nextdoor (9), X (3)	73
Newsletter The Contributor (25), Not stated (2), IBM (1), ULHT Newsletter (2), Teamtalk (1), Old Leake News (1), internal LCHS newsletter (1), Local government newsletter (2), Co-production Newsletter (1), Healthwatch (1)	37
Other (LINCA (8) E-mail (4) Community Connector (1), Sue Ryder Shop flier (1), LPFT (1), Local Councillor (1), Macmillan (3), ELDC information post to parish council (1), PCN (1), Community nursing team (1), Carer (1), Had worked in palliative care (1)	24
GP practice St John's (4), Marisco (1), PPG (2), James Street (2), Not stated (2), Corby Glen (1), Horncastle (1), Stamford Practice (1), Glebe Park PPG (1), Beacon Medical Practice (1), Galletly (1)	17
Website (ICB 4), Palliative and End of Life Care (2), LCHS (2) , Beacon Medical Practice (1), Not stated (1)	10
Hospice St Barnabas Hospice (10) , Via Director of Patient Care (1)	11
Word of mouth	11
Leaflet from registrar or coroner (Sleaford Registry Office (1)	5
Not stated	4
NHS Post bereavement visit/pack	3
Funeral directors	1
Friend	1
Colleague	1
	198

Section 2

About the person you are providing feedback

Conditions were not collated from the last report in order to make comparisons.
The largest number of respondents stated that cancer was the condition that their loved ones died of
48% (56/117) of individuals suffered with the condition for 1 -2 years before they died.
Overall, the largest number of individuals receiving palliative and end of life care died within
2 – 5 years.
Those living with a condition for more than 10 years generally died with a long term health condition
The most common reason that individuals died within 1 – 7 days was through sepsis

	The length of time that individuals suffered the condition before they died										
Condition	**1 – 7 days**	**1 week – 1 month**	**1 – 6 months**	**7 – 12 months**	**1 – 2 years**	**2 – 5 years**	**5 – 10 years**	**10 years or more**	**Not stated**	**Currently receiving treatment**	**Total**
Cancer	0	2	11	5	16	12	6	0	3 (hypopharyngeal cancer (1)	1 (oesophagus cancer)	56
Dementia	0	1	0	0	1	4	4	3	0	0	13
Suffering with a respiratory condition	1 (hospital acquired pneumonia)	1 (pneumonia)	0	1 (COPD and emphysema)	2 (pulmonary fibrosis (1), cystic fibrosis (1))	4 (COPD (1), emphysema (1), pulmonary fibrosis (1), heart failure (1)	2 (COPD (1), (COPD, Asthma and bronceyectisis (1))	2 (COPD & pneumonia (1), COPD (1)	1 (pulmonary fibrosis)	0	14
Old age	1	0	3	0	0	3	2	0	0	0	9
Heart failure (1 core pulmonary)	0	0	0	0	1	3	0	1	0	0	5

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	The length of time that individuals suffered the condition before they died									
Condition	**1 – 7 days**	**1 week – 1 month**	**1 – 6 months**	**7 – 12 months**	**1 – 2 years**	**2 – 5 years**	**5 – 10 years**	**10 years or more**	**Not stated**	**Total**
Liver failure	0	0	1	0	0	0	0	0	0	1
Multiple myeloma	0	0	0	0	0	0	0	1	0	1
Abdominal aneurysm/coronary problems	0	0	0	0	0	1	0	0	0	1
Frailty following a stroke	0	0	0	0	0	0	1	0	0	1
Needed an operation	1	0	0	0	0	0	0	0	0	1
Hip infection	0	1	0	0	0	0	0	0	0	1
Many different illnesses	0	0	0	1	0	0	0	0	0	1
All	0	0	1	0	0	0	0	0	0	1
Suffering with a neurological condition (Parkinson's)	0	0	0	0	0	1	0	0	0	1
Alzheimers	0	0	0	0	0	0	1	0	1	2
Surgery	0	1	0	0	0	0	0	0	0	1

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	The length of time that individuals suffered the condition before they died										
Condition	**1 – 7 days**	**1 week – 1 month**	**1 – 6 months**	**7 – 12 months**	**1 – 2 years**	**2 – 5 years**	**5 – 10 years**	**10 years or more**	**Not stated**	**Receiving treatment**	**Total**
Sepsis (as well as sepsis, 1 individual also had a chest infection and 1 had vascular dementia)	3	0	1	0	1	0	0	0	0	0	5
Stroke	2	0	0	0	0	0	0	0	0	0	2
Heart and kidney failure	0	0	0	0	0	1	0	0	0	0	1
Total											117

Section 3

Care during the last 3 months of life

74% (99/133) of respondents stated that their loved ones spent the majority of time during their last 3 months of life at home.

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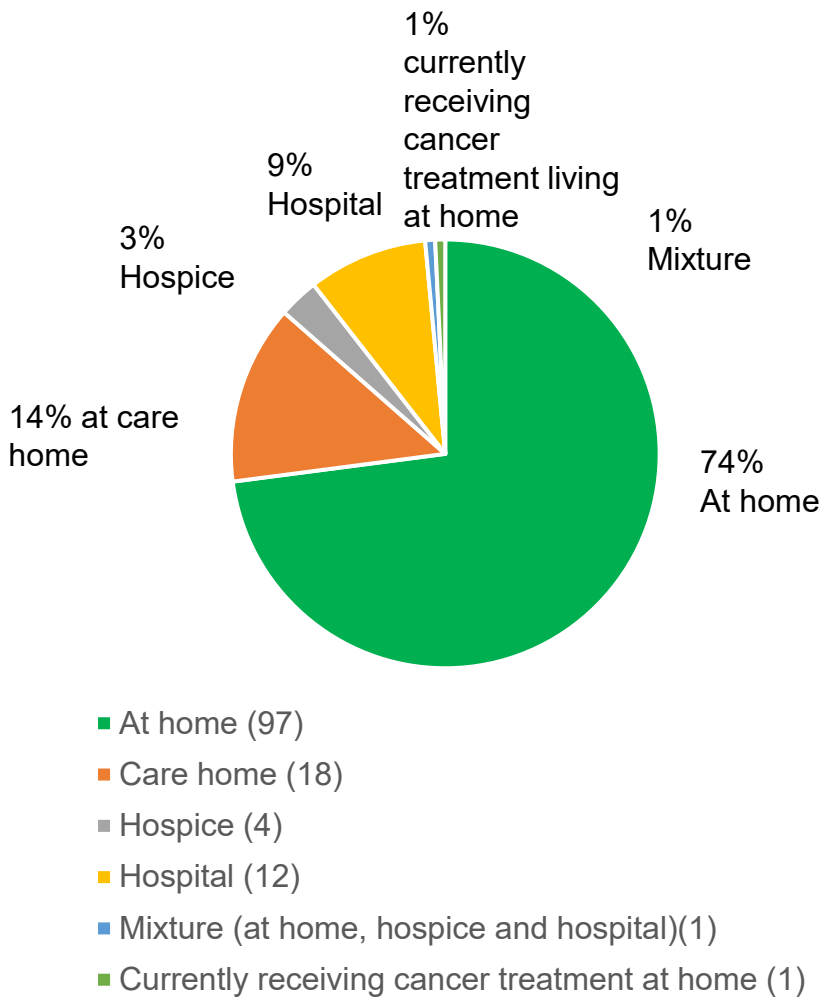
Other locations were at care homes, hospital and at a hospice. Where provided, specific sites are listed below:-

Care home	
Residential care home	2
Holmleigh Care Home, Navenby	2
Fotherby House	1
OSJCT – North Hykeham	1
Methodist Care Home	1
The Georgians, Boston	1
Homer Lodge	1
Brun Lea	1
Care home with nursing	1
Welbourn Nursing Home	1
Beckside – North Hykeham	1
Grand View, Stamford	1



Hospital	
Pilgrim Hospital, Boston	3
Lincoln County Hospital	2
Holbeach Hospital	1
Langworth Ward	1
Castle Hill Hospital	1
Witham Court	1
Peterborough Hospital	1

Hospice	
Butterfly Hospice	2
St Barnabas	1
Thorpe Hall	1

79% (74/119) agreed that they were involved in organising support and decision making
6% (7/119) said they were rarely or never, 3% (3/119) stated that it wasn't relevant to them.
There has been an improvement from the previous report where 72% felt the patient was involved in making decisions about their care as much as they wanted to be.
In summary, experiences were more positively received within a hospice or a care home than within a hospital.
The reasons for feeling involved were:-

Themes for feeling involved	Comments
Role as main carer or advocate	• Many identified themselves as the main or only carer, managing personal and medical care (eg, toileting, showering, feeding and exercising), liaising with GPs, Nurses, Pharmacists and Hospital Teams and taking their loved ones to appointments/treatments/collecting prescriptions. • Many spoke about how their loved ones had discussed their wishes and options together as a family, not just making decisions alone. • Some had professional or clinical knowledge (eg, Marie Curie nurses, ex-health workers), which empowered them to understand systems and advocate effectively. • Power of Attorney (POA) for health and wellbeing was often crucial in ensuring wishes were respected.
Decision making and good communication	• Positive experiences came when professionals consulted families, listened to the patient's preferences, and co-created care plans. • Hospices such as St Barnabas, community health teams and the team on Waddington Ward were praised for involving and supporting families compassionately. • Families valued being kept fully informed and having access to a clear point of contact.
Respect for individuals wishes and dignity	• Families appreciated when patients' choices (eg, to die at home) were respected and supported through practical arrangements. • ReSPECT conversations were held as a family. • Being able to administer medication promptly (eg, under subcutaneous carers' policy) and to act with consent gave carers a sense of privilege and control. • Acknowledgment of the patient's mental capacity and autonomy was viewed as essential to good involvement.
Practical and emotional support	• When services co-ordinated effectively - District nurses, palliative care teams, community hospitals — families felt supported both practically and emotionally. • Emotional and holistic care for the family, not just the patient, was highlighted as a major positive from hospice teams.

Reasons for not feeling involved in organising support and decision making were:-

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Themes for not feeling involved	Comments
Poor communication and lack of transparency	• Some felt excluded from discussions, particularly when the patient was too unwell to make decisions. • Decisions were sometimes made or changed without family consultation.
System failures and bureaucracy	• Families reported having to chase information, clinical staff for visits, services, or care packages - sometimes with lack of coordination between primary, secondary and social care. • Delays in discharge planning, respite or ambulance transfers. • Lack of available care packages meant some individuals/families took on full-time care roles. One respondent reported that they had several emergency GP's call who stated that "you shouldn't have to do this" but offered no alternative. • Several negative experiences were mentioned regarding Louth Hospital. One family commented that their care within Louth Hospital was made worse and went into debt to get the individual a private live-in carer and one paying privately and transferred to a care home.
Lack of empathy and care and compassion in care settings	• Several accounts describe hospital environments as impersonal or neglectful, with 1 respondent mentioning that their loved one was left unattended or inadequately fed/hydrated. • Some professionals were perceived as indifferent or burnt out, lacking kindness or understanding of emotional impact. 1 individual advised that when she tried to speak to someone, she was told that they were "too busy to talk to me which was upsetting".
Disempowerment and exclusion	• Not having Power of Attorney or not being recognised as a decision-maker, made it more difficult • Some relatives felt not listened to or respected, despite being the main carers. • Non English speaking relatives faced additional barriers to involvement.
Inequality and variance in care	• Experiences varied widely between hospitals, community care, and hospices—with hospices typically offering better communication and inclusion.

25% (30/120) agreed that as the carer/family they fully **received as much help from health and social services as they needed when caring for their loved one** (a decrease from the previous report 32%).

37% (44/120) said partially but would have preferred more (an increase from the previous report 23%).
This figure was higher within the east lindsey compared to other district areas.

30% (35/120) reported trying to get more help (increase from previous report 29%)

4% (5/120) did not receive any but did not want any (decrease from previous report 16%)

4% (5/120) was not relevant to them

Themes on what worked well regarding the experience that respondents as carers received are detailed below:-

Themes on what worked well	Comments
Compassionate and caring teams	• District Nurses, Palliative Teams, End of Life Care Teams, Out of Hours Team, Carers, Carers First, Carers Leads at Langworth and LPFT, Nurses at Holbeach and East Elloe Hospital Trust, Operations Centre at Lincolnshire Community Health Services and Community Nurses were frequently praised for being caring, professional, empathetic, and attentive. • Teams from Adult Social Care, NRS, St Barnabas, St Barnabas at Home Grantham Hospital, Marie Curie, Macmillan, Sue Ryder (Thorpe Hall) and Fotherby House Care Home received praise providing exceptional training and support, often going above and beyond for patients and families. • GP practices, especially those with quick response and open communication, were valued for their accessibility and understanding. Tasburgh Lodge, James Street and Kirton Medical Centre were particularly praised for their help and support. • Social workers and Adult Social Care were appreciated when they offered timely, practical, and compassionate help.
Communication and emotional support	• Weekly or regular phone calls (eg, St Barnabas counsellor during COVID) were helpful for emotional support. • Hospice staff who took time to explain what was happening, check on family wellbeing, and involve relatives made a huge difference. • Carers and nurses who listened, included families in care, and treated patients with dignity and respect built trust and comfort.

Themes on what worked well regarding the experience that respondents as carers received are detailed below:-

Themes on what worked well	Comments
Enabling care at home	• When care worked well, people valued the ability to stay at home surrounded by loved ones. • Fast access to equipment (beds, hoists, commodes etc) supported safe home discharges, allowing people to stay at home where they wanted to be. • Collaboration between GPs, District Nurses, and charitable hospice teams enabled joined-up care and symptom control at home.
Excellent inpatient and hospice care	• Skegness Hospital, Waddington Ward, Holbeach Hospital, and Hospice at Home teams were praised for dedication, kindness and preserving dignity. “Skegness Community Nurses were incredible”. “the Nurses on Waddington Ward cared greatly for mum”. • Families appreciated being able to stay overnight during the last few days. • Staff were recognised for their knowledge of the terminal phase, communication skills, and compassionate bedside manner.
Communication and responsiveness	• Some noted that the “whole system worked well” when teams communicated effectively and acted promptly. • Quick response times from nurses and doctors were valued. • Where equipment, medication, and home support were organised early, families felt reassured and supported.
Person centred care	• Teams that cared for both the individual and the family were most appreciated. • Completing the “All About Me Booklet” and attention to small personal details — such as how someone liked their tea or daily routines made a big difference to dignity and comfort. • Families valued being supported not just as carers but as loved ones during difficult times. • Praise and feeling that they were “wrapped around with support” when on the Gold Standard Framework. • Families took comfort when care home staff attended funeral of their loved one.

What could have improved the experience for improving the help received from health and social care

NHS Lincolnshire

Themes for improving the experience	Comments
Delays and gaps in care	• Fast Track care packages were sometimes delayed or incomplete - care was sometimes not arranged until the day they died. • Families sometimes had to chase services to arrange visits, care or equipment. • Delays in transport from hospital to care home, equipment delivery, prescription access and hospital discharge planning disrupted continuity of care. • Delays in staff attending when calling the “green card numbers”. • Would have liked more information from social services, particularly about funding. One respondent commented that they had taken every single penny that their mum had worked her life for. • More care support at home overnight. • Lengthy delay of 10 hours certifying a death.
Better co-ordination between services	• Some experienced fragmented care - repeated assessments, inconsistent communication, and unclear roles across health and social care teams. • Families had to retell their story multiple times to new professionals. • Some noted that no single person seemed accountable for managing the overall care plan. A lack of consistent, named contacts made it difficult to know who was responsible for what. A named contact would be beneficial and a single point of contact or case co-ordinator for each family. • There needs to be re-referral to community services when they are required (individuals don’t always want it at the time they are offered it) so that individuals know what support is available, avoiding potential visits to A&E. Macmillan Nurses are interested in people receiving active treatment. • Cross border issues can complicate care.
Discharge planning	• Reports of inadequate discharge planning left elderly carers unsupported at home. • Some hospitals failed to follow up or ensure joined-up palliative pathways before sending patients home. • Extended hospital stays without physiotherapy or rehabilitation caused avoidable decline in mobility and independence.

What could have improved the experience for improving the help received from health and social care Continued …

NHS Lincolnshire

Themes for improving the experience	Comments
Information and signposting	• Families sometimes did not know what help was available or how to get it. • More help and support. • Support with personal care would be welcomed.
Staffing/system pressures	• Staffing shortages, COVID-related constraints, and time pressures reduced the ability to provide consistent compassionate care. • Several families noted that professionals did their best but were clearly overstretched.
Access to services	• Some were told they “weren’t bad enough” to qualify for specialist nursing or hospice support. • Reliance on charitable organisations (eg, St Barnabas, Marie Curie) highlighted inconsistent access to palliative support. • Concern that Lincolnshire County Council no longer provide carers from Marie Curie. • Lack of availability of carers, choice of provider and being more active in personal cleaning. • Families of veterans and others only received help after contacting external charities like the Royal British Legion where they were provided with an Admiral Nurse. • Waits for urgent visits and equipment. • Gaps in overnight or out-of-hours cover. • Patients discharged from hospital sometimes received no follow-up care or plan in place. • The system was sometimes seen as slow.
Medication	• Families reported delays in pain relief, medication administration, medication reviews or difficulty obtaining pre-emptive medications. • Some found the system too slow in responding to urgent symptom changes. • Syringe drivers being available all of the time. • One respondent described being told “nothing more could be done”. • The hours between 6.00 pm – 9.00 am were felt could be covered better. • Respondents spoke of their negative and worrying experiences waiting between 2 – 5 hours for pain relief. This was sometimes due to the distance that staff travelled. • Doctor arriving to give pain relief after individual had passed away. • One family reported that getting medications from a pharmacy was difficult and they had to travel to get the pre-emptive syringe driver medications. • Greater explanation to carers about end of life medication.

What could have improved the experience for improving the help received from health and social care
Continued …

NHS Lincolnshire

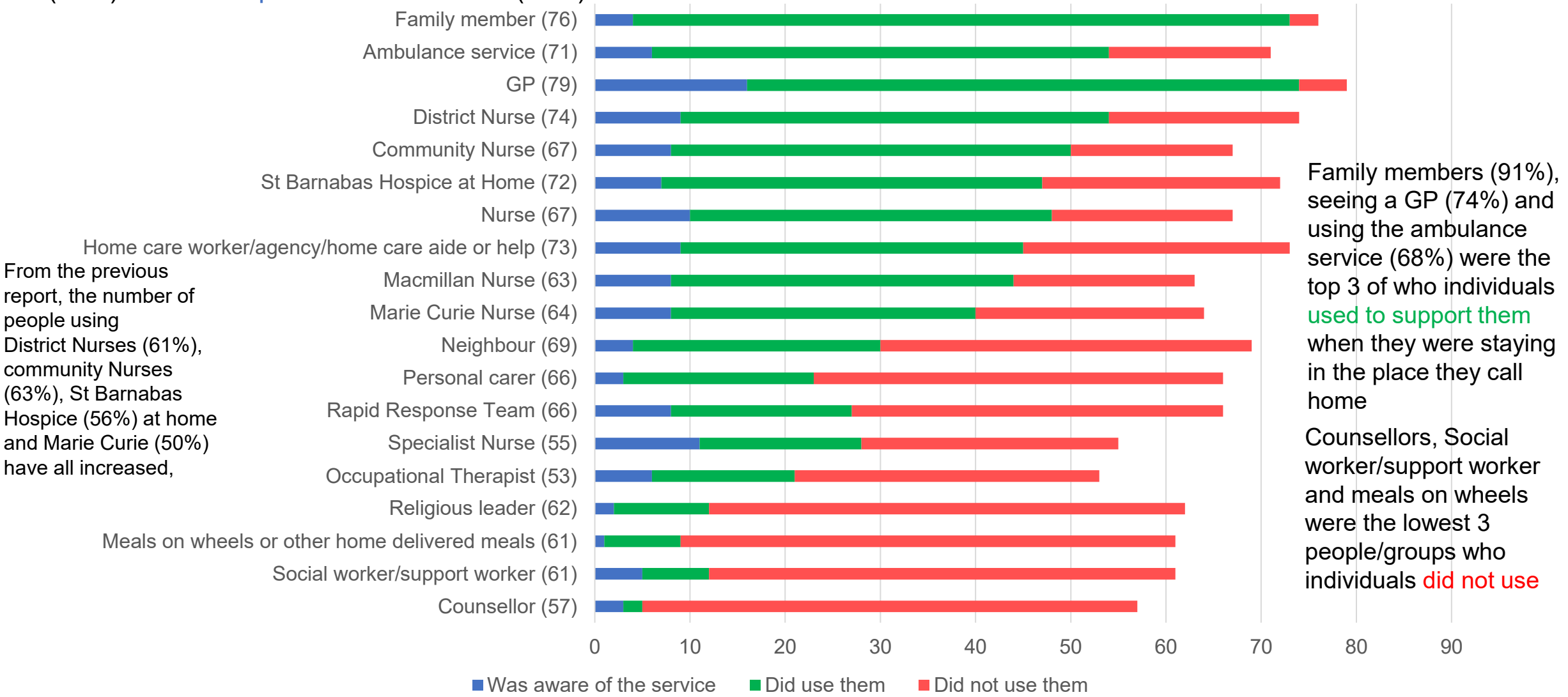
Themes for improving the experience	Comments
Communication issues and compassion	• Some staff were described as having a lack of empathy, poor attitude, being dismissive, cold or lacking kindness and empathy. • Families felt excluded from decision-making, particularly around hospital discharges and end-of-life planning. • There were instances of inadequate communication about what to expect as someone nearing the end of life, leaving families unprepared. • Some families felt isolated and confused, receiving conflicting or incomplete information from different teams. • Lack of communication between GPs, hospitals, community nurses, and social services caused delays, duplication, and distress. • Families sometimes had to chase up-dates. • More regular and honest conversations about care, treatment and prognosis. • Poor handling of end-of-life situations - such as leaving patients undignified after death caused lasting trauma. “Left in A and E for 5 hours in a wheelchair with no sepsis screen until I arrived and dealt with it – by then her blood pressure had dropped to a dangerously low level and she’d been left in her wheelchair in her underwear without any consideration of her dignity”.
Emotional and practical support for families	• Many carers described feeling powerless, isolated, or unsupported, especially non-immediate relatives. • Bereavement and emotional follow-up were inconsistent. • Some felt forced to fight for basic care rather than being guided through the process.
Continuity and stability of staff	• Frequent changes in care providers and teams disrupted trust and consistency. • Patients were passed between services or contractors multiple times. • New carers or clinicians often lacked background information, leading to repeated explanations and errors. • Knowing what time carers, GP’s and community nursing teams would be attending/visiting throughout the day would help families with planning. • Inconsistency in care provided by carers. • Better communication required between District Nurses and Community Nurses.
Holistic and family support	• Carers sometimes felt overlooked and unsupported in their roles. • Emotional, psychological, and bereavement support was not always offered.
Specialist and local provision	• Limited local palliative, dementia carers, Admiral Nurses (working within a PCN and working alongside District Nurses) and respite care meant families had to manage alone or travel long distances. • Sometimes delays in accessing specialist teams (eg, Parkinson’s Doctor/Consultant Nurse, incontinence or palliative).

Section 4

Care at home

79% (86/109) of respondents stated **that they stayed in the place that they call home within the last 3 months of life.** When they were at the place they called home in the last 3 months of life, respondents stated that they were aware or had received help from the following listed below:-

48% (42/86) of respondents thought that services worked well together (this figure had decreased from the previous report where 74% felt they worked well together). 42%(36/86) thought that they didn't work well, 5% (4/86) had not requested care and 5% (4/86) did not know



From the previous report, the number of people using District Nurses (61%), community Nurses (63%), St Barnabas Hospice (56%) at home and Marie Curie (50%) have all increased,

Family members (91%), seeing a GP (74%) and using the ambulance service (68%) were the top 3 of who individuals used to support them when they were staying in the place they call home

Counsellors, Social worker/support worker and meals on wheels were the lowest 3 people/groups who individuals did not use

During the last 3 months of life, while they were at home, 65% (57/88) of respondents felt that their physical symptoms were managed fully or most of the time. 35% (31/88) of respondents felt that they were not really or not at all.

Respondents felt that the following worked well when receiving care at home

Staffing	• Community nurses, Macmillan, St Barnabas, Marie Curie, Carers, Continence Team and District Nurses, LIVES Team were consistently praised for their dedication, compassion and professionalism. • Many families noted that these teams "worked well together" and "made the experience peaceful and dignified." • Specific individuals - such as "the Nurse from the Surgery who implemented fast track" and "the weekend nurse who communicated with the GP", "night sitters who allowed the family to get sleep and knowing that someone who knew the signs to look out for" — were highlighted for going above and beyond.
Collaboration between services	• Positive co-ordination between Macmillan, St Barnabas, District Nurses and GPs made care smoother and more reliable. • Families appreciated when communication worked - when clinicians kept in touch and responded quickly to changing needs. • Teams who provided joined-up, responsive support (eg, quick communication with GPs, timely symptom management) made a significant difference. • Use the "All about Me" booklet.
Comfort and familiarity of being at home	• Being at home offered peace, dignity, and comfort - familiar surroundings, own food, family, and friends nearby. • Patients felt empowered and respected with choices maintained and last wishes honoured. • Remaining at home often helped preserve emotional wellbeing, described as "mentally beneficial" and "comforting."
Timely and practical support	• Equipment (such as hospital beds and syringe drivers) was usually delivered promptly with NRS staff described as "polite and careful." • "Fast track" referrals and access to "just in case" medication kits offered reassurance and reduced anxiety. • The presence of overnight sitters and continuous care support allowed family carers to rest and feel secure.
Personal and family support	• Nurses were often attentive not only to the patient but also to family wellbeing - offering breaks, emotional support and guidance. • Families valued being part of care decisions and appreciated the trust placed in them to contribute to care at home. • Carers described feeling supported, respected, and reassured by staff who genuinely cared.
Effective symptom management	• When managed well, patients were "settled," "at peace" and "rarely in pain." • Good communication and timely medication management (once properly set up) ensured comfort and dignity at end of life.
Pride and gratitude	• Families expressed deep gratitude and pride for both the care teams and their loved ones' strength. • The experience, though complex, was often described as ultimately working well - allowing loved ones to stay where they wanted, surrounded by care and compassion.

Respondents felt that the following could be improved when receiving care at home

NHS Lincolnshire

Themes for improving the experience	Comments
Access to equipment and medication	• Medication and equipment was a key theme to loved ones being comfortable at home. Medication supply was often incomplete or mismanaged (eg, lack of medication, mistakes with syringe drivers, incorrect doses, late prescriptions, GOLD sheet requiring signature, greater awareness by carers using it at home). • Equipment such as hospital beds and recliner chairs were delayed, unsuitable or unavailable. • Poor co-ordination between GP surgeries, pharmacies, and community teams caused gaps in symptom control. • Opportunity to purchase/rent dementia chairs at home to help with balance and co-ordination.
Communication and co-ordination	• Poor communication between services (GPs, district nurses, Macmillan, hospitals, pharmacies) caused confusion, distress, and delays. (One family reported that a District Nurse visited their mum and left an end of life folder but did not explain anything to the family and concerns expressed that a male care worker had been sent when the individual lived on their own). • Families had to chase updates or repeat information to multiple professionals. • End-of-life documentation (e.g., RESPECT forms, Gold Sheets, fast-track paperwork) was frequently incomplete, delayed, or not explained to families with ReSPECT form wishes not always respected. • Carers were not always told what to expect, what was happening or what support was available. • A single point of contact (particularly a GP assigned and not a locum) or joined-up approach across agencies was requested. • End of life care should be treated as an emergency. • Better explanation of what home care services are. Offer a follow-up in a couple of months to check whether peoples wishes have changed.
Delays in care and response times	• Reports of slow response for pain relief, night sitters, equipment delivery, and fast-track setup. • Patients were left in pain for long periods while waiting for nurses or medication authorisations. • Urgent calls sometimes took over an hour for a response or several days for action. • Some care and medication were only arranged hours or days before death, despite needing earlier. • Provide palliative patients with a direct admission policy to allow for a seamless admission to hospital.
Inadequate staffing and resources	• Lack of overnight staff and limited out-of-hours cover meant families faced distressing waits. • Shortages of trained carers and nurses led to inconsistent or cancelled visits. • Families were told “there’s no one available” despite on fast-track end-of-life care. • No hospice at home provided despite a GP referral. • Continuing healthcare being refused. • Being told that didn’t quality for night care because didn’t have “complex needs”. • Advanced Clinical Practitioners and Doctors being available in palliative care in the community.

Respondents felt that the following could be improved when receiving care at home

Continued …

NHS Lincolnshire

Training, empathy and professionalism	• Carers and nurses varied in quality. • Families asked for more empathy, understanding, and sensitivity in communication and care delivery. • Several accounts described unprofessional or insensitive behaviour, including lack of acknowledgment after a death. • Need for better training in end-of-life communication, symptom recognition, and emotional support for both patients and families.
Information, guidance and support for families	• Families often had to find their own information. • Requests for clearer explanations, practical guidance, and emotional support. • Bereavement follow-up was not always offered. • Families described exhaustion and loneliness, saying “weekly check-ins” or “more proactive contact” would help. • One respondent reported that they suffered a tendon injury and needed to see a GP as they were lifting their mother of the floor due to a fall.
Inequality of access and service gaps	• Some families reported receiving no home care at all despite repeated requests. • Support varied by area, time of day, or individual staff availability. • Services like Marie Curie were missed or no longer available. • Calls for more consistent access to palliative specialists at home — as are available in hospices or inpatient settings. • More local support to avoid travel. One respondent who is currently going through treatment for oesophagus cancer reported that he needs to have his chest drained at the Respiration Unit at Lincoln County Hospital. It is a complex procedure and queries if a Community Nurse who is going in to his home already can be trained so that can do this to avoid all of the travelling when they would be going into the house. The individual has been been advised not to drive now and wife doesn’t drive so would rely on patient transport to help with appointment. It is a round trip of 50 miles from his home to Lincoln Hospital to receive treatment for 10/15 minutes where chest needs to be drained.
System issues	• Over-reliance on families to coordinate care and advocate for patients. • Hospital discharges without assessment or adequate care in place. • Administrative errors such as referrals sent to wrong addresses, miscommunication between services, and lost paperwork. • Lack of clarity about fast-track processes and limited understanding among some staff.
Respect, dignity and respect	• Patients’ voices and choices were sometimes ignored or overridden. • Families felt professionals made assumptions based on diagnosis or age rather than listening. • End-of-life care should be personal, respectful and guided by patient wishes, not system convenience. • Greater compassion and recognition of the emotional weight for families were frequently requested.

Section 5

Urgent Care provided out of hours (evenings, nights, weekends and bank holidays

We asked respondents to tell us **how many times they had used the out of hours service, who they visited, the reasons and whether they received the outcome they wanted.**

NHS Lincolnshire

67% (75/113) of individuals stated that they had needed to use the out of hours service in the last 3 months of life, 27% (31/113) had not needed to use the out of hours service and 6% (7/113) did not know.
Compared to the last report individuals needing to use out of hours has decreased where 85% was reported in the last report.
Data has been broken down into provider and if they received the outcome they wanted.

We asked respondents to tell us how many times they had used the out of hours service, who they visited, the reasons and whether they received the outcome they wanted.
These are detailed below based on condition, where stated with the highest number highlighted

NHS Lincolnshire

Cancer

Provider	Number of times contacted and number of people that contacted					
	Not contacted	Contacted 1 time	Contacted Twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	1	1	5	2	0	2
111	4	3	4	0	1	1
PSPA/Green card	2	2	2	1	1	8
District Nurses	1	1	2	1	0	4
Macmillan Nurses	3	1	2	2	2	2
Lifeline pendant	4	1	0	0	0	1
Hospice	2	2	0	0	0	0
Urgent Treatment Centre	3	2	1	0	0	2
Waddington Ward/Bostonian	5	3	1	0	0	0
Marie Curie	2	1	1	1	1	2
Rapid Response Team	2	2	1	1	1	1
Parish Priest	0	0	0	0	0	1

Dementia

Provider	Number of times contacted and number of people that contacted					
	Not contacted	**Contacted Once**	**Contacted Twice**	**Contacted 3 times**	**Contacted 4 times**	**5 times or more**
GP	0	0	1	0	0	1
PSPA/Green card	0	1	1	0	0	1
District Nurses	0	0	1	0	0	1
Marie Curie	0	0	0	0	0	1
Rapid Response Team	0	0	0	0	0	1

Core pulmonary

Provider	Number of times contacted contacted and number of people that contacted					
	Not contacted	**Contacted Once**	**Contacted Twice**	**Contacted 3 times**	**Contacted 4 times**	**5 times or more**
111	0	0	0	0	0	1

Respiratory condition

Provider	Number of times contacted and number of people that contacted					
	Not contacted	Contacted Once	Contacted Twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	0	0	1	1	0	2
111	0	0	0	0	0	1
PSPA/Green card	0	0	0	1	0	1
District Nurses	0	0	0	0	0	2
Macmillan Nurses	0	1	0	0	0	0
Lifeline pendant	0	0	0	1	0	0
Hospice	0	1	0	0	0	1
Marie Curie	0	1	0	1	0	0

Surgery

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted Once	Contacted Twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	0	0	0	0	0	1
111	0	0	0	0	0	1
District Nurses	0	0	0	0	0	1

Neurological condition

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	0	0	1	0	0	0
District Nurses	0	0	0	1	0	0

Sepsis

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	0	0	1	0	0	0

Liver failure

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	0	0	0	0	0	1
Marie Curie	0	0	0	0	0	1

Heart failure

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	0	0	1	2	0	0
111	0	0	0	0	0	1
PSPA/Green card	0	0	0	0	0	1
District Nurses	0	0	0	0	0	1
Macmillan Nurses	0	0	0	0	0	1
Lifeline pendant	0	0	0	0	0	1
Hospice	0	0	0	0	0	2
Marie Curie	0	1	0	0	0	0
Rapid Response Team	0	0	1	0	0	0

Hip infection

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
PSPA/Green card	0	0	0	0	0	1
Rapid Response Team	0	1	0	0	0	0

Old age

NHS Lincolnshire

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
GP	2	0	1	0	0	0
111	1	0	0	0	0	0
PSPA/Green card	2	1	0	0	1	1
District Nurses	2	1	1	0	0	0
Macmillan Nurses	2	1	1	0	0	0
Community Nurses	0	0	1	0	0	0
Lifeline pendant	1	2	0	0	1	0
Hospice	3	0	0	0	0	0
Waddington Ward	3	0	0	0	0	0
Marie Curie	3	0	0	0	0	0
Rapid Response Team	2	0	0	0	0	0

Alzheimers

Provider	Number of times contacted and number of people contacted					
	Not contacted	Contacted once	Contacted twice	Contacted 3 times	Contacted 4 times	Contacted 5 times or more
111	0	1	0	0	0	0
PSPA/Green card	0	0	0	1	0	0
District Nurses	0	1	0	0	0	0
Macmillan Nurses	0	0	0	1	0	0
Marie Curie	0	0	1	0	0	0

61% (43/71) of respondents advised that the care received when they needed urgent out of hours in the last 3 months was very good/good. 34% (24/71) advised that it was poor/very poor, 6% (4/71) did not know.

The reasons for what worked well were:-

Theme	What worked well
Compassionate and supportive caring staff	• Dedicated, empathetic teams from charities and community services (Macmillan, Marie Curie, St Barnabas, District Nurses). • Staff were described as reassuring, helpful and always there when needed. • Joint teamwork across services (District Nurses, GP, hospice teams). • Paramedics and hospice staff described as thorough and kind; clear explanations given to patients and families. • Qualified nurses on site at Holbeach Hospital.
Responsive services	• Quick responses to phone calls and visits. • Knowing that there was a telephone number to call. The SPA 1 number to telephone was helpful, as well as Addenbrookes emergency line and the 24 hour chemotherapy line at the hospital. • SPA team consistently returned calls, even on weekends and followed up with a follow-up call/visit. • Ambulance teams and emergency responders were described as prompt, calm and effective, able to offer support such as changing catheters or medication and taking their loved ones to A&E. • It is a large county and there was a rapid service. • Helped support with pain relief, setting up syringe driver.
Collaborative multidisciplinary support	• Positive mentions of multiple services working together - Marie Curie, District Nurses, St Barnabas, GP support, and rapid response teams. • This collaboration created a more integrated and supportive experience.

Suggested areas of improvement required when receiving care out of hours

Some families reported excellent care and could not fault their experience. Marie Curie nurses were repeatedly highlighted as compassionate and knowledgeable, though under-resourced.

Theme	What didn't work well
Reducing delays and improving response times	• Long waits for visits, which caused distress. • Long distances travelled and winter conditions add to delays. • The need for more staff—nurses, doctors, Marie Curie teams—to reduce waiting times for assessments and pain relief. One team covering 45 miles was felt excessive. • Faster response needed especially for those with green/gold cards or expected end-of-life deterioration. • More staff available overnight, especially in rural areas such as Skegness and for those that have complex needs. • Feeling that a visit was declined and offered hospital or stay at home alternatives.
Better pain and symptom management	• Several patients experienced unmanaged pain or suffered due to lack of timely morphine or pain-relief interventions. • Concerns that recommendations were not followed, resulting in inadequate pain relief until final hours. • Requests for more prescribers, including Macmillan nurses, to avoid delays in accessing medication. • Need for professionals who understand end-of-life pain and distress. • Greater explanation to families about using end of life medication.
Communication and feeling listened to	• Families felt dismissed or unheard; some felt told "you're dying so let's discharge you," which was upsetting. • Receiving a Marie Curie leaflet in the post advising that care had been allocated and when daughter telephoned the SPA line was advised that they didn't know what they were talking about. • Desire for staff to listen to patient wishes and respect the choices of those nearing end of life. • Better communication about what to expect during the dying process. • Giving advice over the phone without knowing the patient can feel condescending.
More personalised care	• Need for hands-on support with personal care, especially for older people or those with dementia. • Families highlighted repeated A&E attendance from frail older people without flags raised or proactive follow-up. • More regular contact from staff who know the patient's circumstances. • Ensuring DNR, green card and gold card status are recognised and acted upon.
Alternatives to Accident and Emergency for palliative patients	• A&E environment described as chaotic, distressing and unsuitable for terminally ill patients. • Need for a separate, calm place for those requiring urgent care but not emergency treatment. • Transport difficulties made A&E attendance or return home challenging.

Suggested areas of improvement required when receiving care out of hours

NHS Lincolnshire

Theme	What didn't work well
Continuity and co-ordination	• GP follow-up sometimes did not occur. • Patients not always seen by their own consultant after admission. • Calls routed through 111 were challenging because the service is geared to acute, not complex, chronic or end-of-life needs. • The need for better handover between OOH teams, GP practices, consultants, and community nurses.
Supporting families and carers	• Families need clearer information on symptoms to look out for so they can seek help earlier. • Requests for trained night-time carers so family members can sleep. • Support to help relatives honour the patient's wish to be cared for at home when possible.
Workforce and service design	• Understaffing in Marie Curie teams and community services leads to long waits. • Need more trained palliative-care specialists, especially for home visits. • Concerns raised about specific care providers (e.g., Cera Care, Pro Care). • Recognition that dementia and end-of-life care need a higher profile in Lincolnshire. • Strong feedback not to remove the OOH service.

Of those respondents who stated where they lived and who received out of hours care, rates of satisfaction for have been broken down across geographical locations. Of those that responded, satisfaction was more positive within West Lindsey and Boston and more negative in Lincoln district where 50% stated that it was good and 50% poor.

	Boston	East Lindsey	Lincoln	North Kesteven	South Holland	South Kesteven	West Lindsey
Very good	1 (25%)	4 (20%)	3 (27%)	2 (22%)	4 (57%)	7 (44%)	1 (33%)
Good	2 (50%)	8 (38%)	2 (18%)	3 (33%)	0 (0%)	4 (25%)	2 (67)
Poor	1 (25%)	7 (33%)	2 (18%)	3 (33%)	2 (29%)	0 (0%)	0
Very poor	0	1 (5%)	3 (27%)	1 (11%)	0 (0%)	4(25%)	0
Don't know	0	1 (5%)	1 (9%)	0 (0%)	1 (14%)	1 (6%)	0
Total	**4**	**21**	**11**	**9**	**7**	**16**	**3**

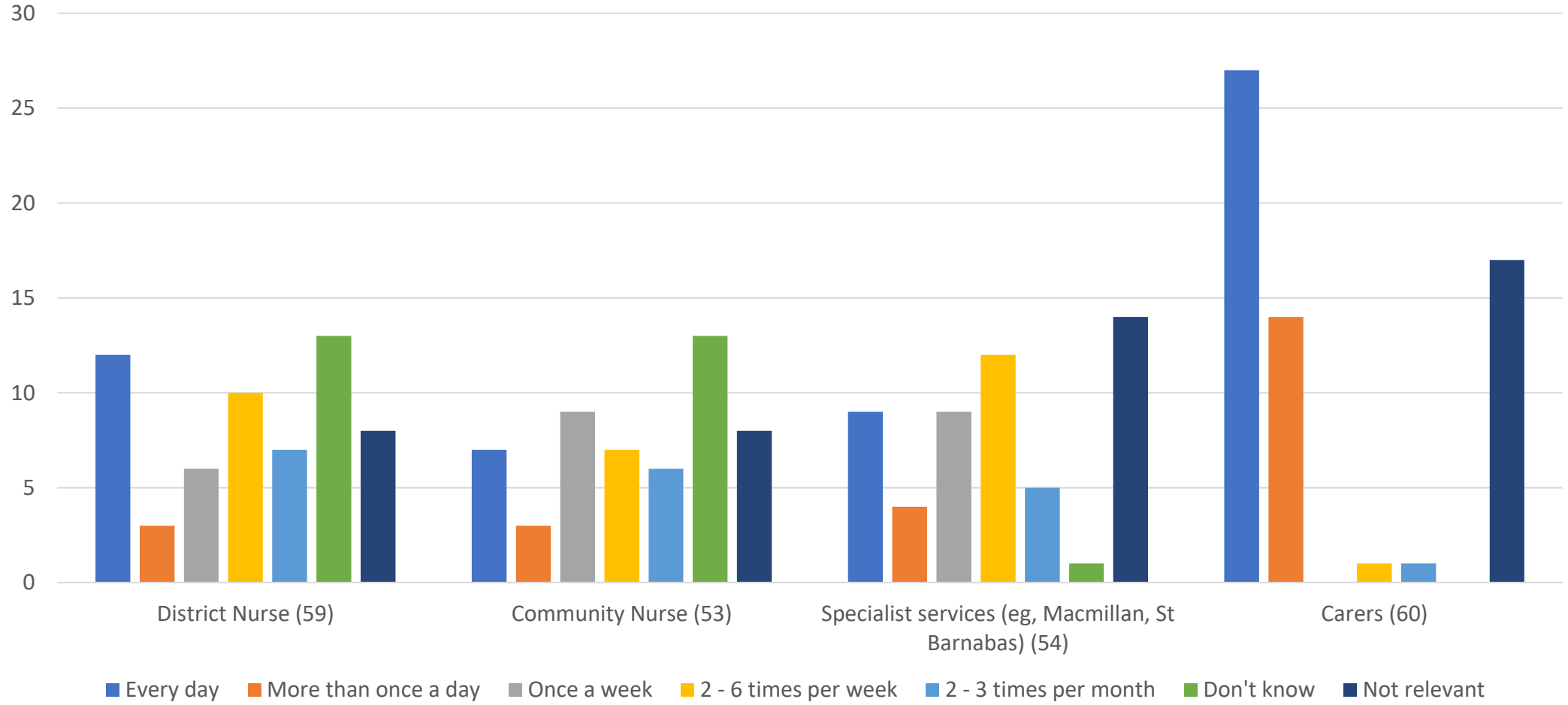
Section 6

District, Community Nurses, Specialist Services or Carers

In the last 3 months, 71% (81/114) did use, 20% (23/114) did not use and 9% (10/114) did not know if their loved ones had used District Nurses, Community Nurses, specialist services and carers.

Respondents reported that they visited on the number of occasions listed below.

Respondents reported that whilst the lowest number of respondents used carers, when they did, 45% visited the most on daily occasions

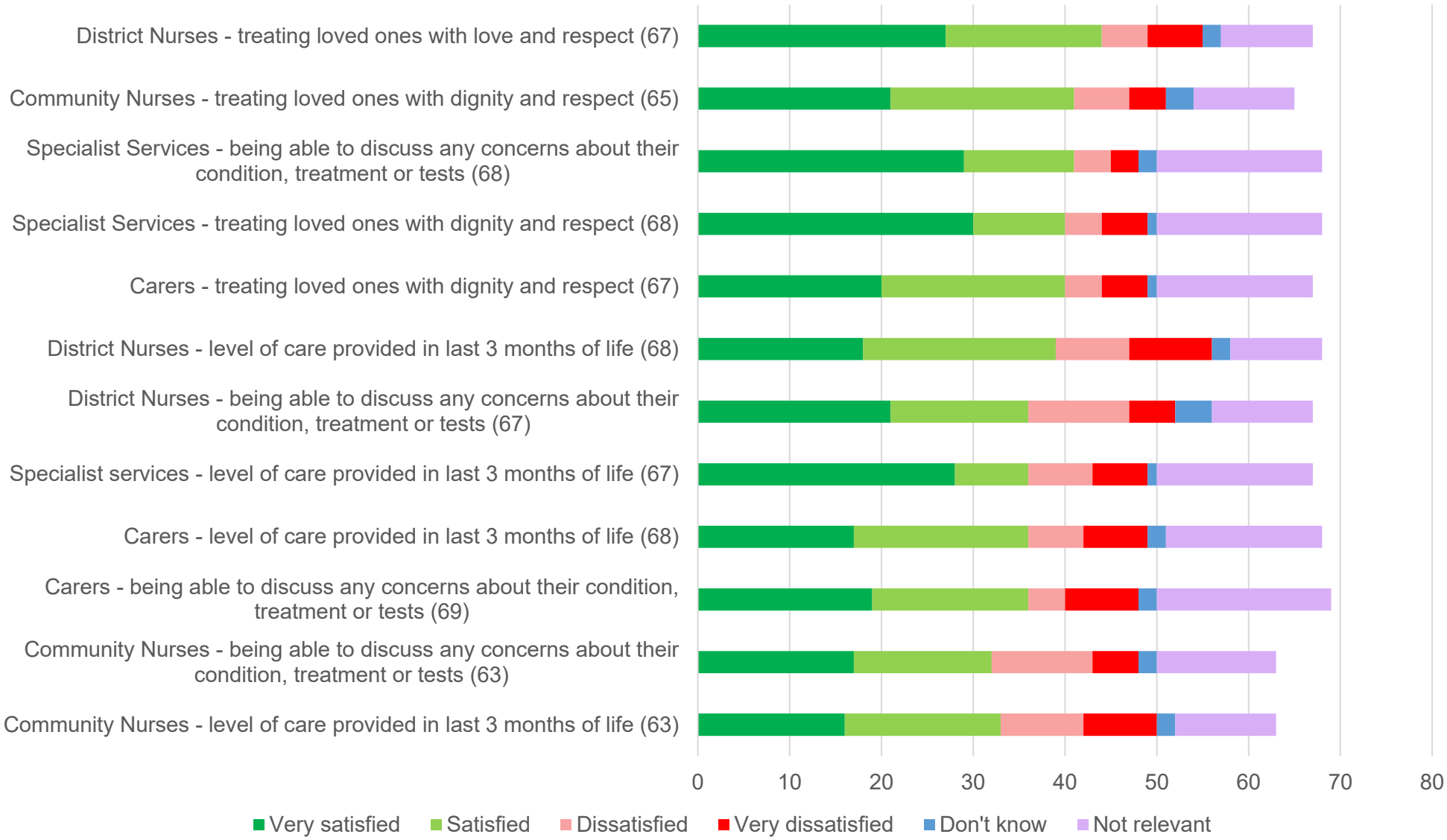


The last report captured District Nurse and Community Nurse data together.
For this year District Nurses, 22% of respondents did not know how many times they visited. 20% were visited every day by District Nurses (an increase from the last report 18%).
For Community Nurses, 25% of respondents were unaware of how many times they had visited. 17% visited once a week.

The below graph shows the extent of **how satisfied respondents were with the support from District Nurses, Community Nurses, specialist services and carers**

Overall, the top 3 highest rates of satisfaction were from community nurses and specialist services treating loved ones with dignity and respect and being able to discuss concerns about their condition with specialist services and the top 3 higher rates of dissatisfaction were levels of care provided in the last 3 months and being able to discuss any concerns with community nurses and carers

NHS Lincolnshire



Overall, 58% were satisfied with support from specialist services and 14% dissatisfied

Overall, 59% were satisfied with support from District Nurses and 22% dissatisfied

Overall, 55% were satisfied with support from Community Nurses and 23% dissatisfied

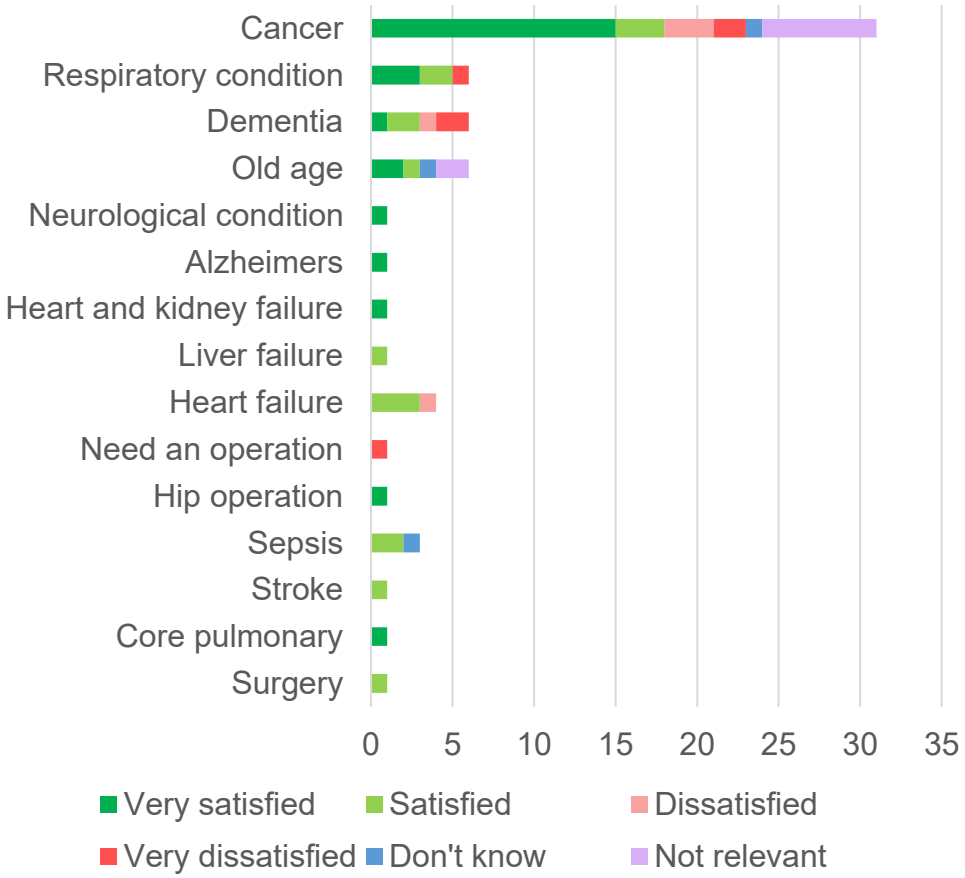
Overall, 55% were satisfied and 17% dissatisfied with support from Carers

Rates of satisfaction where stated, across condition, that the person died from:-

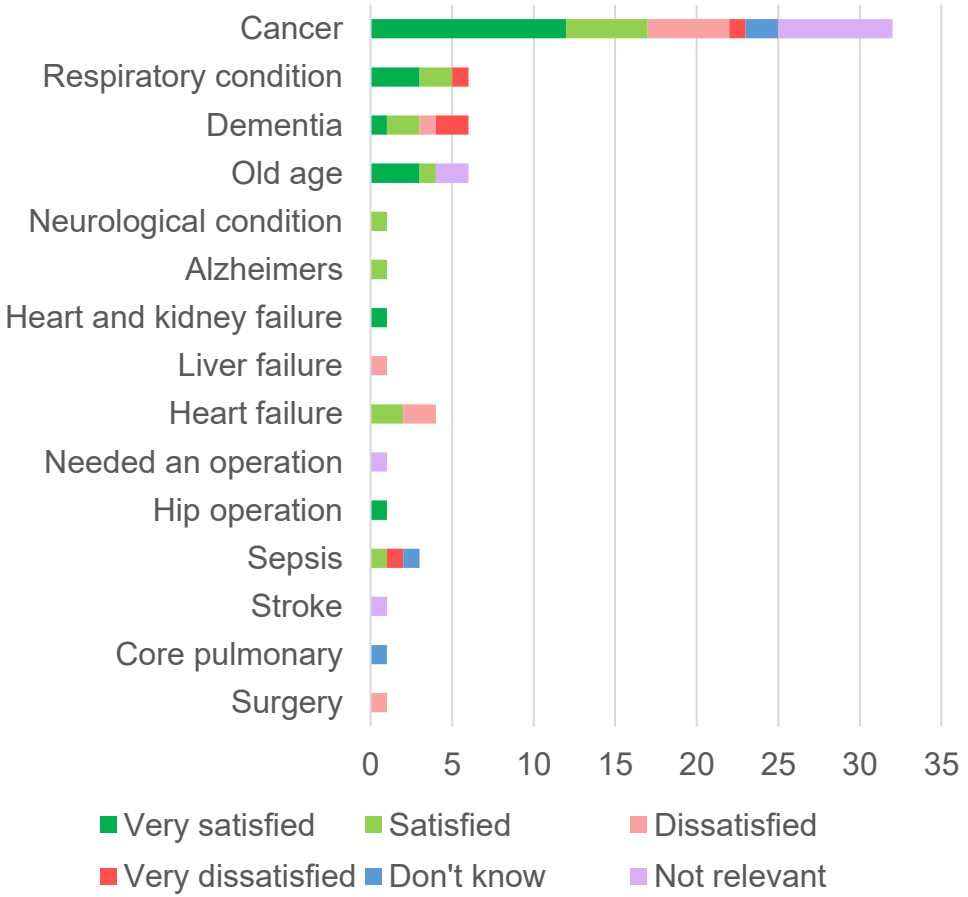
NHS Lincolnshire

District Nurses

Your loved one being treated with dignity and respect



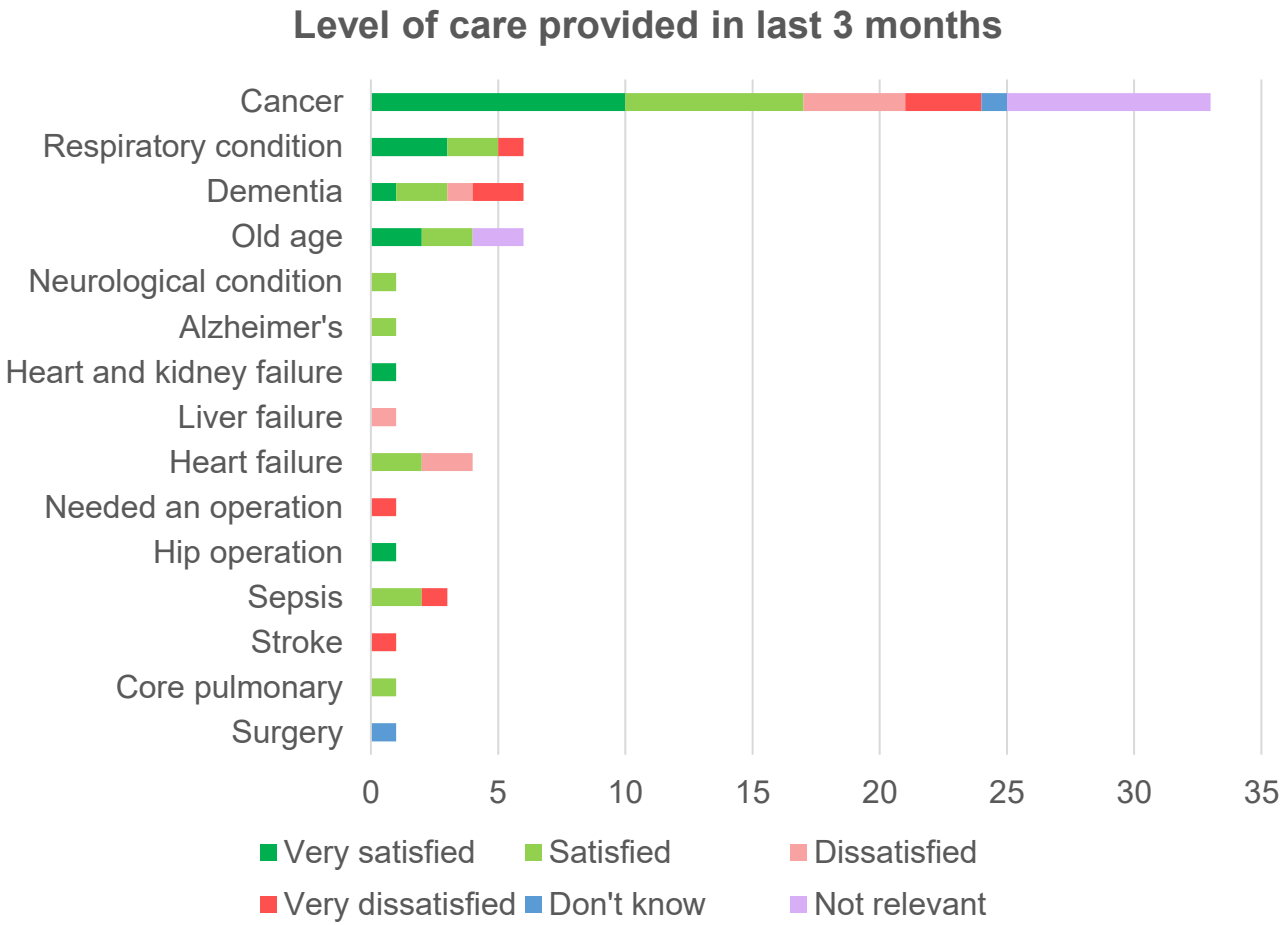
Were able to discuss any worries and fears you may have had about their condition, treatment or tests



Rates of satisfaction, across medical condition that the person died from:-

NHS Lincolnshire

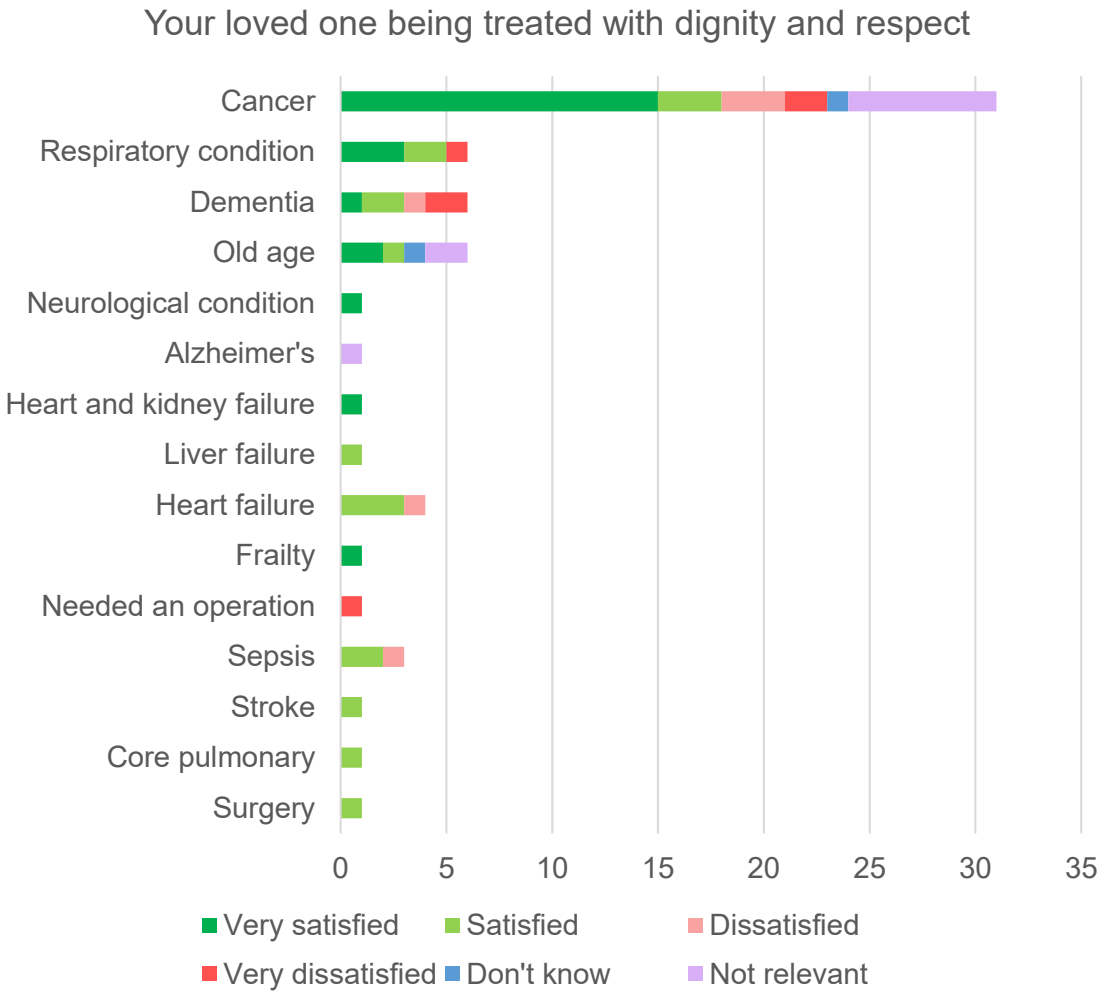
District Nurses



When looking at the data, across medical condition that the person died from:-

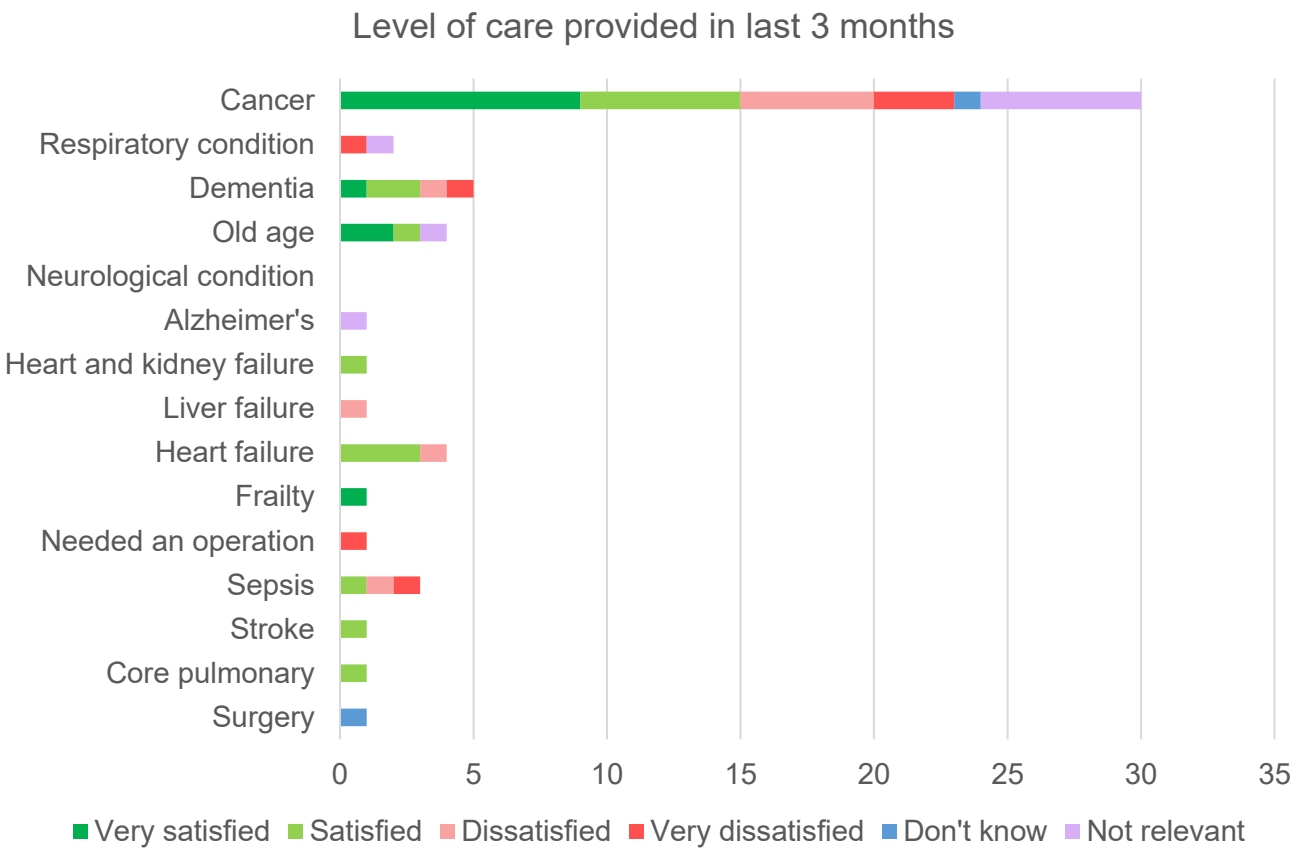
NHS Lincolnshire

Community Nurses



When looking at the data, across medical condition that the person died from:-

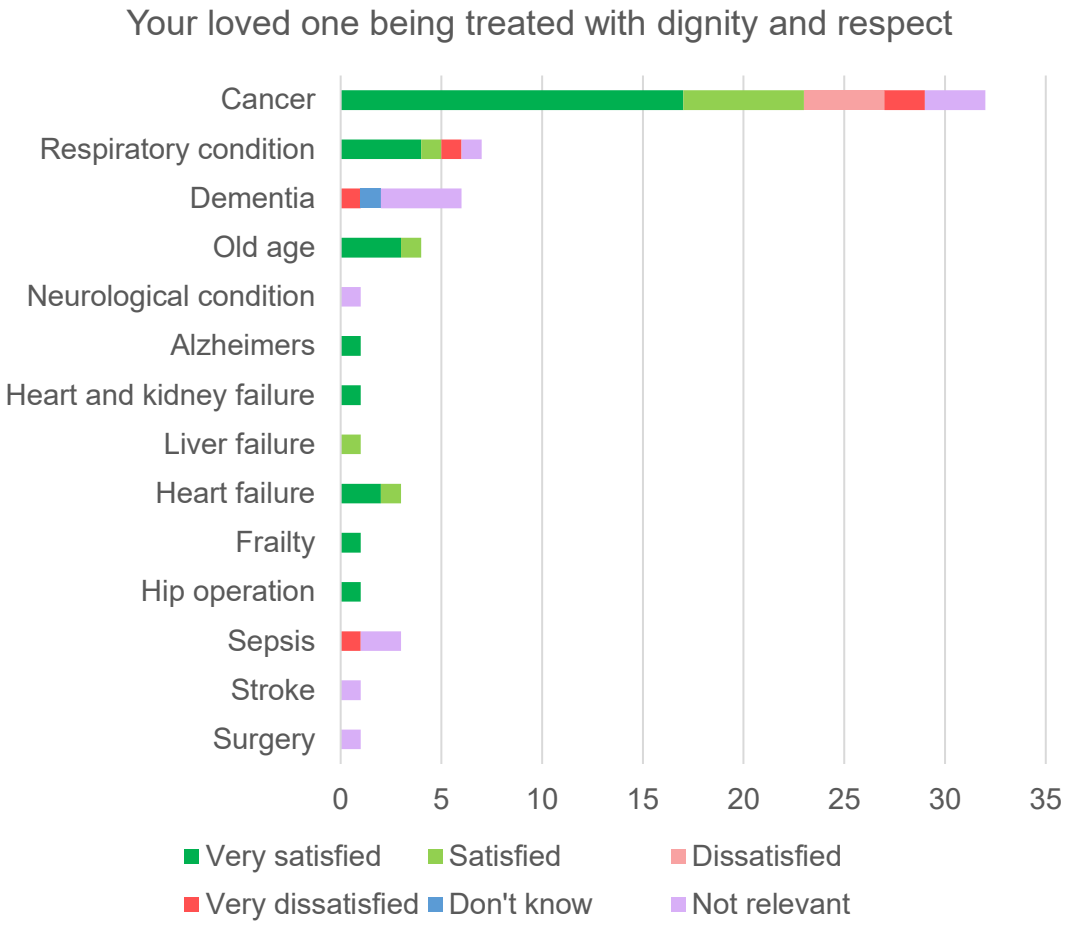
Community Nurses

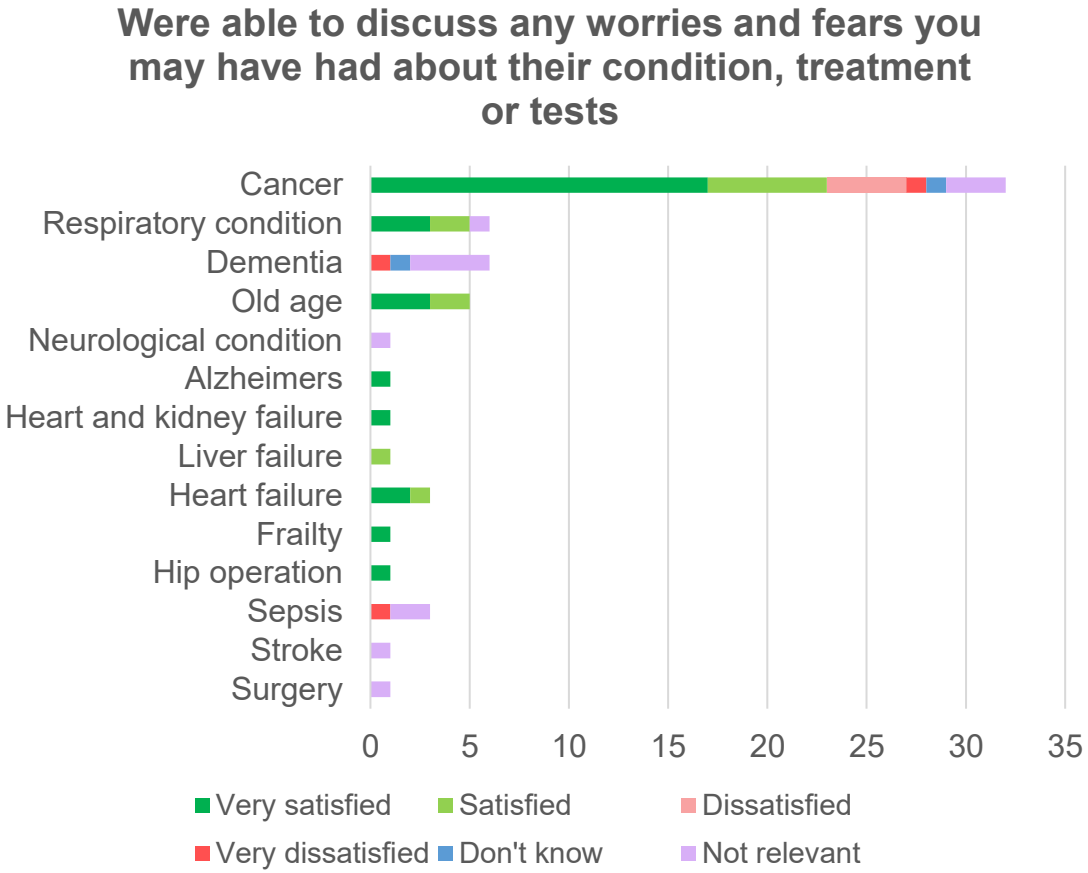


When looking at the data, across medical condition that the person died from:-

NHS Lincolnshire

Specialist services

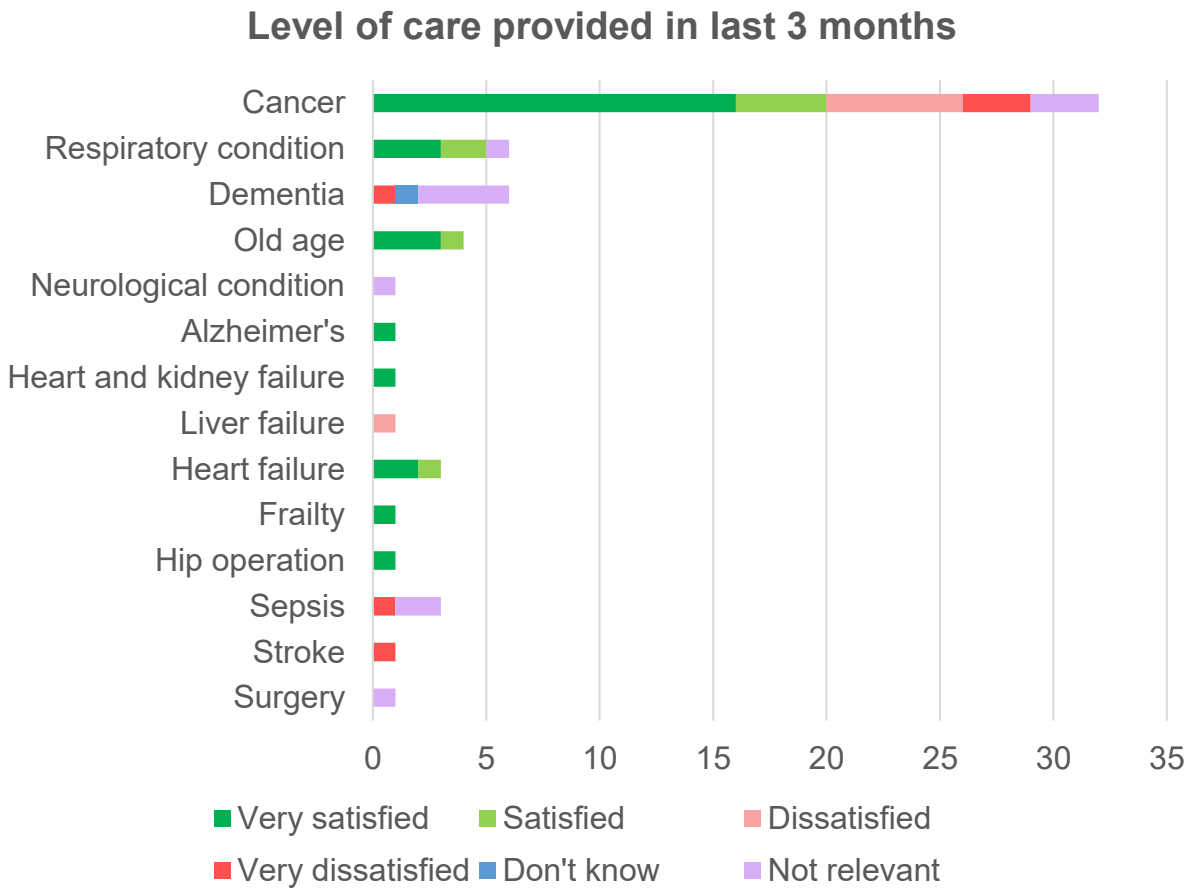




When looking at the data, across medical condition that the person died from:-

NHS Lincolnshire

Specialist services

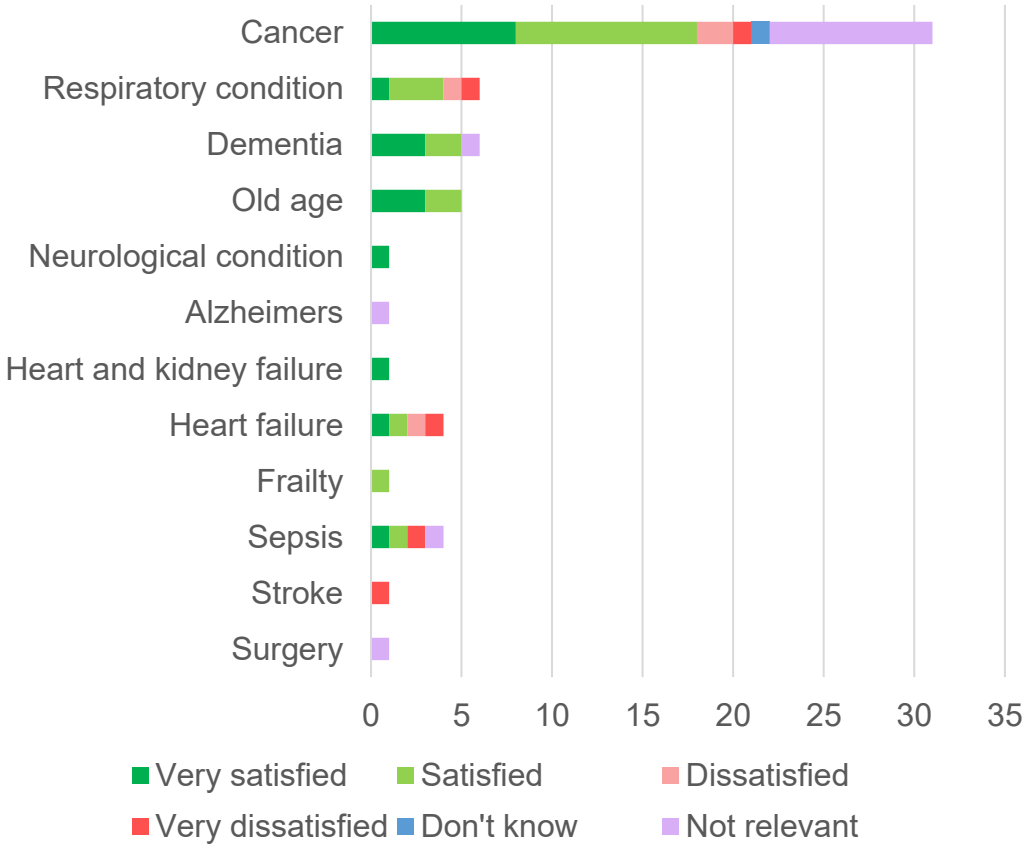


When looking at the data, across medical condition that the person died from:-

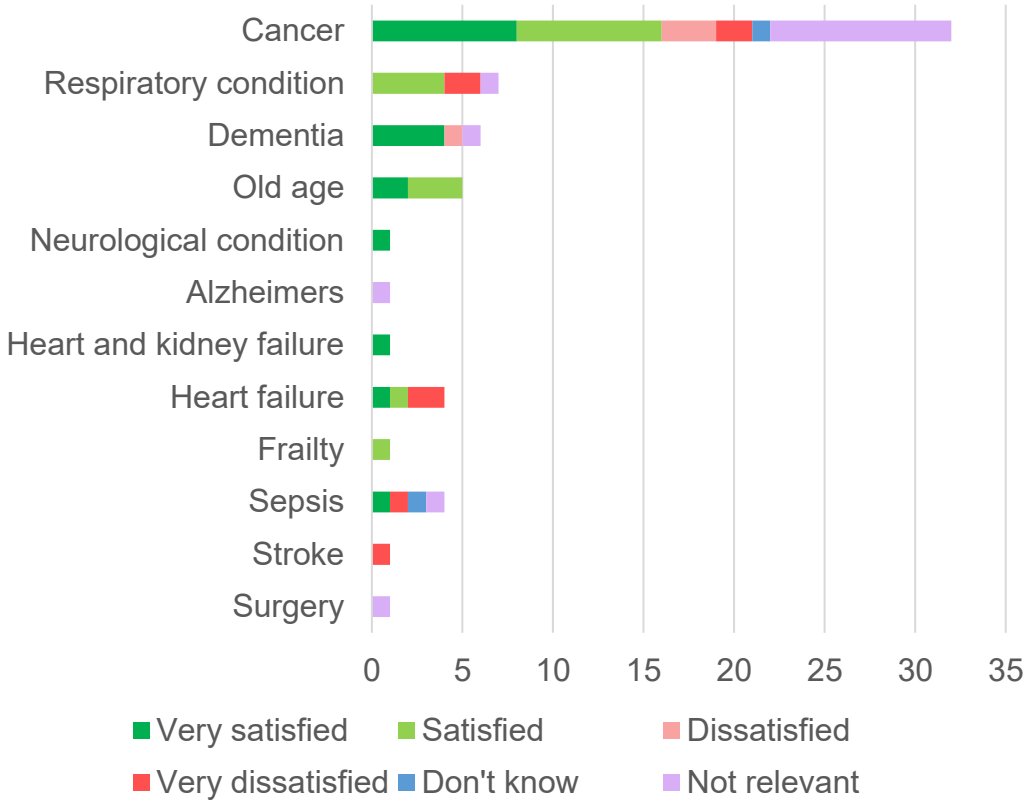
NHS Lincolnshire

Carers

Your loved one being treated with dignity and respect



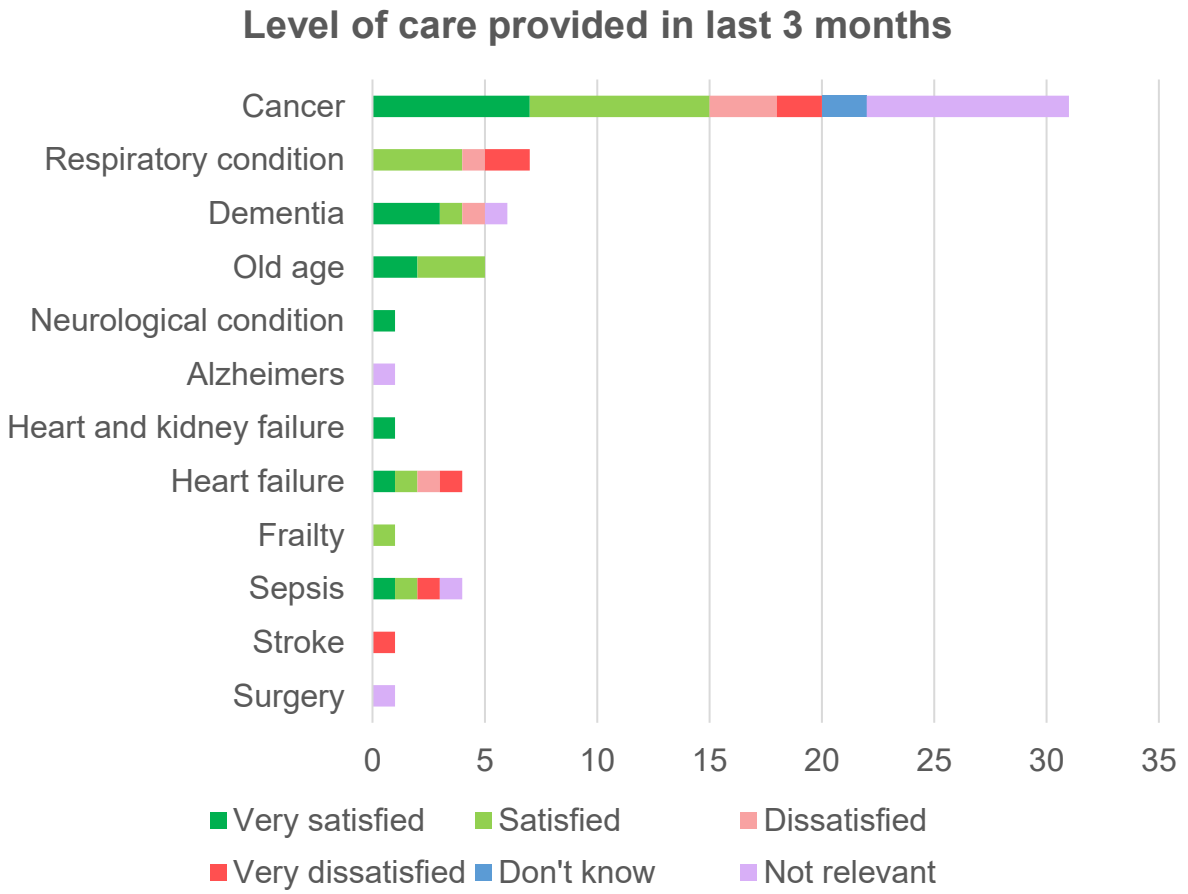
Were able to discuss any worries and fears you may have had about their condition, treatment or tests



When looking at the data, across medical condition that the person died from:-

NHS Lincolnshire

Carers



The reasons for what worked well when receiving care from District Nurses, Community Nurses, specialist services and carers:

NHS Lincolnshire

2 respondents commented that they were unpaid carers for their loved ones

District Nurses	Community Nurses	Specialist services	Carers
• They attended. • Caring, particularly when discussing Respect form. • Helpful and practical at arranging what was required. • Thorough. • Empathethic and efficient. • Friendly. • Home visits - when unable to attend the GP surgery and not well enough to get to clinic. • Arranged equipment. • Never too busy to help. • Consistency of staff and timings of visits. • Knew the individuals needs.	• Very accessible via SPA. • Was able to get leg dressings. • Community Nurses from James Street Practice fantastic. • Empathetic, efficient, caring and thorough. • Did their job. • Professional. • Always felt they were available when needed. • Good communication with family. • Community nurses assigned to the practice were lovely (Old Leake).	• Excellent. • Understanding. • Friendly. • Comforting and compassionate. • Empathetic. • Lovely night carer. Overnight sitters is an excellent service. • Attended as soon as telephoned, any time of the night, never made to feel that was overreacting. • Knew they were if needed them. • St Barnabas went above and beyond. • Excellent at what they do. • One individual commented that their father would have died in hospital if it had not been for St Barnabas. • St Barnabas brilliant. • High level of knowledge and expertise. • Nothing was too much trouble for Macmillan Nurse helping with pain and sickness. • Regular contact and review. • Family supported with bereavement. • Butterfly hospice were amazing. • Occupational therapist was greatly appreciated. • Sub-cut carers policy and advice. • Good support by the Continence Team.	• Good. • Family were put at ease as individual was cared for well. • Amazing support. • Continuity. • Helped to keep wife clean and exercised. • Professional. • Some were brilliant. • Talked to family member even when unconscious. • Provided with 3 carers. • Helping Hands caring without exception. • Care provided within the last 2 weeks. • Carer Leads at Witham Court provided dignity and respect. • Best care provided. • Help with feeding, shopping and cleaning.

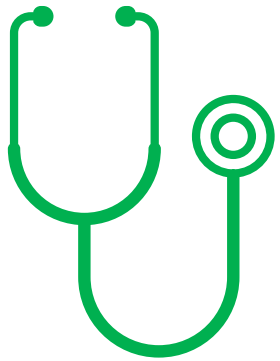
The reasons for what requires improvements when receiving care from District Nurses, Community Nurses, specialist services and carers:

NHS Lincolnshire

District Nurses	Community Nurses	Specialist services	Carers
• Unable to get one – not enough staff (comment from East Lindsey – Alford) • Rude staff member. • Duty of candour. • Did not see what was happening at home as spent little time there. • More staff. • District Nurse visits stopping as individual was stable although individuals condition was declining. • Communication. • Misdiagnosed UTI. • Inconsistent as could be dismissive to the carer. • Didn't have the option – sometimes had to contact when on the doorstep. • Joined up and better communication. • More staff. • Follow advice provided by the specialist team leading on the care of the patient. • More male nurses. • Responsibility passed to family when felt should be dealt with by the District Nurse.	• Concerns were shared by individual about appointment. Advised to keep chasing but felt there was no professional challenge. • Was unable to get one. • Unsure if saw one. • Didn't keep next of kin informed. • More staff. • Provide correct information. • Co-ordinated care. • Communication. • Unable to get one (East Lindsey district – Alford). • Didn't have the option – sometimes had to contact when on the doorstep. • Better communication. • Struggled to deal with individuals complex needs so were reluctant to visit and meant suffered more than needed to. • Speaking to husband more about wife's care. • Community nurse, with training, providing assistance with chest being drained so don't need to travel to hospital. • More male nurses.	• Didn't turn up. • Dismissive. • Weren't able to access St Barnabas support until the last couple of days. • Family felt failed by the designated Macmillan Nurse. • Co-ordinated care. • Should have helped individual so that they could die sooner. • Funding for additional care provision. • Availability. • Communication. • More staff for quicker response. • Availability for overnight care at home. • Better communication. • For St Barnabas to hand services over to Macmillan or Marie Curie. • St Barnabas cancelled visits and when telephoned they would not attend home. • More empathy. • Macmillan to offer a face to face service for more vulnerable individuals. • Marie curie booklet being received by loved one caring for mum but when telephoned SPA line they did not know about it.	• Unable to get carer. • Was mixed as different care companies and some inconsistency in standard of care and dignity provided. • Better staff training and refresher for longer term employees. • Was not treated with dignity and respect. • More consistent timings to be provided and know when attending. If individuals were receiving 4 visits per day, some had a visit 1 hour later. • Personalised care. • Didn't complete tasks on daily notes. Was required to telephone the care company. Didn't feel that the company cared. • Self funded. • Additional help with feeding, shopping and cleaning. • Left for longer periods of time that was felt unreasonable causing agitation and in uncomfortable positions. • English language was poor from some carers. • Listen more to unpaid carers. • More male carers. • Carers to be qualified in palliative/end of life care. • Some carers require better supervision. • One respondent felt that his wife's jewellery had been taken by carers.

Section 7

Care from the GP/Practice Team



GP practices where patients were registered, if respondents stated.

The largest percentage of individuals were registered at practices within East Lindsey

(please note that during 2022/23, individuals within the postcode received a lower level of satisfaction for the postcode NG31. It must be noted that the levels of response for this postcode – Grantham location are relatively low in order to make any meaningful comparisons)

NHS Lincolnshire

4% (4/96) West Lindsey

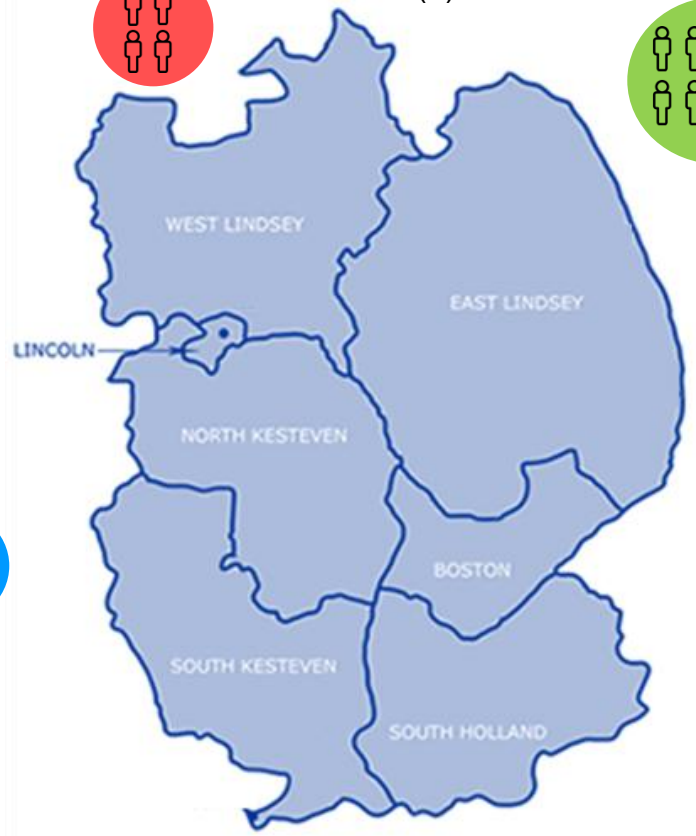
Caskgate (1)
Nettleham (1)
Welton (1)
Glebe Practice (1)

32% (31/96) East Lindsey

Beacon Medical Practice (5)
North Thoresby (5)
East Lindsey (Newmarket) (3)
Marisco (3)
Tasburgh Lodge (3)
Horncastle Medical Grp(2)
Market Rasen (1)
East Lindsey (The Wolds) (1)
New Coningsby (1)
Hawthorn (2)
Spilsby (1)
Stickney (1)
Marsh Medical (2)
Woodhall Spa New (1)

14% (13/96) Lincoln

Boultham Park Medical Practice (2)
Brant Road (1)
Cliff House (2)
Richmond Medical (2)
Woodland Medical (2)
Heart of Lincoln (2)
Minster (1)
Lindum Medical Practice (1)



7% (7/96) Boston

Greyfriars (2)
Hawthorn (2)
Kirton (1)
Old Leake (1)
Parkside (1)

8% (8/96) North Kesteven

Sleaford Medical Group (4)
Church Walk (1)
Lindum Medical (1)
Heath Surgery (1)
Washingborough (1)

17% (16/96) South Kesteven

Glenside (1)
Caythorpe and Ancaster (4)
St Johns Medical Practice (3)
St Peter's Hill (3)
New Springwells (2)
Market Cross (2)
Swingbridge (1)

Other (1) not stated
Prefer not to say (1)

16% (15/96) South Holland

Lakeside (4)
Bourne Galletly (3)
Littlebury (2)
Abbeyview Surgery (1)
Long Sutton (1)
Deepings (1)
Hereward (1)
Holbeach Medical Centre (1)
Munro (1)

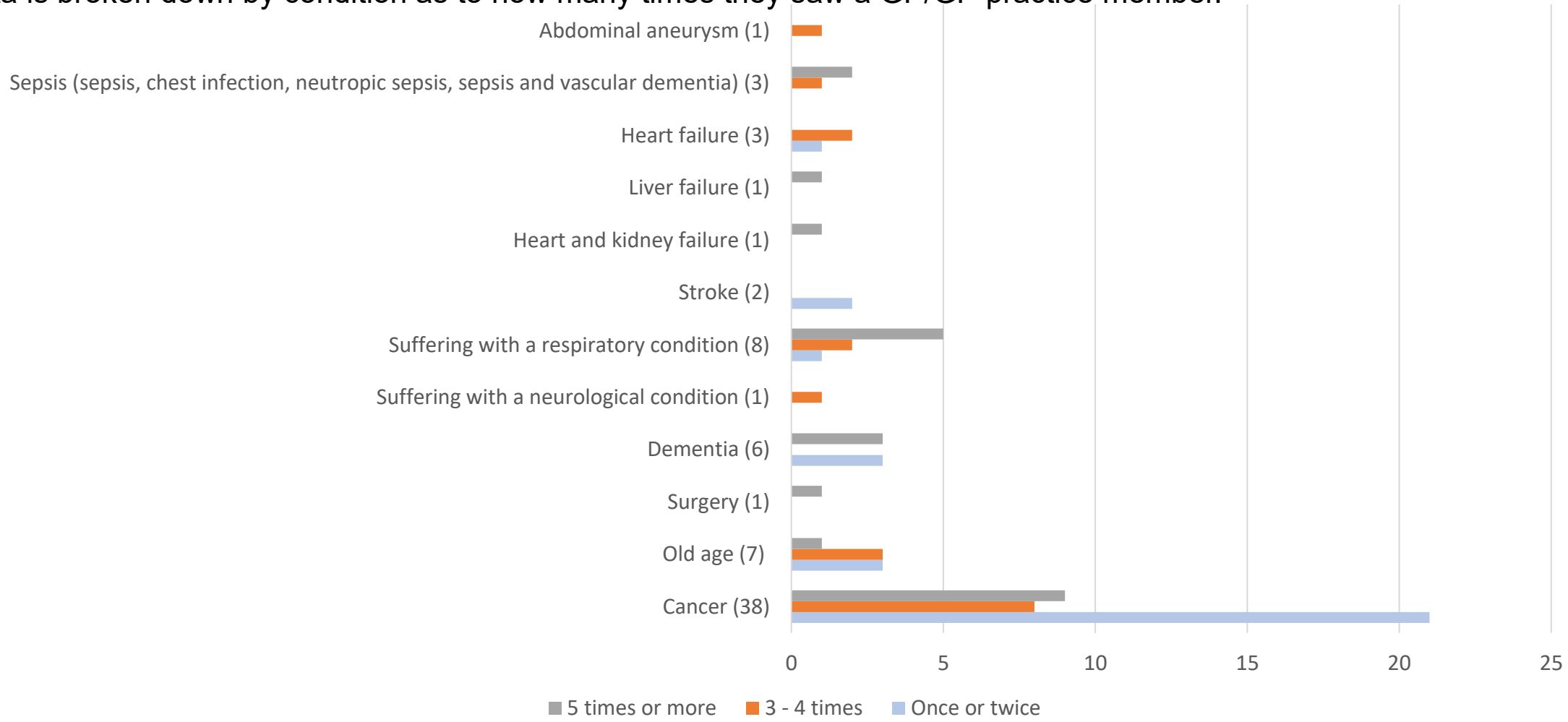
We asked respondents to tell us in the last 3 months how many times they saw a GP/GP practice team member

Overall, 69% saw a member of the GP practice team. A decline from the previous report of 75%.

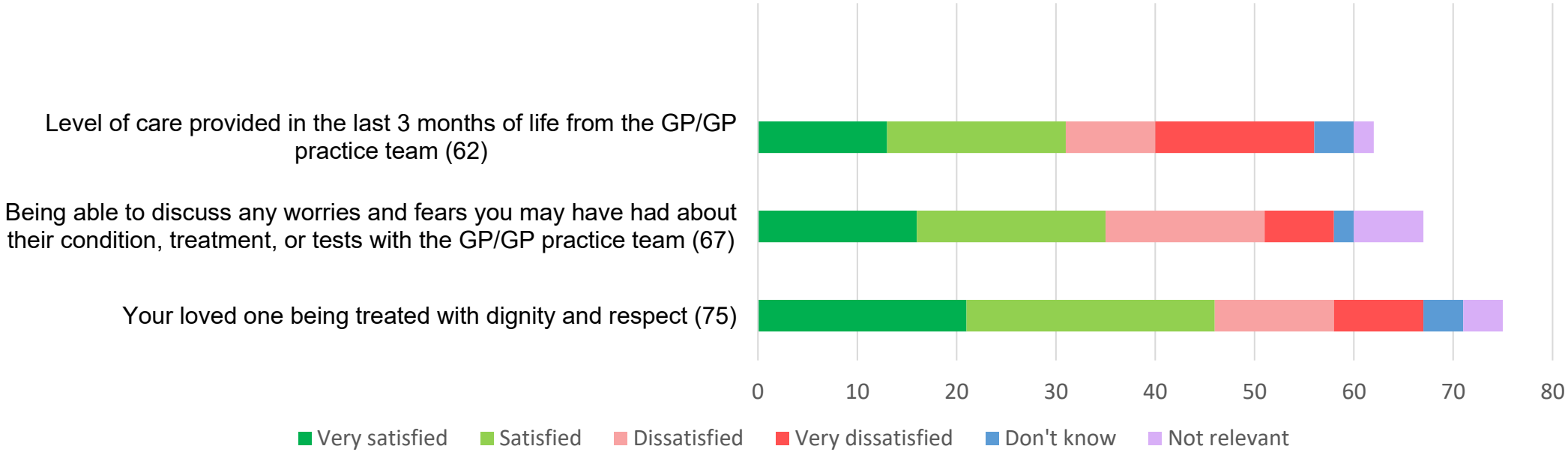
The highest number of respondents - 32% (36/113) had seen a GP/GP practice team member once or twice within the last 3 months. This was consistent from the previous report.

Being seen once or twice with cancer was the most popular response.

Data is broken down by condition as to how many times they saw a GP/GP practice member.



Levels of satisfaction with GP/GP practice team



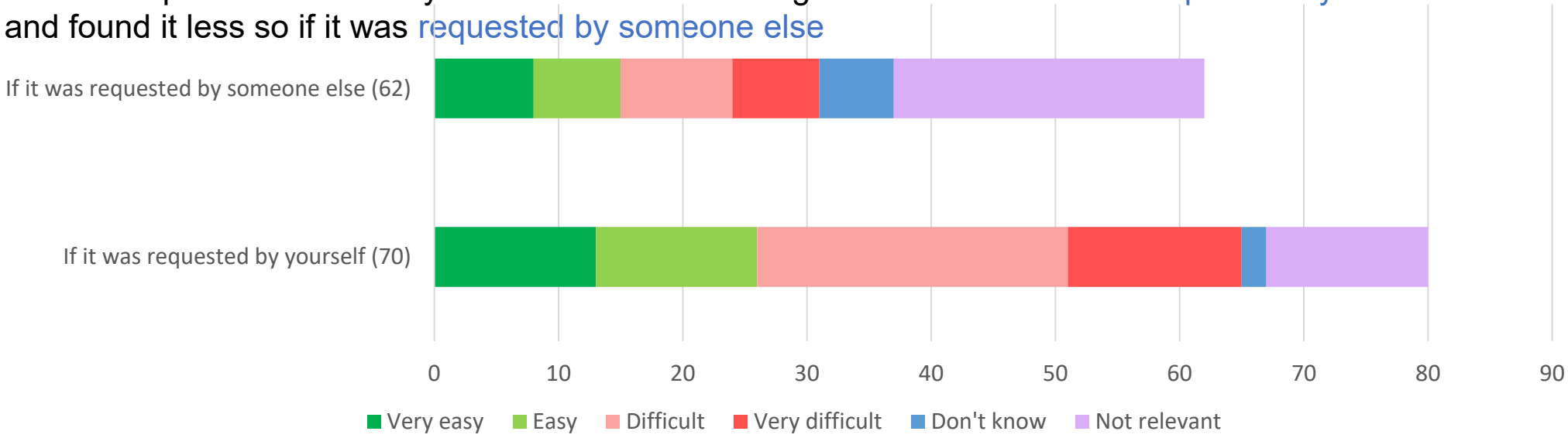
NHS Lincolnshire

52% felt satisfied that they were able to discuss their worries and fears about their condition with the GP/GP practice team. (this has decreased slightly from 57% within the last report

54% felt their loved one was treated with dignity and respect (last report 66%)

We asked respondents to tell us how easy it was to arrange a home visit

41% of respondents said they found it difficult to arrange a home visit if it was requested by themselves and found it less so if it was requested by someone else



What worked well when receiving care from the GP practice/GP practice team were:-

NHS Lincolnshire

Theme	What worked well
Compassionate and person centred care	• Several GPs were described as empathetic, kind, and thorough in their approach, in particular, Dr Hurst, Dr Savory, Dr Howarth, the Marsh Practice and Greyfriars Surgery. • GPs took time to listen, examine patients carefully, and communicate outcomes with care. • Families appreciated when GPs knew patients personally — understanding their history, preferences, and family circumstances. • When the GP team was aware and attentive, families felt genuinely supported and reassured. • Paramedic and Nurse Practitioners visited on behalf of GP.
Responsiveness and availability	• Many noted that responses to enquiries and prescription requests were prompt, often within the same day. • When a GP identified a serious problem (eg, sepsis or a serious problem), hospital admissions were arranged quickly and smoothly. • Some families valued the availability of appointments and home visits and the timely follow-up that followed. • Provided contacts for other departments and issued medication when required.
Teamwork and collaboration	• There was good liaison between GPs, nurses, and care home teams, especially in managing symptoms, pain, and anxiety. • The start of “end of life” support processes (like the Gold Sheet and ReSPECT form) was handled well, with all teams working together once the situation was recognised. • GPs worked effectively with community and specialist nurses (particular mentions were Vicky from Sleaford Medical Group, Chris Thomas from Enhance, and the Greyfriars team) to co-ordinate care and provide continuity.
Supportive practice staff	• Receptionists were praised for being understanding, helpful, and supportive — especially when they knew the family personally. • Practice nurses and community nurses were described as lovely, compassionate, and responsive. • Good liaison between care home nurses and GP Specialist Nurse at Practice. • Team members often went “out of their way” to make sure patients received what they needed.
Consistency and Trust	• Families valued monthly appointments where the GP had time to listen and engage meaningfully. • Consistent communication and reliability — GPs doing what they said they would — built trust and comfort at difficult times.

What didn't work well when receiving care from the GP/GP practice team were:-

NHS Lincolnshire

Lack of home visits	• Respondents said home visits sometimes did not happen or were refused, even when the patient was seriously ill or unable to travel. • Visits often occurred only at the very end of life, rather than when they could have made a meaningful difference. • Some reported having to insist or repeatedly call before a visit was agreed to. • Once the diagnosis of end of life was declared this made things easier.
Poor co-ordination and communication	• Disjointed care between GPs, hospitals, and specialists - discharge summaries and information were not shared effectively resulting in families needing to chase the information themselves. • Families struggled to get hold of the right person responsible for ongoing care. • Communication was through AskMyGP. • Communication failures led to gaps in care, especially between hospital discharge and GP/district nurse involvement. • Negative experiences were reported at Parkside Surgery, Stickney Surgery, Newmarket Surgery, Marsh and North Thoresby Surgery. A negative experience had resulted in an individual changing GP practice. • Errors on paperwork meant that the practice called the individual when they were unable to answer the telephone. • Loved one unable to order catheters for mother's care, unable to order medication as medication was marked as needing review. • Cross border communication improvements required when registered at a Lincolnshire GP practice but living and receiving care from hospital in another ICB area (Grimsby).
Accessibility	• Reports of dismissive responses from on-call GPs suggesting A&E instead of visiting, causing distress and delays. • Some felt reluctance or unwillingness from doctors to leave the surgery.
Continuity of care	• Frequent changes in GPs or locums meant patients and families had to repeatedly explain complex situations. • Lack of a single point of contact or care coordinator made the process confusing. • Families wanted the same GP to see palliative patients for continuity and trust.
Attitude	• Several comments described rude, unhelpful, or dismissive attitudes from GPs during home visits. • Families felt some doctors lacked empathy or failed to properly examine or engage with the patient. • A few noted good care later on, but only after escalation or persistence. • Feeling listened to by GP and taking concerns seriously and not being dismissed as an "old person" dismissing concerns. • Training, particularly for reception staff.
Overstretched staffing	• Respondents perceived surgeries as very busy and under pressure, leading to delays, missed calls, and reduced availability for home visits. • Some felt that paramedics or nurses stepped in where GPs could not or would not attend.

Section 8

Care homes

66% (69/104) of respondents stated that they did not live or stay in a care home during the last 3 months of life

NHS Lincolnshire

18% (19/104) lived in a care home as a resident, 6% (6/104) lived in a care home as respite, 8% (8/104) a palliative care bed within a community hospital, 2% (2/104) did not know

Satisfaction was high across all areas of care.
Level of satisfaction have decreased slightly in being able to discuss worries 69% compared to 80% within the last report.

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied	Don't know	Not relevant
Your loved one being treated with dignity and respect (27)	52% (14)	19% (5)	4% (1)	4% (1)	4% (1)	19% (5)
Being able to discuss any worries (26)	46% (12)	23% (6)	8% (2)	8% (2)	4% (1)	12% (3)
The physical symptoms and needs were managed (eg, pain, breathlessness) (26)	46% (12)	31% (8)	8% (2)	4% (1)	4% (1)	8% (2)
The holistic needs and symptoms were managed (26)	44% (11)	16% (4)	16% (4)	4% (1)	8% (1)	12% (3)
The spiritual needs and symptoms were managed (26)	35% (9)	23% (6)	8% (2)	8% (2)	4% (1)	23% (6)
Care received from the Care Home Team in the last 3 months of life (25)	44% (11)	24% (6)	12% (3)	4% (1)	8% (2)	8% (2)

When we asked respondents what worked well in care homes:-

NHS Lincolnshire

Theme	What worked well
Kind and caring staff	• Many families and residents praised the staff for being compassionate, gentle, and genuinely caring. Words like “amazing,” “kind,” and “thoughtful” appeared repeatedly. • Particular mentions were Holbeach and East Elloe Hospital Trust where they were “amazing” and Beckside where once there, felt could be their “daughter”. Residents had expressed satisfaction to family with the care received, describing it as “excellent” and saying they had “no complaints.”
Dedicated and supportive teams	• Several comments noted that staff were responsive, attentive, and provided good physical care. In particular, managers were recognised for being efficient, approachable, and supportive not only to residents but also to their families.
Excellent end of life and respite care	• Care homes were commended for their sensitive approach during end-of-life care. Families appreciated that staff were experienced, well-equipped, and offered emotional support, allowing relatives to focus on being family members rather than full-time carers. • One family highlighted being given a room to rest between bedside visits. • Another expressed gratitude for being able to trust the team completely at such a difficult time.
Good communication and co-ordination	• In positive examples, care homes worked closely with hospitals and community services - for example, making smooth referrals for Discharge to Assess (D2A) and providing much-needed respite care after hospital stays.

When we asked respondents what required improvements/solutions in care homes:-

NHS Lincolnshire

Theme	Issue
Respect for personal beliefs and preferences	• A resident who had been vegetarian all her life was persuaded to eat meat when her dementia was advanced, which caused distress for her family. • Unfortunately, it wasn't always individuals wishes to be in a care home.
Communication with families and next of kin	• Families sometimes felt excluded or uninformed about clinical visits, updates, and decisions (eg, medical interventions, GP appointments, ReSPECT forms being completed, transfers). Increase in communication/up-dates after each visit to family was welcomed and being informed when visits were taking place.
Inclusion and listening to families/partners	• Some family members, especially non-English speakers, felt unheard or overlooked in care discussions.
Co-ordination with external agencies	• A care home welcomed the opportunity of hearing back from Lincolnshire Integrated Care Board as to whether admissions for end-of-life care were being accepted or not.
Speaking levels and responsiveness	• At busy times (eg, during meal service), staff shortages meant residents' immediate needs, such as toileting assistance, were not always met promptly.
Emotional support during transition	• Families experienced stress and confusion when loved ones were moved from hospice to care home.
Equipment	• Dementia chairs should be made available within care homes.

Section 9

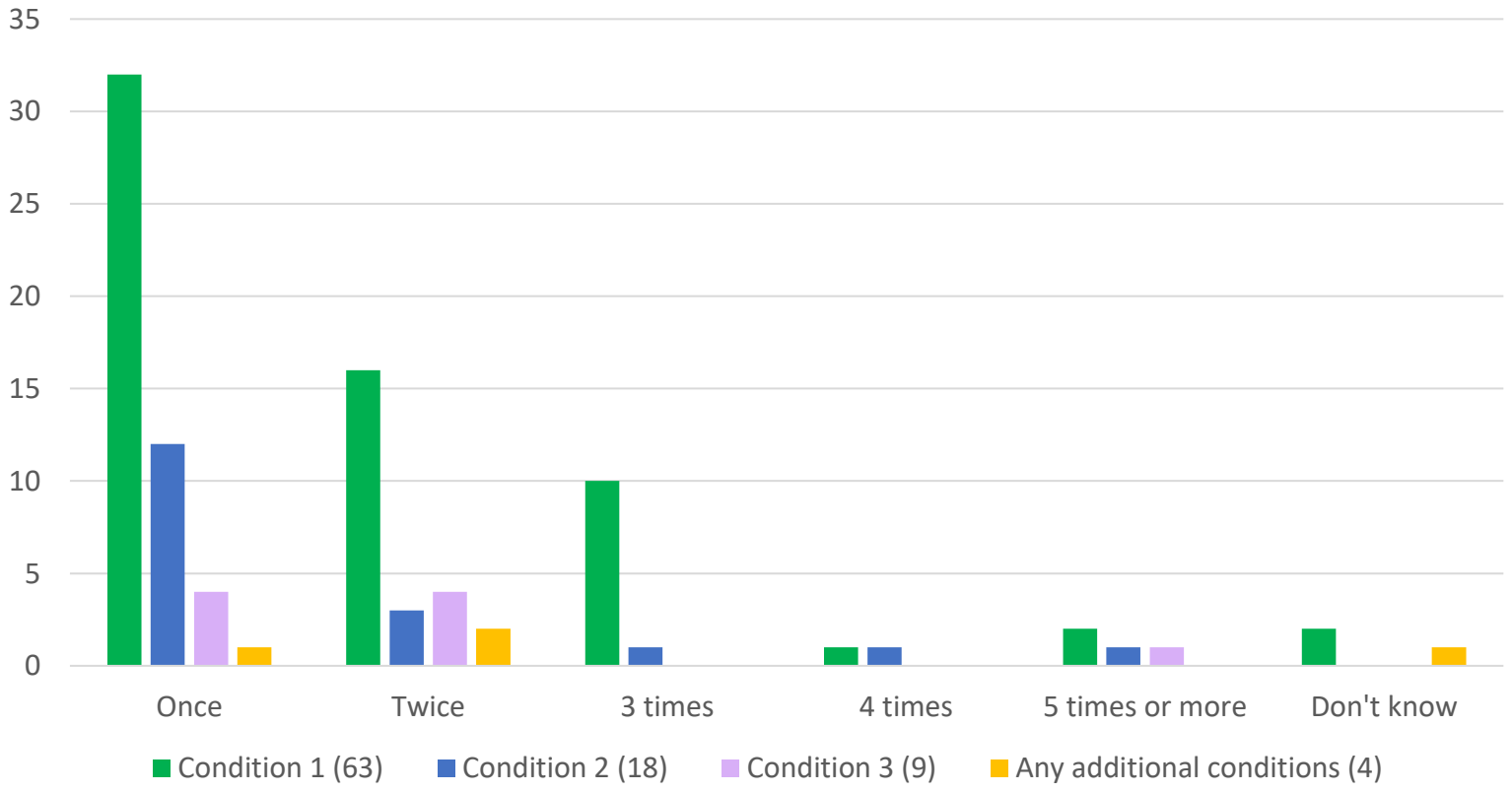
Last hospital admission

We asked respondents to tell us how many times they were in hospital during their last 3 months of life and for what condition:-

NHS Lincolnshire

66% (67/102) had stayed in hospital, 32% (33/102) had not stayed in hospital, (2/102) did not know

Where stated, individuals had stayed at the following hospitals during their last 3 months of life:-
49% (30/61) had stayed in Lincoln County Hospital, 16% Pilgrim Hospital (10/61), 11% Peterborough Hospital (7/61), 10% Grimsby Hospital (6/61), 3% Nottingham City Hospital (2/61), 3% Skegness (2/61), 3% Witham Court (2/61), 3% Grantham Hospital (2/61), 2% Holbeach Hospital (1/61)



Condition 1 conditions included:-(diagnosis, scans, tests, COPD, infection following a fall, acute lymphoblastic leukaemia, cancer, emphysema, heart attack, bowel cancer and confusion, stroke, infection, neutropenic sepsis, vascular dementia, heart failure, broken ankle, UTI, gastric bleeding/anaemia, suspected sepsis, heart failure, blood transfusion, urinary sepsis, lost use of legs, chest infection, ascites

Condition 2 conditions included:- cancer related, perforated stomach, bowels, hip infection, sepsis, COPD, emphysema, colitis, sepsis, renal cancer, chest infection, excess fluid, liver haemerage, acidosis keytone, fall and obstruction.

Condition 3 conditions included:- needing laxatives, breathing issues, polymelgia rheumatica, end of life care, pneumonia, sepsis and vomiting.

The extent to how respondents were satisfied or dissatisfied with the following received at hospital

The highest levels of dissatisfaction were not being able to discuss worries and fears about their condition, tests or treatment, the care received during the last 3 months of life, holistic and spiritual symptoms and needs being managed, hospital services working together with GP and other services and continuity of care.
Compared to the last report, level of satisfaction has decreased in being able to discuss any worries. 38% compared this year compared to 57%.

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied	Don't know	Not relevant
Doctors treating your loved one with dignity and respect (66)	15% (10)	33% (22)	15% (10)	24% (16)	11% (7)	2% (1)
Nurses treated your loved one with dignity and respect (66)	24% (16)	44% (29)	14% (9)	11% (7)	8% (5)	0% (0)
Other hospital staff(eg, physiotherapists, occupational therapists, health care support workers etc) (65)	15% (10)	38% (25)	8% (5)	6% (4)	12% (8)	20% (13)
Being able to discuss any worries and fears you may have had about their condition, tests or treatment with staff at the hospital (65)	20% (13)	18% (12)	29% (19)	23% (15)	8% (5)	2% (1)
The physical symptoms and needs were managed (eg, pain, breathlessness) (64)	17% (11)	25% (16)	20% (13)	30% (19)	8% (5)	0% (0)
The holistic symptoms and needs were managed (63)	13% (8)	16% (10)	16% (10)	33% (21)	13% (8)	10% (6)
The spiritual symptoms and needs were managed (63)	8% (5)	11% (7)	11% (7)	17% (11)	19% (12)	33% (21)
Care received from hospital in the last 3 months of life (62)	13% (8)	19% (12)	19% (12)	37% (23)	6% (4)	5% (3)
Continuity of care received from staff at the hospital in the last 3 months of life (62)	11% (7)	26% (16)	13% (8)	31% (19)	6% (4)	13% (8)
Hospital services worked well together with the GP and other services outside of the hospital (64)	8% (5)	11% (7)	20% (13)	30% (19)	14% (9)	17% (11)

Information about what worked well at their last hospital admission

NHS Lincolnshire

Theme	What worked well
Compassionate and caring staff	• Across several wards and departments, families praised staff for being kind, respectful, and attentive. Individual nurses and doctors stood out for their warmth and empathy, taking time to comfort both patients and relatives during difficult moments. • One family described the nurse caring for their father as “lovely and always took the time to speak with me.” • Another shared how “even the kitchen staff came and comforted us” during a resuscitation — showing teamwork and compassion beyond roles.
Excellent end of life care	• Where end-of-life care worked well, staff were described as “amazing,” “respectful,” and “supportive.” • Toghill Ward at City Hospital was highlighted for its outstanding compassion and collaboration in helping a patient be closer to home. • In Intensive Care and MEAU (Medical Emergency Assessment Unit), families appreciated the considerate care and space provided to ensure a dignified, peaceful death. • Families who stayed with their loved ones noted that staff made this possible, offering privacy, flexibility, and emotional support — “nothing was too much trouble.”
Respect for individual needs	• Some staff made the effort to read and act upon personal profiles such as the “This Is Me” booklet for a patient with young-onset dementia. This personalised approach made a meaningful difference in care and understanding.
Effective communication and continuity of care	• Although communication was inconsistent overall, there were examples of clear, coordinated care: • Staff explained treatment plans and discharge processes effectively. • Hospital teams liaised well with community and hospice services, ensuring symptom management and continuity post-discharge.
Teamwork and responsiveness	• When critical moments arose, such as during a resuscitation, families were deeply moved by the rapid, unified response from the entire hospital team — describing it as “a true team effort” and “amazing to witness.”
Flexibility for family involvement	• Some hospitals allowed family members to visit freely, stay overnight, and be directly involved in care — especially valuable at the end of life. This flexibility brought comfort to both patients and relatives, ensuring no one was left alone.
Kindness and professionalism	• While experiences varied, some facilities and wards were singled out for their consistently compassionate approach. • Waddington Ward and Grimsby Hospital were mentioned as kind, considerate, and professional. • The Intensive Care Unit (ICU) team was commended for providing “wonderful care” and supporting both the patient and family throughout a critical period.

Information about what requires improvement of receiving care and support in the last hospital admission

NHS Lincolnshire

Theme	Improvements
Communication and co-ordinated care	• Families reported poor communication between hospital teams, unclear updates, lack of communication around clear treatment plans, more assistance in place when individuals went home, faster meetings with palliative care teams and the need to "chase" specialists or discharges. Some individuals had made a complaint. • More knowledge around palliative care pathway. Education, specialist nurse or teams in these areas. • Ensure that palliative care services are aware of the admission and involved in care arrangements. • Priority for palliative care patients. • Ensure that relevant hospital paperwork is with the individual on return (eg, Discharge and ReSPECT form). • Increased and more consistent communication and explanation about palliative care to individuals and their families. • Duplication of correspondence.
Delays in clinical decisions and end of life planning	• Delays in diagnosis, medication reviews, and palliative transitions led to unmanaged pain and distress. In one case, a patient waited over 48 hours for transport after being declared end-of-life so arranged their own private transport. • Lengthy waits in ambulances or on wards. • One respondent reported that pressure sore prevention protocols were followed moving the individual to an inflatable mattress using a hoist but this caused additional pain. • Better route to hospital for palliative care patients (one individual had to queue for over 36 hours).
Pain medication and pain access	• Patients were left without pain control for extended periods or required staff to fetch medication from other wards.
Environment and safety concerns	• Incidents of distress and fear due to receiving bad news about their loved one, ward disturbances and patients feeling unsafe or isolated. • Instances where individuals felt that the quality of care was not as good as should be – instances where individual had to urinate on floor as there were no commodes, individual with a perforated stomach sitting in a chair from Monday tea time to Wednesday morning, individual trying to lay in bed when slept in a reclining chair at home due to bad back, feeling that didn't care if patient ate, no physiotherapy provided, lack of knowledge how to change colostomy bag.
Staffing levels and time pressures	• Staff described as caring but overstretched, with limited time to communicate or offer reassurance. Some families perceived neglect linked to staff shortages. An example was when an individual was left without medication due to GP needing to sign medication leading to distress as there were not enough GPs. • Recruit more clinical staff.
Attitudes	• Reports suggested that older patients received less attentive care, and families felt their loved ones' needs were deprioritised.

Section 10

Last in-patient hospice admission

79% (70/89) did not stay at a hospice at any time during the last 3 months of life
3% (3/89) stayed in a hospice for respite care
17% (15/89) stayed in a hospice for end of life care
1% (1/89) did not know

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Hospice where individuals stayed, where stated

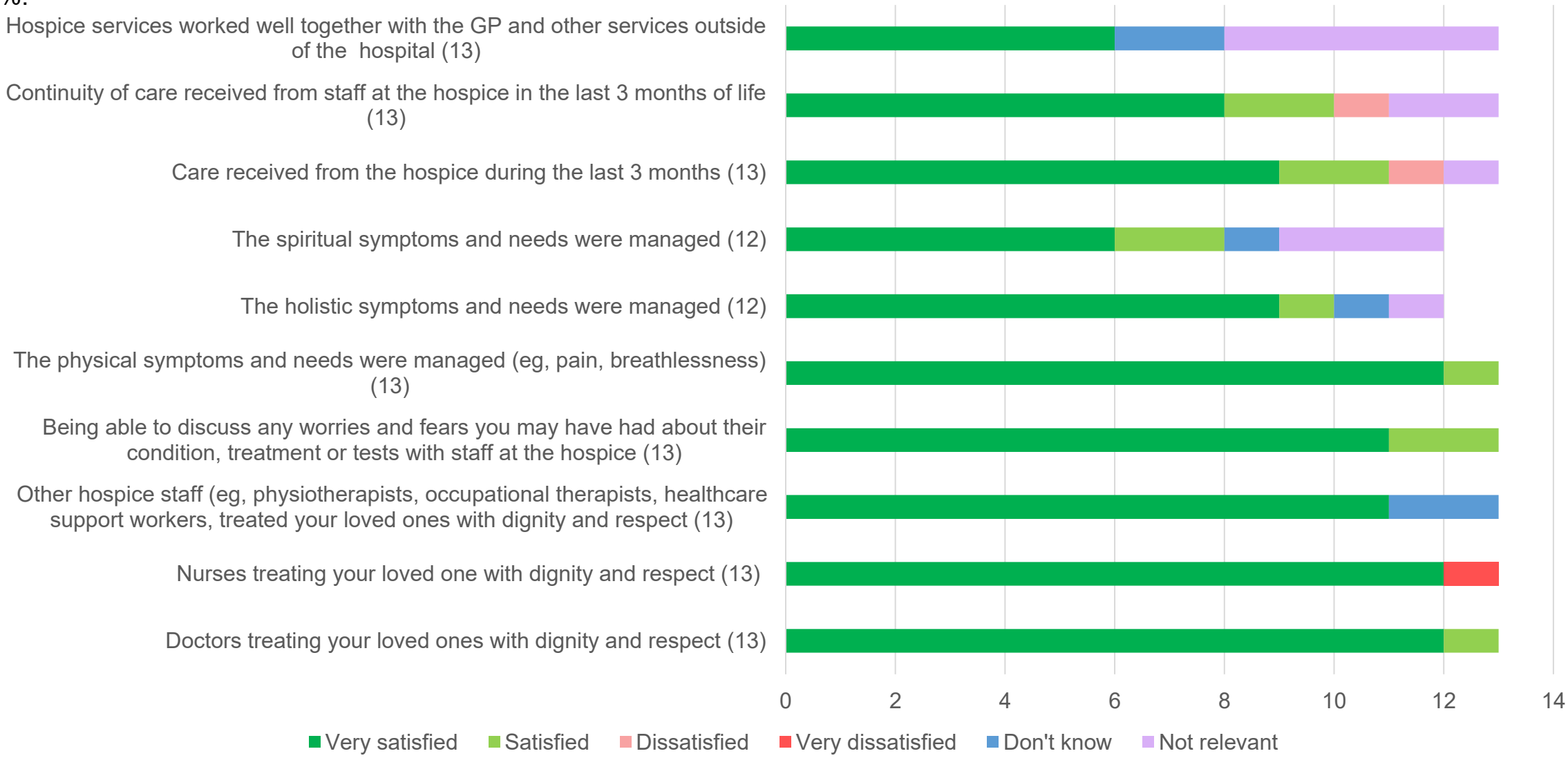
Hospice for respite care	Hospice for end of life care
St Barnabas, Grantham Hospital (1) Thorpe Hill, Sue Ryder (1)	St Barnabas (site not stated) (9) St Barnabas, Nettleham Road (2) St Barnabas Hospice in the Hospital, Grantham (1) Butterfly Hospice (1) Skegness – End of Life Ward (1) Thorpe Hall (1)

Number of times they were in the hospice	Conditions
1 time	Cancer (6), Dementia (1), ILD/pulmonary (1), stroke (1), multiple myeloma (1), leukaemia (1), lymphoma (1), COPD (
Twice	COPD (1), cancer (1), pain relief (1)

Respondents were asked to rate their levels of satisfaction with hospice services.

Overall, from 13 respondents, they were very satisfied or satisfied with the care received at the hospice.

The only level of dissatisfaction related to 1 respondent being dissatisfied with the care received and continuity of care received during the last 3 months of life and being very dissatisfied that nurses were not treating their loved one with dignity and respect. Level of satisfaction in being able to discuss any worries has increased to 100%, previous report 93%.



What worked well in the hospice was:-

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Themes	Positive comments
Compassion and care	• "The care was exemplary". • "Amazing compassion and care to the patient and family".
Holistic approach	• "Excellent holistic palliative care". • "The holistic approach – seeing the patient". • "Everything – care for patient and all family members (and friends that visited)".
Staffing	• "Hospice staff were amazing". • "Treated us all with dignity and empathy at such a hard time". • "Staff were fantastic". • "The staff were kind and caring and provided a good end of life for my mother in law and the rest of the family".
	• "My husband was transferred from hospital to St Barnabas for his end of life care. This was a much calmer setting for him".
Communication	• "Only good communication was driven by the hospice".

4/7 stated that there was "nothing" that could have been improved

What could have been improved with the hospice was:-

Themes	Negative comments
Staffing	• An individual nurse not acting professionally, compassionately or caring about her impact.
Transfer from hospital to hospice	• If the individual could have been referred earlier by the hospital it would have been better - not the hospice fault at all, they tried to make it happen.

Section 11

Experience in last two days

For the majority of the last 2 days of life, 67% stated that this was where wanted to be.

47% (46/97) were at home (previous report 27%). 100% stated that there is where they wanted to be.

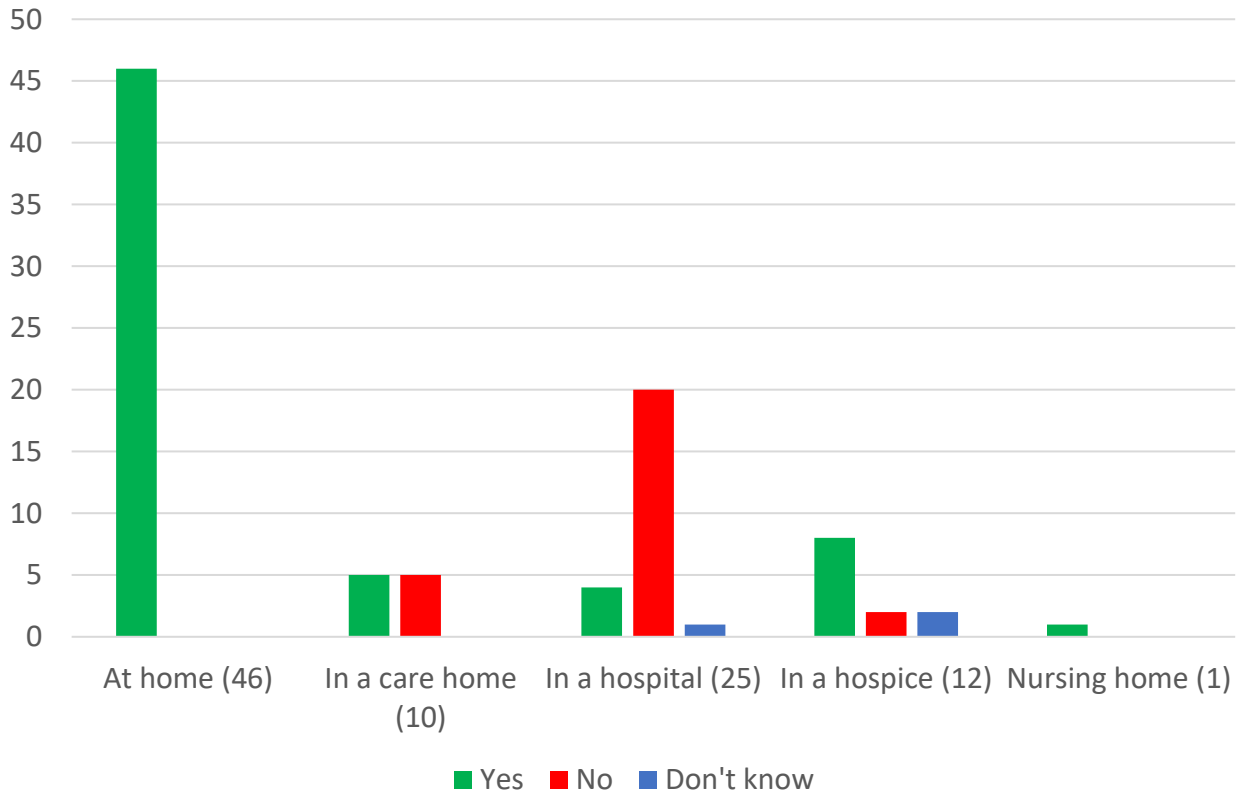
10% (10/97) were in a care home (previous report 17%). 50% (5/10) stated that this is where they wanted to be and 50% was not where they wanted to be.

27% (26/97) were in hospital (same figure from previous report). Of those that wanted to be in hospital were at Lincoln Hospital, Peterborough Hospital, Skegness Hospital – Gloucester Ward and Diana Princess of Wales Hospital.
Of those that did not want to be in hospital, 3/4 were at Pilgrim Hospital, Boston, 1/4 at Skegness.

13% (13/97) were in a hospice (previous report 14%).
Of those that stated they wanted to be 67% (8/12) were at St Barnabas and those did not want to be (2/8) were at St Barnabas, 1/8 not stated. (2/8) did not know.

1% (1/97) was in a nursing home (Holbeach and East Elloe Hospital and was where they wanted to be.

1% Didn't know.



We asked respondents to tell us in their opinion about the help that their loved ones received in the last 2 days of life

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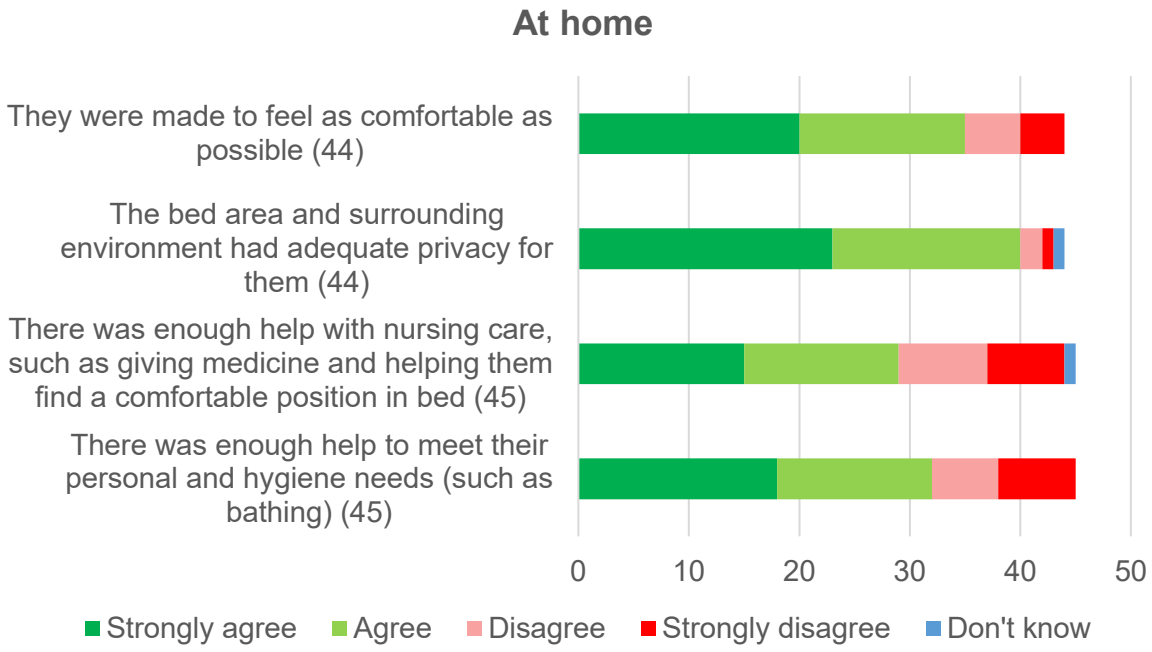
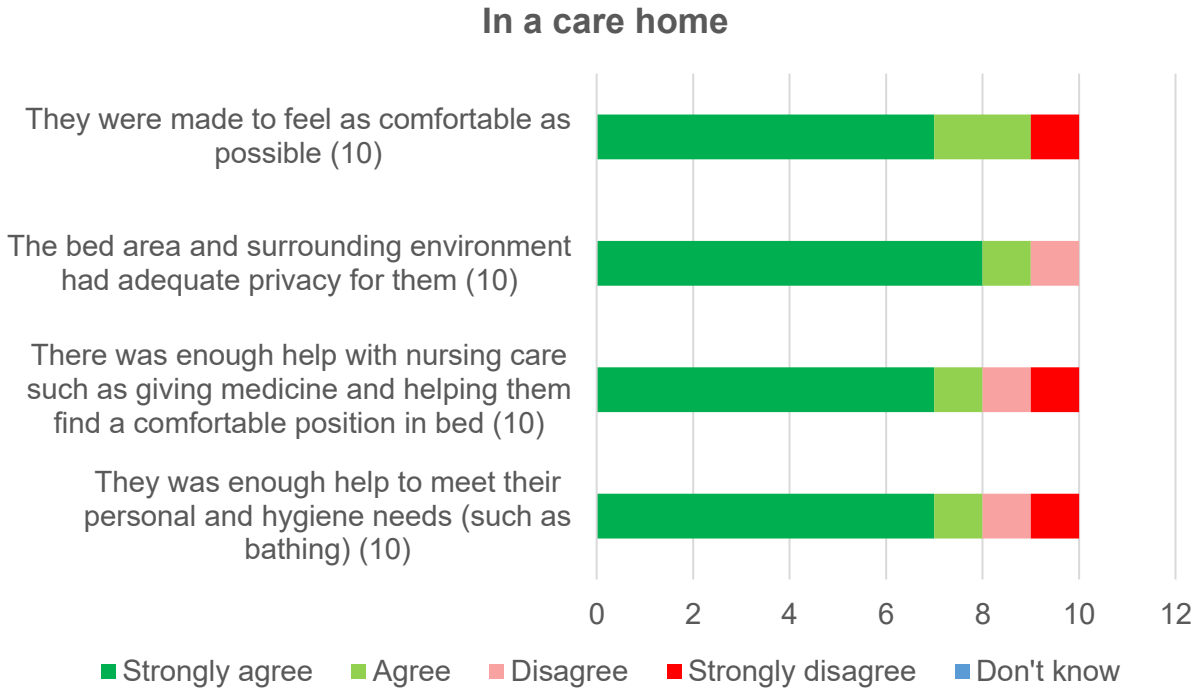




80% agreed that they were made to feel as comfortable as possible and 20% disagreed.

91% agreed that the bed area and surrounding environment had adequate privacy (previous report 88%) and 7% disagreed (2% previous report).

64% agreed that there was enough help with nursing care (same figure as last report) and 33% disagreed (22% previous report).

71% agreed that there was enough help to meet their personal and hygiene needs (66% from previous report) and 29% were dissatisfied (22% previous report).

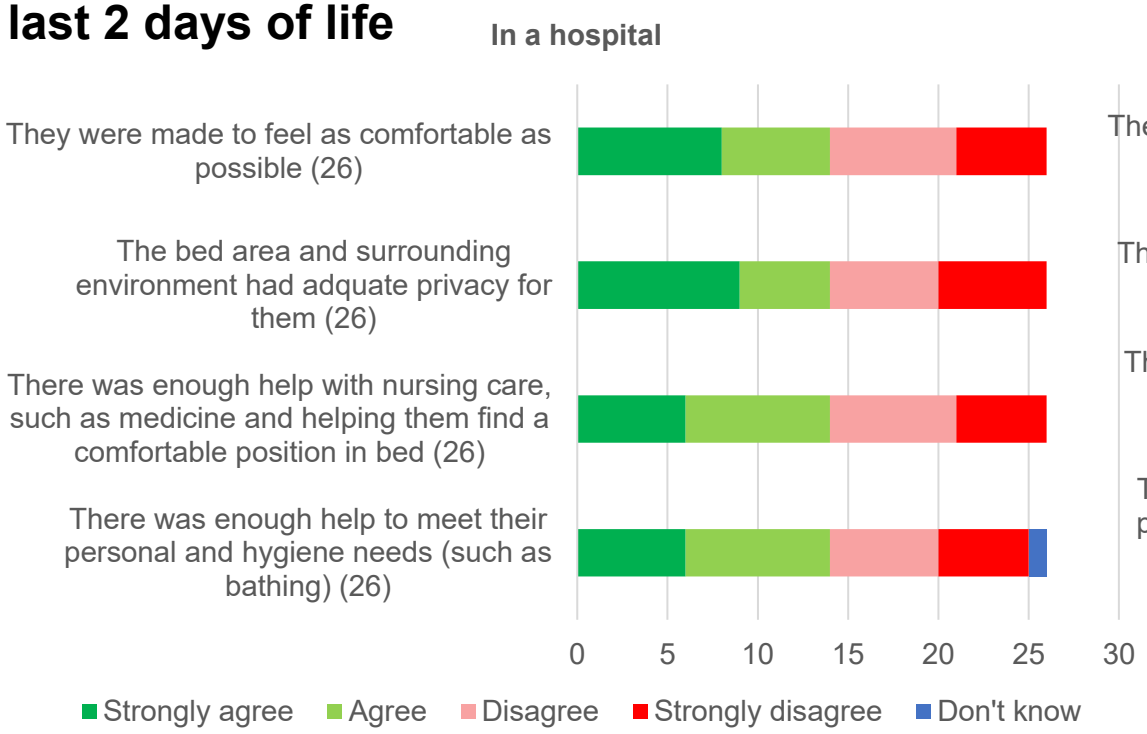
90% agreed that they were made to feel as comfortable as possible and 10% disagreed (there is no data to compare from last report).

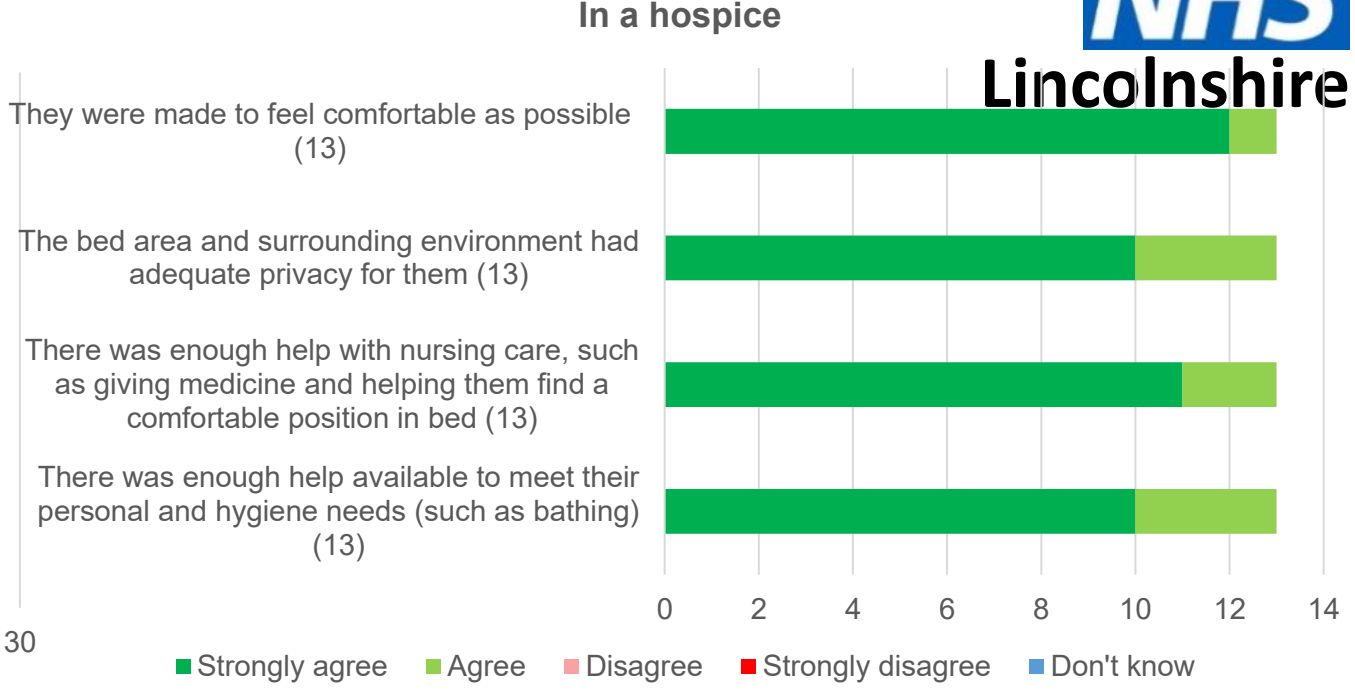
90% agreed that the bed area and surrounding environment had adequate privacy and 10% disagreed (there is no data to compare from last report).

80% agreed that there was enough help with nursing care and 20% disagreed (there is no data to compare from last report).

80% agreed that there was enough help to meet their personal and hygiene needs and 20% were dissatisfied (there is no data to compare from last report).

We asked respondents to tell us in their opinion about the help that they received in the last 2 days of life





54% agreed that they were made to feel as comfortable as possible and 46% disagreed.

54% agreed that the bed area and surrounding environment had adequate privacy (previous report 54%) and 46% disagreed (40% previous report).

54% agreed (previous report 45%)that there was enough help with nursing care and 46% disagreed (31% previous report).

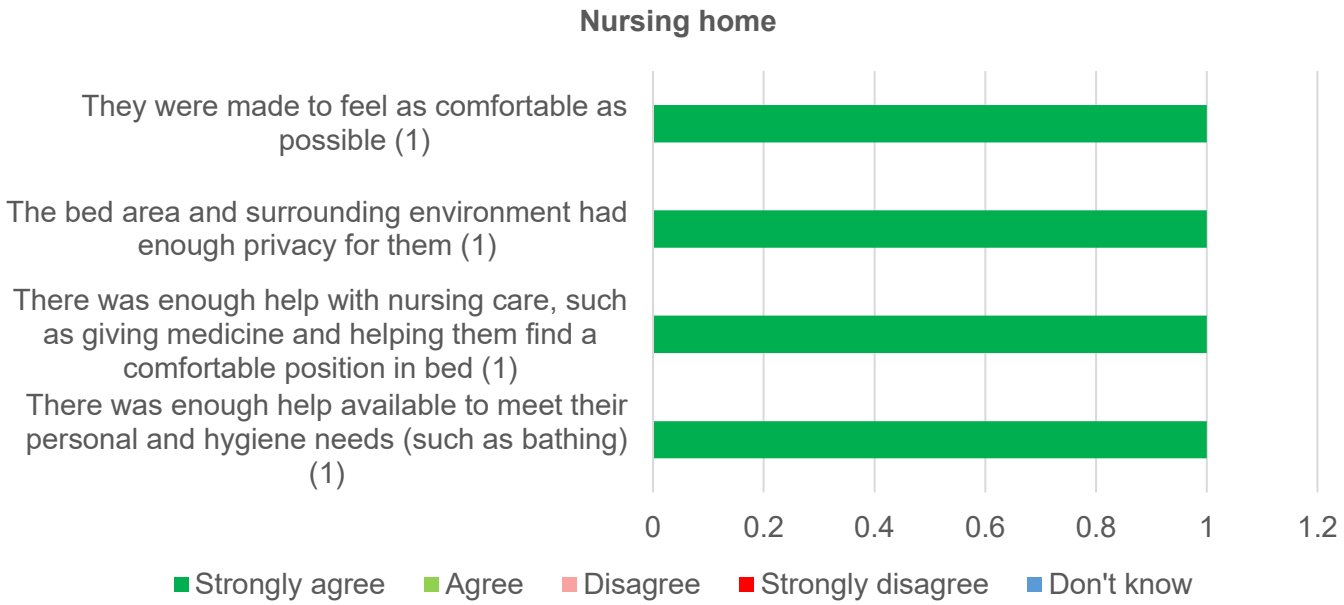
54% agreed (previous report 41%) that there was enough help to meet their personal and hygiene needs and 42% were dissatisfied (33% previous report) and 4% did not know.

100% agreed that they were made to feel as comfortable as possible and 0% disagreed.

100% agreed that the bed area and surrounding environment had adequate privacy and 0% disagreed.

100% agreed that there was enough help with nursing care and 0% disagreed.

100% agreed that there was enough help to meet their personal and hygiene needs and 0% were dissatisfied.



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100% agreed that they were made to feel as comfortable as possible and 0% disagreed.

100% agreed that the bed area and surrounding environment had adequate privacy (previous report %) and % disagreed (previous report).

100% agreed that there was enough help with nursing care (same figure as last report) and % disagreed (% previous report).

100% agreed that there was enough help to meet their personal and hygiene needs (% from previous report) and % were dissatisfied (% previous report)

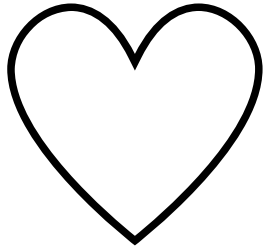
It must be noted that the response was very low with only 1 response.

Experiences were more positive in a hospice and nursing home in the last 2 days of life.

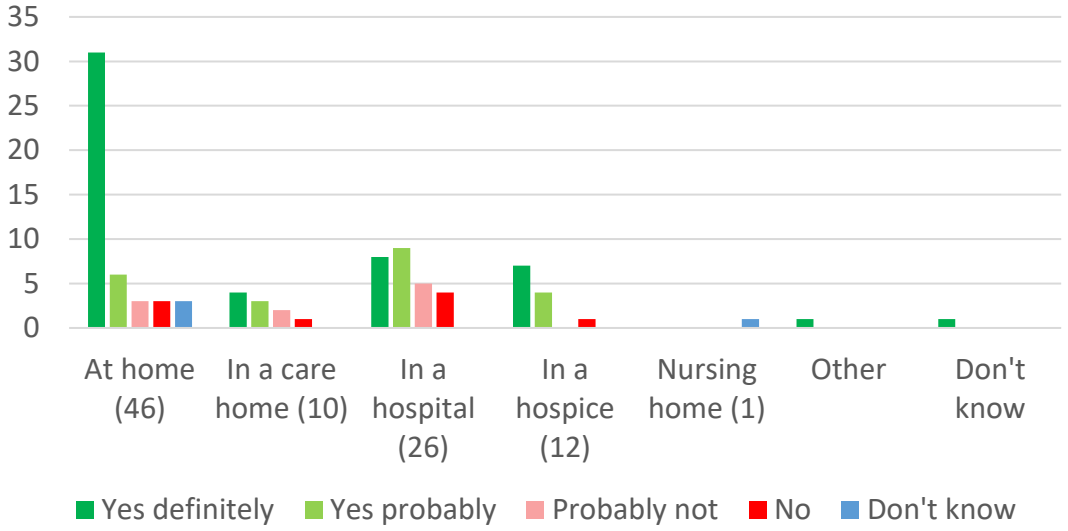
The most negative feedback received about the help that they received within a hospital within the last 2 days of life.

Section 12

In the lead up to their death



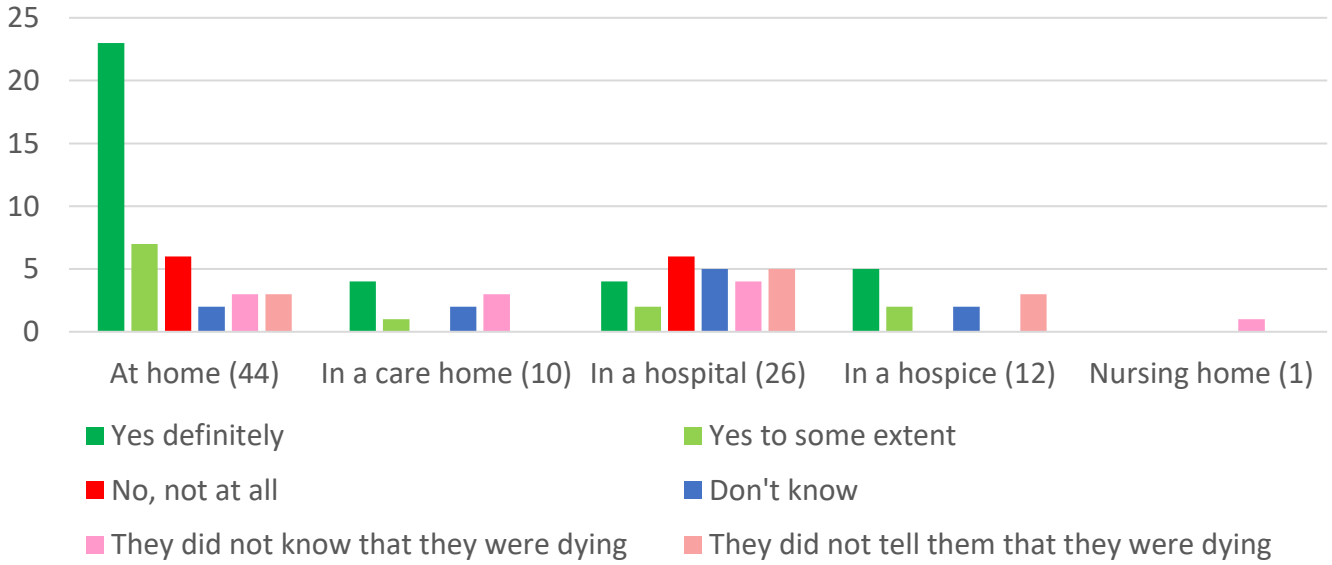
When we asked respondents to tell us whether their loved ones knew that they were going to die



80% (37/46) of those who were at home knew that they were going to die
70% (7/10) who were in a care home knew that they were going to die
65% (17/26) who were in a hospital knew that they were going to die
100% (1/1) did not know who were in a nursing home

(this figure was overall 72% from the last report)

Respondents were asked to tell us if the person who told them that they were going to die broke the news in a caring manner



68% of those at home felt that they were broke the news in a caring manner.
50% were told in a caring manner within a care home. 30% did not know that they were dying.
19% were told in a caring manner within a hospital setting.
23% (6/26) were not told in a caring manner at all, 19% (5/26) did not get told that they were dying.
58% (7/12) were told in a caring manner within a hospice.
25% (3/12) did not tell them that they were dying.
(this figure was overall 54% from the last report)

When asked if respondents were contacted soon enough to give them time to be with them before they died.

100% of respondents were with their loved ones in a hospice and nursing home

The highest percentage – 38% of people who were not with their loved ones were in a hospital.

(39% were with the patient before they died from the previous report and 25% contacted to get there)

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	At home	In a care home	In a hospital	In a hospice	Nursing home
Yes	24% (11)	44% (4)	27% (7)	92% (11)	100% (1)
I was already there	70% (32)	33% (3)	35% (9)	8% (1)	0%
No	7% (3)	22% (2)	38% (10)	0	0%

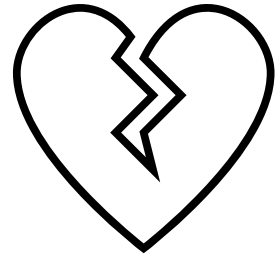
14% (12/85) were prevented from being with their loved ones when they died

The top reasons for this were due to travel, distance, sudden death and covid restrictions:-

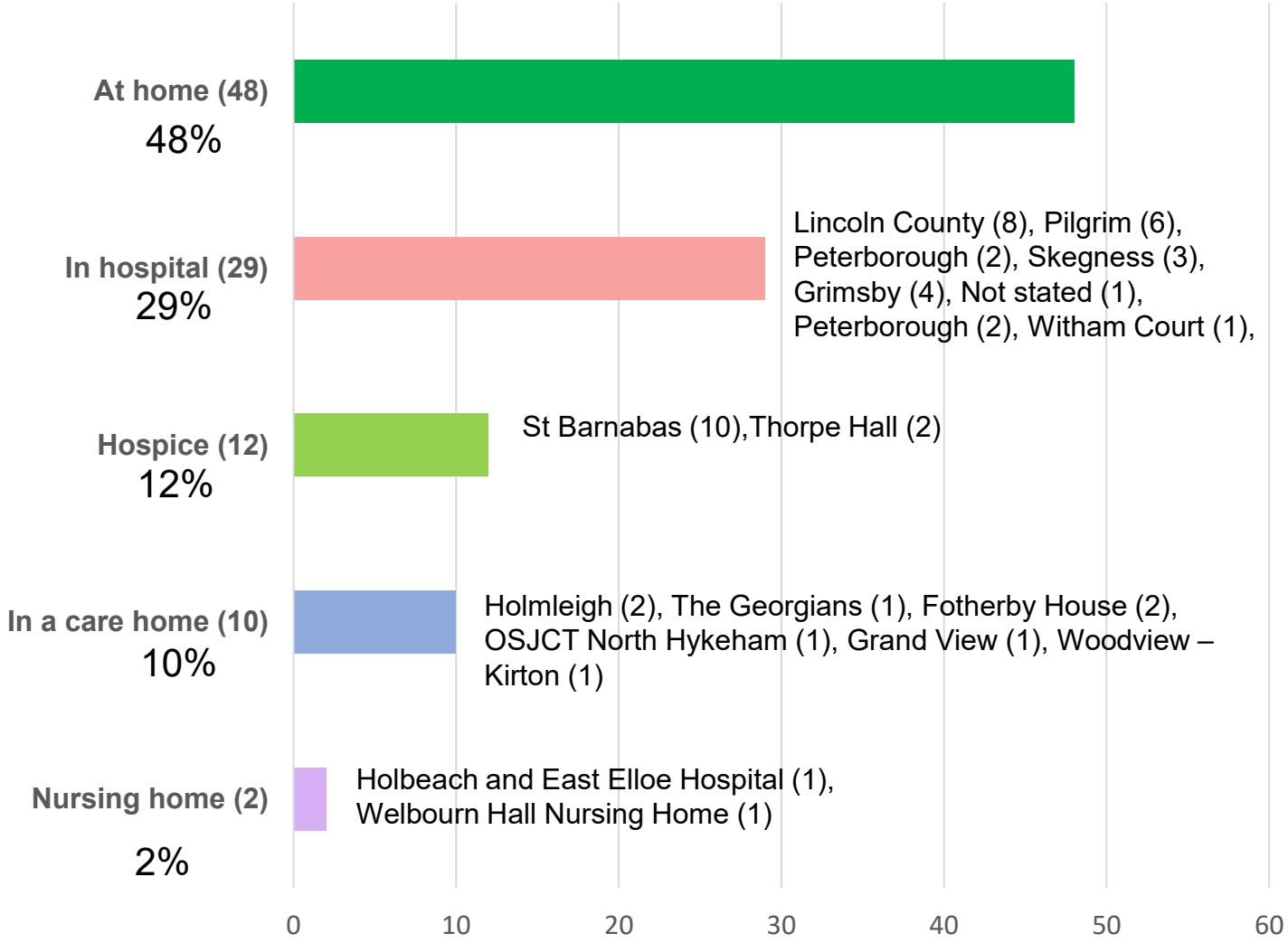
Travel	**2**	**Didn't know was dying**	**1**
Distance	**2**	**Not being notified was rapidly declining**	**1**
Covid restrictions	**2**	**Seriously ill in hospital**	**1**
Sudden death	**2**	**Just missed the moment**	**1**
Left to give family time	**1**		

Section 13

Circumstances surrounding their death



48% (48/101) of respondents stated that they died at home
Locations where loved ones died, if stated, are listed below



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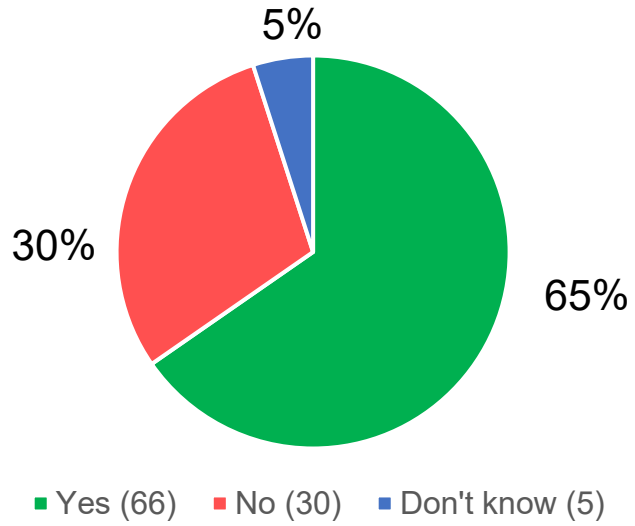
65% (66/101) of respondents felt that they had enough choice about where they died



This figure has increased from the previous report where 45% felt they had enough choice

Respondents told us the reasons for thinking they had enough choice about where to die

Many families expressed satisfaction and gratitude that their relative's wish to die in their preferred place - mostly at home - was achieved. The comments highlight the importance of respecting individual preferences, maintaining dignity, and ensuring appropriate support to make home death possible. Success in this area was supported by early discussions, clear communication of preferences, effective coordination of care, and strong family commitment. When these elements were in place, families felt that their loved one's death was dignified and peaceful.

Respecting Personal Wishes and Maintaining Dignity	A strong theme across the feedback was the value placed on ensuring that the person's wishes were honoured. Families described a sense of peace in knowing that their loved one's preferences were understood and respected, even when they could no longer communicate these directly. • Several families reported that being at home reflected the individual's personality and sense of identity. • Where mental capacity was declining, next of kin acted according to previously known wishes, ensuring decisions aligned with what the person would have wanted. • Dying in familiar surroundings was viewed as essential to maintaining dignity and comfort at the end of life.
Family advocacy	Families often played a central role in enabling home death. • Many described advocating strongly to ensure that the individual's choice was upheld despite practical or clinical challenges. • Determination and perseverance from both the person and their carers were key factors in achieving this outcome. • Relatives expressed pride in having "done right by them until the end," reinforcing the emotional importance of supporting choice.
Supportive care and provision	• In some cases, access to community nursing teams, carers, and appropriate equipment helped families to care for their loved one at home. • Families appreciated clear communication, ReSPECT forms and guidance from healthcare professionals that recognised and supported the person's choices. • Where coordination between services worked well, families felt reassured and able to focus on comfort and presence rather than logistics.
Comfort and familiarity	Remaining at home was described as providing emotional and physical comfort. • Familiar surroundings and items – such as using their own toilet, listening to their own music in their own surroundings and the presence of family and pets created a calm and reassuring environment. • Even when the person's awareness was reduced, relatives felt that they were settled and where they wanted to be.
Empowerment and control	• Several accounts highlighted that individuals maintained control and autonomy in their final days. • People made conscious decisions about where and how they wished to die, sometimes choosing to stop treatment or decline hospital transfer. • This contributed to a dignified and person-centred end-of-life experience.
Emotional fulfilment and gratitude	Families frequently reflected on feelings of pride, relief, and gratitude in being able to fulfil their loved one's wishes. • Achieving the preferred place of death was seen as a final act of love and respect. • Despite the emotional and practical challenges, many described the experience as a "blessing" and found comfort in knowing the death occurred in line with the person's values and choices.

Barriers to feeling that there was not enough choice about where they could die

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Families expressed frustration and sadness that their relative's wishes regarding place of death could not be fulfilled.

The main barriers identified related to limited service capacity, poor communication and planning, lack of timely clinical or community support and system constraints in health and social care coordination.

Overall, these accounts highlight gaps in communication, coordination, and service availability that prevented people from dying in their place of choice. Earlier identification of end-of-life needs, timely access to community and hospice services, and clear, compassionate communication between professionals and families are key areas for improvement.

Lack of timely communication	• A number of families reported that they were unaware their loved one was approaching the end of life until very late. Had they known this, they may have made other choices. • In several cases, the person had not been identified as being in the final phase of life, it was sometimes sudden resulting in missed opportunities to plan or discuss preferences. • Families felt unprepared and unsupported, often learning of the situation only once active dying had begun. One respondent commented that they had not yet received an appointment through from the hospital. • Some expressed distress that end-of-life decisions were made without their knowledge or consent.
Limited access to community and specialist support	• The absence of 24 hour specialist resource. • Families described being unable to arrange home-based care, specialist palliative input, or appropriate equipment in time. • Requests for district nursing or syringe driver support were sometimes declined or delayed. • Without sufficient home-based resources and clinical support they were unable to provide, families were left unable to manage symptoms safely and comfortably. • Lack of carers to offer support at home.
Insufficient hospice, hospital or care home facilities	• Even where a hospice or preferred care home was identified, access was sometimes restricted. • Several families reported that no bed or room was available, or that transfer could not be arranged quickly enough. • Several families stated that their loved ones were unable to be moved to their place of choice due to weekend cover. • In some areas, the nearest suitable facility was a considerable distance away or required financial top-up fees that families could not afford. One respondent stated that it would have cost an additional £300 to have them in a care home closer to home. • These limitations meant some individuals died in hospital or care homes that were not their or their family's choice. • Hospital was described as being noisy, busy surroundings and being scared to go in to hospital.

Barriers for feeling that there was not enough choice about where they could die Continued . . .

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Decisions made without families wishes	• Some respondents felt that decisions about end-of-life care location were made by professionals without adequate discussion or shared decision-making. • Some felt there was no alternative. • Families expressed concern that their relative's wishes were overridden or not taken into account. • In a few cases, individuals were transferred to hospital or placed on end-of-life care pathways without family understanding or approval. • This lack of communication contributed to feelings of helplessness and mistrust.
Challenges in managing symptoms at home	• Where families attempted to honour wishes to remain at home, symptom control was sometimes inadequate or not relieved with care at home. • Pain management, breathlessness, and withdrawal of oxygen were described as distressing and poorly communicated. • Families felt unsupported in managing complex care needs and were unsure how to seek timely help.
Rapid deterioration or unforeseen clinical events	• Condition deteriorated quickly so was unable to die at place of choice, despite the best efforts. • Due to their condition, was unable to be moved.
Emotional impact	• Families described strong emotional impacts arising from these barriers. • Many felt guilt, regret, or anger that they were unable to fulfil their loved one's wishes. • A lack of information, planning, and professional guidance added to the emotional strain of the final days. • Some expressed a sense that the system prioritised institutional processes over compassionate, person-centred care.

The reasons for choosing to die at home were:-

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Comfort and familiar surroundings	• Wanted to be in their own environment, using familiar things like their own bed, chair, or toilet. • Felt more relaxed and in control at home. • “She felt safe at home.” • “He wanted to stay in his comfortable happy place with his dog.” • “Peace, comfort, family and dog around and privacy.” • “It was home.”
Family presence and love	• Desired to be with loved ones rather than strangers or staff. • Importance of dying surrounded by family and love. • “To be with family in their personal space.” • “She died holding her son’s hand and that meant a lot.” • “Mum wanted to be where she felt love was all around.” • “His home and to have me by his side.”
Control, independence and dignity	• Wished to remain in control of their care and circumstances. • Avoid being forced or over-medicated. • Wanted to die on their own terms. • “He wanted to… go in his sleep in his own time when he was ready, not forced upon.” • “He didn’t like morphine and was more in control at home.” • “His own time, his terms, his house, his choice.”
Negative feelings about hospital or care settings	• Fear, dislike, or bad experiences in hospitals or care homes. • Perceived lack of care, dignity, or attention. • “She felt they didn’t care in hospital, too busy.” • “Hated hospital, she was scared to go back in.” • “Bad experiences in the hospital during their illness led to a fear of going to hospital.” • “She had hated her time in hospital, The care had been so bad.”
Personal or shared history of the home	• Home as a place of identity, achievement, and pride. • Strong emotional and historical attachment. • “He was proud of what he had achieved and worked for, he wanted to stay in his family home.” • “With family and where dad died.” • “Loved their home, cared for by family.”

The reasons for choosing to die at home were:-

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Practical and emotional continuity	The home offered routine and normality, eg, watching TV or listening to music. Allowed for ongoing connections with pets, familiar surroundings, and daily life. • "He could watch his programmes, listen to his music, use his own toilet." • "To be comfortable in her own surroundings with family."
Rejection of institutional isolation	Did not want to be isolated or surrounded by unfamiliar people or rules. • "Not isolated in a care home with unfamiliar people." • "Wanted family to come and see her but I had to stick to the rules on Covid."
Expressions of love and commitment	Some loved ones spoke of fulfilling the wishes of their loved one. • "My wife wanted to be at home." • "My husband wanted me to care for him." • "I know he would have wanted to be at home… he died in my arms."

There were **no clear reasons expressed for not wanting to die at home**.
All participants who mentioned home felt that it was the **preferred, ideal, and most comforting setting**.
Any deviations from home deaths appeared to result from **practical barriers** — such as declining health, loss of communication, carer exhaustion, or COVID restrictions — rather than opposition to home as a place of death.

The reasons for choosing to die in a care home were:-

Comfort and privacy	Some families felt the care home provided comfort, dignity, and privacy in the final days. • "Comfort for Mum and her family and privacy and being in an environment specialising in end-of-life care." • "Her comfort."
Specialist care and support	Chosen (or accepted) because the care home could meet complex care needs better than home. • "Capacity, frailty, dementia and environment to meet their needs." • "It was the care home where she lived."
Familiarity and residence	For some, the care home was **already their home**, so it felt like a natural place to die. • "It was the care home where she lived." • "Home of family/friend."

NHS Lincolnshire

Overall, dying in a care home was rarely a clear personal choice. Most people expressed a preference for home, with care homes often chosen (or defaulted to) due to frailty, dementia, clinical judgment, or lack of options.
When viewed positively, care homes were valued for comfort, privacy, and specialist support, but negative responses centred on loss of control, lack of communication, and unmet wishes for a home death.

The reasons for choosing not to die in care home were:-

Preference to be at home	Many expressed a clear wish to die at home, surrounded by family and familiar surroundings. • "Did not want to die in hospital, wanted to die at home." • "She wanted to be at home but this was not possible." • "He wanted to be at home with me."
Lack of choice or control	Some deaths in care homes occurred by default, not by choice — due to health system decisions, limited options, or sudden deterioration. • "No choice at all really." • "She had no choice." • "Not given any choice due to a lack of communication on their behalf." • "We were advised they could not be moved."
Clinical or logistical complaints	Decisions often made by professionals, sometimes against the person or family's wishes. • "Decision was made by clinicians to move mum to a nursing bed at a care home." • "He couldn't move, neuropathy had really taken hold." • "It felt in his best interests in the moment."
Negative feelings of regret	Some expressed resentment or sadness that the person didn't die at home, or frustration with how it was handled. • "She wanted to die at home – or rather she didn't want to die and shouldn't have, but for your incompetent staff." • "It appeared to be rushed… it would have been better to have stayed in the ward area."

Reasons for choosing to die in a hospice were:-

Specialist and compassionate care	Hospices were valued for their expertise in end-of-life care, with staff trained to manage symptoms and provide comfort.
Peaceful and supportive environment	The peaceful atmosphere of hospices was a reason for preference.
Better alternative to hospital	Some saw the hospice as a preferable alternative to hospital - calmer, more dignified and less clinical.
Care needs were unable to be met elsewhere	In certain cases, hospice care was chosen because home care wasn't feasible. "Couldn't return home."

Reasons for not choosing to die in a hospice were:-

Preference for home	The most common reason for not wanting hospice was a strong wish to die at home surrounded by family.
Emotional factors	Hospices, while caring, are still institutional environments, meaning patients might feel separated from loved ones or their familiar surroundings.

Most participants viewed the hospice positively, recognising its specialist, peaceful, and compassionate care, and often seeing it as a better alternative to hospital. However, when a preference was expressed, home remained the ideal place of death, with hospice chosen mainly due to practical limitations — such as complex care needs, or inability to return home.

NHS Lincolnshire

Reasons for choosing to die in a nursing home were:-

Specialist and compassionate care	It was local to the family and provided excellent palliative end of life care.

Reasons death occurred in a hospital were:-

Sudden, unplanned or unexpected death	Death happened quickly, or unexpectedly meaning no opportunity to plan or transfer.
Advised could not be moved	Unable to be moved. Lack of communication.
Lack of communication/no choice	Families were not offered alternatives or informed early enough to plan.
Clinical needs/complexity	Complex needs such as dementia, frailty or rapid deterioration meant hospital was judged the only option.
Staff led decisions	Decisions seemed to prioritise staff or ward rather than the person's comfort.

Reasons for not choosing to die in a hospital were:-

Preference for home	Many wanted to die at home with family or in a familiar place.
Comfort, dignity and privacy	Home or specialist settings were seen as more comfortable and private.
Distrust or dislike of hospitals	Some strongly disliked hospitals or found them distressing.
No opportunity to express choice	People died in hospital despite wishes because choice was not offered or explored.
Death was avoidable	Some felt that death should not have died and that care failures led to hospital death.

We asked respondents to tell us if they received enough help and support by the healthcare team at the actual time of the death. Overall, 52% felt supported with 39% feeling unsupported. Hospices receiving the most positive experiences. 9% did not know

NHS Lincolnshire

	At home	In a care home	In a hospice	In hospital	Nursing home
Yes	54% (24)	44% (4)	91% (10)	36% (10)	50% (1)
No	39% (17)	44% (4)	9% (1)	50% (14)	50% (1)
Don't know	7% (3)	12% (1)	0% (0)	14% (4)	0% (0)

The reasons for feeling supported were:-

Compassionate kind and supportive staff	• Described as kind, considerate and respectful. • Staff were "very supportive", "brilliant", "amazing", "constantly checking on us" • Staff cared for the family as well as the person dying ("took good care of me", "concerned I would be ok going home", there was nothing they could do, we were given a cup of tea and hugs and left").
Clear communication and explanations of what was happening	• Teams explained the dying process and bodily changes. • Staff or specialist teams (eg, Resus lead) explained what had happened and next steps. • Care home and hospice staff kept families fully informed of changes.
Presence of specialist end of life teams	• Marie Curie nurses, Macmillan nurses, St Barnabas nurses, LIVES doctor, Dementia specialists, paramedics. These teams provided reassurance, expertise and emotional support.
Practical information about what to do next	• Help with verifying death and calling relevant services. • Guidance about contacting undertakers. • Support from district nurses or out-of-hours teams. • "Green card" or written information explaining what would happen next.
Being given time, space and privacy	• Staff allowed families to be alone as much as they wished. • Privacy to say goodbye. • Option to stay overnight or be called in time to be present at the end.
Responsive help when needed	• Families could call for extra help and received it. • Rapid attendance from nurses, doctors, or sitters. • Medication and advice readily accessible in hospital.
Feeling supported at the moment of death	• Professionals were physically present during the final moments (night sitters, hospice nurses). • They ensured family could be called in time.

The reasons for not feeling supported by healthcare staff at the actual time of death were:-

NHS Lincolnshire

Long delays in verifying death or attending	• Multiple reports of hours-long waits (2, 8, 9+ hours) for verification of death and signing death certificate. • Families left sitting with the deceased for long periods unsure of what to do. • Lack of staff trained to verify death or attend promptly. Suggestion for a funeral directors to undertake this for planned deaths. • Delays especially during evenings/weekends.
Lack of communication	• Not informed that death was imminent or had occurred ("just called to say she had died. No time given not told if alone or peaceful"). • No explanation about what to do while waiting. • No follow-up contact for bereaved relatives. • GP did not call or communicate.
No support available	• Reports of no help at all. • Told to call services that passed responsibility between 999, GP, 111, out-of-hours. • Families left to organise themselves.
No staff available	• There were no staff available. • Nurse left for lunch during a critical moment. • Only care home staff present without additional support.
Poor quality of care	• Staff described as "awful", "appalling", "very poor", or dismissive. • Nurse not introducing themselves, leaving family unsure who to turn to. • GP instructing a carer to verify death despite being unqualified.
Distressing or unsafe circumstances	• Family refused admission to say goodbye. • 999 operator instructing CPR despite clear ReSPECT form. • Person dying alone or with no one present (eg, during an absence or while family not allowed in).
Lack of planning and co-ordination	• Death felt rushed with no preparation for the family. • Paperwork not completed at the time of death. • Previous failures by healthcare system eroding trust (historic issues with GPs, mental health services, cancer care).
Inconsistencies	• Some staff (eg, hospital team) supportive, but others failed to provide essential help, leading to mixed experiences.

The reasons for feeling unsure if they were supported at the time of death were:-

NHS Lincolnshire

Unsure about whether the right actions were undertaken	• Conflicting instructions (eg, antibiotics only available in hospital vs. instructions not to admit). • Being told the person would die at home without clarity on alternatives.
Not being present at the time of death	• Asked to leave the room, then discovering the person had died while they were in the corridor. • Only one relative present and others unable to arrive in time.
Difficulty accessing staff or unclear who to approach	• Family had to actively look for a nurse to confirm death. • Nurses were busy, coming and going, which left families unsure if enough support was provided.
Staff did what they could under pressure	• Acknowledgement that nurses were busy but tried to attend. • Families unsure if more could have or should have been done.
Emotional support provided but limited medical involvement	• Staff offered tea, hugs, and the chance to see the person afterwards, but there was little practical intervention available. • This left families unsure whether that level of support was appropriate or sufficient.

Overall, 78% (75/96) of respondents felt that staff treated them and their family in a sensitive manner after their loved one had died (this has increased from the previous report where 72% was reported)

NHS Lincolnshire

The reasons for this were:-

Positive comments	Negative comments
Kindness, compassion and sensitivity:- • Staff described as kind, sensitive, caring, compassionate, thoughtful, well-meaning. • Staying with the family during or after death, offering emotional support (tea, hugs, company). • Staff showing personal warmth,	**Disrespectful or dismissive behaviour** • Families felt patronised, dictated to, hounded, or ignored. • Family members treated as "a number" rather than a person. • Complaints or concerns dismissed: "no care, no compassion, just lets jump to the next task." • Family receiving a phone call when they had died.
Respect for family and time:- • Allowing family to stay with the deceased until after death or until relatives arrived. • Time provided to grieve and prepare: "time allowed to be with family member," "handled things very well." • Respect for family wishes regarding faith, funeral arrangements, and personal items.	**Mismanagement of personal items or clothing.** • Rush or lack of consideration in handling the body: losing individuals clothes, moving deceased without family present. • Delays or errors in death certification. **Pain management** Provided with pain relief earlier.
Professional care for the deceased:- • Attending to the deceased with sensitivity (cleaning, laying out, checking death). • Marie Curie, St Barnabas, and hospice nurses noted for **exemplary care**. • Bereavement teams providing thoughtful touches (bags for personal items, explaining next steps).	**Lack of emotional support or guidance** • Little emotional guidance in confronting a death. • Families left alone during critical moments, sometimes while staff were on break. • Limited sensitivity from staff, even if silent or polite.
Support beyond clinical duties:- • Helping the family navigate practical matters (eg, escorting home, coordinating with funeral directors). • Emotional reassurance during stressful moments (nurses staying until funeral directors arrived, offering phone support).	**Pressure to make funeral arrangements quickly** • Feeling rushed in a deeply emotional situation.
	Poor communication Staff not introducing themselves, poor explanations of procedures. Delays in contact (eg, nurse arriving hours later after a call). Miscommunication about care, timing, or procedures left families unsure or upset.

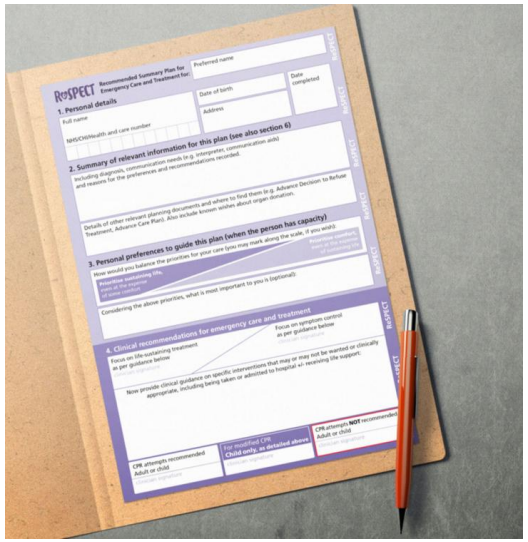
When looking back over the last 3 months of their life, 63% (60/95) of respondents felt that they were involved in decisions about their care, 25% (24/95) felt that they weren't and 12% (11/95) were unsure. The reasons were:-

NHS Lincolnshire

Being involved in decision making	Not being involved in decision making
Medical knowledge or terminology:- • Family members with medical knowledge could ask informed questions and guide care decisions.	**Patient incapacity** Dementia or cognitive decline prevented patients from understanding or making decisions: "He had dementia so had no understanding." "She was not always in a mental state to understand the situation." "Vascular dementia… non-verbal for the last month."
Family meetings and structured discussions • Formal or informal family meetings helped clarify wishes and plan care. • Nurses and clinicians explained options: "All aspects were discussed fully," "Macmillan nurses talked her through what she wanted on her own."	**Lack of communication** Families felt left "in the dark" about care plans or responsible clinicians. • No overarching support or clarity on who was in charge of care. • Needed to chase or coordinate themselves. **Pain relief** Traumatic for the family at the end as kept needing to ask for pain relief.
Respect for patient wishes:- • Where patients were able, their decisions were central: "Mum was at the centre of everything that happened and her wishes were respected." • Legal frameworks like LPOA facilitated involvement in decisions.	**Service failures or neglect** • No care provided when leaving hospital • Feeling that was let down by hospital, community services and GP. • Care options were restricted or overridden: "They could not make arrangements for him to be home," "Reluctant to accept as much care as they needed." • Frustration with bureaucracy or mismanagement:
• **Use of specialist services** CNS (Clinical Nurse Specialist) or Macmillan nurses assisted in explaining care options and end-of-life planning.	**Emotional distress and lack of support** • Family felt unsupported and powerless to influence decisions during critical moments. • Negative experiences compounded by previous failings of healthcare staff:

60% (58/97) of respondents stated that a ReSPECT form had been completed
16% (16/97) had not completed a form
24% (23/97) did not know

(Respondents within South Holland and Boston districts reported that individuals had all completed ReSPECT forms)



44% (39/88) of respondents felt that there were no decisions that were taken about their care that they would not have wanted (previous report 53%)
32%(28/88) felt that decisions were taken that they would not have wanted (previous report 26%).
24% (21/88) did not know (previous report 21%).

The reasons provided why decisions were taken that they **would have wanted** were:-

Respectful, person centred decision making	• Families were grateful for all the help and support received. • Decisions were made with full awareness of the individuals needs, ensuring that what was received and preferences were respected and what they would have wanted. • ReSPECT forms were initiated thoughtfully, allowing decisions to be guided by wishes.
Compassionate care and emotional support	• St Barnabas and Butterfly nurses were described as wonderful, offering both practical care and emotional reassurance. • They helped individuals understand and come to terms with this stage of her life's journey, providing comfort, dignity, and compassion.

The overarching reasons why decisions were taken that they would not have wanted centre on wishes being ignored, lack of respect for advance decisions, inappropriate or withheld medical treatment, being placed somewhere they did not want to be, and a general loss of autonomy at a vulnerable time.

The reasons provided why decisions were taken that they would not have wanted were:-

Treatment given or withheld against wishes	• Were not always pain free – sometimes slow relief or taken off medication that wanted to stay on and a change in medication. • ReSPECT Form:- - Not being contacted before or after completing ReSPECT form. - The number of ReSPECT forms being completed. - Form being completed without discussion with loved one meaning some information was omitted. - Not being completed very well. • Being put on end-of-life care when would not have consented to this. • Not being treated in time for sepsis. • Left to die slowly with pain relief only, no food or drink.
Location of care	• Unwanted place of death. • Not provided with a side room due to condition (neutropenic sepsis).
Lack of clarity and planning	• While the wish to avoid invasive treatment was respected, there was no clear plan for what should happen after that decision. • Individual was placed on a non-invasive ventilator for a period, but no one appeared to consider the broader picture or the next steps, leaving the family uncertain whether the care aligned with the overall wishes.

41% (40/97) of respondents stated that since their loved one had died, they had not been offered anyone to talk to from health, social services or from a bereavement support service/group about their feelings following their death
31% (30/97) did not want to
4% (4/97) Did not know
1% (1/97) was not applicable.
23% (22/97) had spoken to someone (this figure has increased from the previous report 22%)

Of those that had spoken to someone, this was through:-

St Barnabas	4	Lawyers and health ombudsman	1	Butterfly Hospice	1
Macmillan Nurse	2	United Lincolnshire Hospitals NHS Trust	1	Private counselling	1
Counselling through work	2	Support Nurse	1	Family and friends	1
Bereavement group	2	Counselling offered	1	Community Nurse	1
GP Surgery	2	Marie Curie	1	Griefkind	1
Bereavement counsellor	1				

Comments provided if respondents stated that they had spoken to someone from health, social services or from a bereavement group or service were:-

Emotional distress for ongoing counselling	• Many described overwhelming grief, trauma, or distress surrounding the circumstances of their loved one's death. • Several sought further counselling through work, privately, or via St Barnabas because the emotional impact continued long after the loss. • Some felt isolated or worsened by certain support groups, prompting them to seek alternative therapeutic help.
Lack of support during end of life experiences	• People sought someone to speak to because they had been the main carer with little or no help, often feeling abandoned or overwhelmed. • Shock or dissatisfaction with aspects of care (e.g., inadequate admission processes, limited professional presence) left individuals needing to debrief, process events, or seek validation.
Bereavement and support service	• Many attended bereavement groups, such as those offered by St Barnabas, to find connection, understanding, or structured emotional support. • Some engaged with multiple services—St Barnabas nurses, Macmillan nurses, bereavement groups, Carers First workers, coroners—seeking clarity, comfort, or guidance. • Following his wife's death, one respondent had set up a male bereavement group so that men could talk to men if they wished. Unfortunately it had to be closed down due to lack of space. The respondent volunteers at an in-care hospice.
Need to raise concerns or seek accountability	• Individuals contacted professionals or organisations (eg, Trust Boards) to raise concerns about care quality or systemic failings. • Sharing their loved one's story or submitting formal concerns was a way to process their experience and advocate for change.
Continued caring responsibilities	• Some sought therapy or advice because they were still caring for another family member, making grief more complex and ongoing. • Support was needed to manage the emotional strain of simultaneous caregiving and bereavement.
Closure, understanding or reassurance	• People spoke to coroners or healthcare professionals to better understand the circumstances of death. • They reached out to professionals simply to have someone acknowledge their experience, provide reassurance, or help them navigate life after their loss.

Comments provided if respondents stated that they did not want to speak to someone from health, social services or from a bereavement group or service were:-

Feeling overwhelm and avoidance	• Some feel that talking about the experience would be too upsetting or retraumatising, bringing back painful memories. • Others avoid conversations because they are still grieving or simply not ready to revisit what happened. • The distress of knowing their loved one was "let down," regardless of the circumstances, makes engaging in discussion too emotionally difficult.
Anger and dissatisfaction	• Anger about the situation or the way care was handled can make people unwilling to talk. • Some felt that when teams discussed care, they offered excuses or passed responsibility between services, reducing trust and discouraging further conversation.
Feeling that support wasn't needed	• When individuals believe their loved one received good care, and they feel grateful for the support they had, they may not see the need to talk further. • A sense of peace or closure can reduce the desire for additional emotional or follow-up conversations.
Perception that information is no longer relevant	• Some feel that the care experience happened too long ago (eg in 2015) for further discussion to be useful. • The passage of time can make revisiting the events feel unnecessary or disconnected from their current situation.

Comments provided if respondents stated that they were not offered to speak to someone from health, social services or from a bereavement group or service were:-

Negative experiences with support services	• Some individuals felt that previous interactions with "bereavement services" or hospital staff were poor, dismissive, or anxiety-inducing. Experiences such as repeated questioning about Respect forms or very poor care left families feeling distressed and unsupported. • No support from Lincolnshire. Tried to refer themselves to Grimsby. Carers Support.
Lack of proactive support or follow-up	• Several noted that no one offered them the chance to talk or receive emotional support after the death. • Families felt abandoned at key moments—such as district or hospice nurses not being available on the last day. • As carers, some felt they were dismissed or overlooked entirely when their caring role ended.
Practical issues	• Instead of bereavement support, some people were contacted about administrative or financial matters (eg., deferred payment schemes). • Being directed to external services (eg. "call Cruse").

Comments provided if respondents stated that they were not offered to speak to someone from health, social services or from a bereavement group or service Continued …

Long term caring and relief	• After many years of intensive caring, some felt emotionally exhausted or relieved that their loved one was no longer suffering, which influenced their perception of support needs. • For some, the end of a long illness meant they did not feel the same need for formal bereavement support, even though none was offered.
Would not take up support even if offered	• A few individuals acknowledged that while support was not offered, they likely would have refused due to personal coping styles or a desire not to revisit painful experiences.

What worked well around the circumstances around their death during their last few days prior to death were:-

NHS Lincolnshire

Moving from hospital to hospice

St Barnabas support

City Hospital worked quickly to get him back to Grantham

On their own in a ward with family

Was as comfortable as possible

Pain relief:- At home and Marie Curie kept the pain relief high

Personalised care

Night time support excellent

Care from family at home

Carers

Most things

Hospital Staff helpful. Care at Skegness

Hospice care

Open visiting

Care from family and friends

Community Teams support

Nurses visiting daily

District Nurses

Care and support to the individual and family

Clear and compassionate care from A&E Doctors

Care Home helping to prepare family

Medicine in a pump

Suggestions about what could be improved around the circumstances around their death during their last few days prior to death were:-

NHS Lincolnshire

Better room "he was afraid in the room when alone"

Being told timescales of deterioration

Co-ordinated care

More supportive night staff that remained awake and alert

More discussion with other relatives

Better communication

"Not let her linger so long"

Waiting time for pain relief:-
- syringe driver
- Pain relief being issued when 111 suggested it be prescribed

Admission to the oncology ward

Transfer to nursing home sooner

More skilled staff

Family being heard

Earlier visit from GP

Easier process to leave hospital

More visits

Night carers so family could sleep

More support

Unable to provide spiritual support due to morphine as was unconscious

"Wife's opinion given priority. Not listened to because of limited English"

Better communication from GP

Appropriate accommodation as limited at Witham Court

Conversations about Do Not Resuscitate

Suggestions about what worked well around the circumstances around their death when they died:-

NHS Lincolnshire

Time to spend with individual after they passed

Macmillan Nurse

Family being present

Personalised care

No support needed

Was quick

"Was on my own with him which is what he wanted"

The Nurse was very helpful and understanding

The palliative care 24 hour helpline

Most things

Marie Curie respectful and kind

Having family there

Care from Nurse

They were at peace

Care from Nurse

Care and support to the dying family member and the rest of the family

Great support from hospital. Received a phone call the next day to see how family were and explain next steps

Calling the "Green card"

Care home staff supporting

Settled and peaceful

Wishes respected

Doctors and Nurses to support resuscitation

Hospice team offered support

Further suggestions about what could be improved around the circumstances around their death when they died were:-

NHS Lincolnshire

No after care

Macmillan Nurse visited and did not realise he was dying

What to expect

Attending the death quicker

What happens next

Receiving pain relief for longer

Knowing who the individuals Nurse was

Care provided

Reduction in time following the new legislation for certification of death and growing concerns and the impact this will have on morgues and funeral parlours
(1 respondent commented that they had to wait between Jan – March for their mother's funeral)

More support

More skilled staff

Further suggestions about what worked well around the circumstances around their death after their death:-

NHS Lincolnshire

Good explanation of what happens next

Medical examiner contact was quick

Funeral Directors: Lovely. Respectful Professional

St Barnabas – everything prepared

Undertaker

Peaceful

Personalised care

Carers were sensitive and caring

Laid to rest

Death certificate received swiftly

Care to the individual and family

Carers final visit after death

Visit from Nurse

Most things

Bereavement support Team lovely, kind and compassionate

Staff invited to funeral

Care for me

The process from being told of death, all the way through to registering death, helped by each team and who to speak to next

Ward tried their best with the little support they have

Marie Curie Nurses – helpful and compassionate

Macmillan Nurse

Established men's bereavement group and became a volunteer

Further suggestions about what could be improved around the circumstances after their death

NHS Lincolnshire

No after care

Staff acting professional

Time taken for Nurses to arrive

Apology when needed

More skilled staff

The time taken for someone to come to the house to collect individual

What happens next

Provided with the chance to visit individual before being taken for post mortem

More support

More visits

Trauma support offered to relatives

Local post mortem service

Some respondents had had to make a complaint due to the treatment

Length of time to investigate complaints

Section 14

Equalities and Health Inequalities Monitoring

NHS
Lincolnshire

Under the provisions of the Equality Act 2010, all NHS organisations are required to demonstrate that their processes are fair, and that they are not discriminating or disadvantaging anyone because of their age, disability, gender reassignment status, marriage or civil partnership status, pregnancy or maternity, race, religion or belief, sex or sexual orientation.

NHS Lincolnshire

Ethnicity	Responses	
Bangladeshi	0%	0
Indian	0%	0
Pakistani	0%	0
Any Other Asian Background - Filipino (1)	1%	1
African	0%	0
Caribbean	0%	0
Any Other Black Background	0%	0
White and Asian	0%	0
White and Black African	0%	0
White and Black Caribbean	0%	0
Any Other Mixed Background	0%	0
White British/Scottish/Northern Irish/Welsh	94%	84
Any Other White Background German Dutch/English	 1 1	 1 1
Chinese	0%	0
Gypsies & Travellers	0%	0
Any Other Ethnic Group	0%	0
Prefer not say	1%	1
Answered	100%	89

Age	Responses	
Age 16 and below	0	0%
17 – 20	0	0%
21 - 29	0	0%
30 – 39	5	5%
40 – 49	14	15%
50– 59	27	30%
60- 69	18	20%
70-79	19	21%
80 – 89	7	8%
90 +	1	1%
Prefer not say	0	0%
Answered	91	100%

Under the provisions of the Equality Act 2010, all NHS organisations are required to demonstrate that their processes are fair, and that they are not discriminating or disadvantaging anyone because of their age, disability, gender reassignment status, marriage or civil partnership status, pregnancy or maternity, race, religion or belief, sex or sexual orientation.

NHS Lincolnshire

Religion	Responses	
Atheist	8	10%
Buddhist	0	0%
Christian	52	63%
Hindu	0	0%
Jain	0	0%
Jewish	0	0%
Muslim	0	0%
Sikh	0	0%
No religion	12	15%
Prefer not to say	6	7%
Agnostic	1	1%
Roman catholic	2	2%
Any other religion Agnostic Roman catholic Not stated	4 1 2 1	5%
Answered	82	100%

Gender	Responses	
Male	15%	13
Female	81%	70
Non-binary	0%	0
Intersex	0%	0
Prefer to self identify	1%	1
Prefer not to say	2%	2
Answered	100%	86

NHS Lincolnshire

Do you consider yourself to have a disability?	Responses	
Yes limited a little	27%	17
Yes, limited a lot	20%	13
No	51%	33
Prefer not say	2%	1
Answered	100%	64

Pregnancy and maternity - are you an expectant mother or given birth in the last 26 weeks?	Responses	
Yes	1%	1
No	99%	66
Rather not say	0%	0
Answered	100%	67

Are you the same gender that you were assigned at birth?	Responses	
Yes	100%	76
No	0%	0
Prefer not to say	0%	0
Answered	100%	0

Sexual orientation	Responses	
Bisexual	2%	2
Gay	0%	0
Heterosexual	90%	73
Lesbian	0%	0
Prefer to self – identify	1%	1
Rather not say	6%	5
Answered	100%	81

Carer - Do you look after, or give any help or support to family members, friends, neighbours or others?	Responses	
Yes	Primary carer of child/children under 18 – 5	19%
	Primary carer of disabled child/children - 1	4%
	Primary carer of disabled adult (18 and over) – 4	15%
	Primary carer of older person – 9	35%
	Secondary carer – 7	27%
Answered	26	100%

Health inequalities data

What is your main language	Responses	
English	98%	87
German	1%	1
Dutch/English	1%	1
Total	100%	89

Employment status	Responses	
Employed full time	34%	30
Employed part time	13%	11
Not employed and looking for work	0%	0
Not employed and not looking for work	3%	3
Retired	36%	31
Self employed	7%	6
Student	0%	0
Prefer not to say	2%	2
Other	3%	3
Total	100%	87

NHS Lincolnshire

Experience of any of the following:-	Responses	
Currently working in the farming industry	22%	2
Worked in the farming industry:-	11%	1
Currently homeless	0%	0
Experience of being homeless:-	22%	2
Currently serving in the reserve or regular armed forces	0%	0
Have served in the armed forces	44%	4
Refugee, asylum seeker or immigrant	0%	0
Previous experience of being a refugee, asylum seeker or immigrant	0%	0
Total	100%	9