



Leeds Palliative
Care Network

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Leeds

Bereaved Carers Survey about End-of-Life Care in Leeds

People's experience of end-of-life care and support for their friend / relative in hospices, hospitals, in their own homes and care homes

2021-2022

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Summary

Introduction

Healthwatch Leeds worked with Leeds Palliative Care Network to find out about people's experiences of end-of-life care for their relative or friend in a hospital, community (including GP surgeries, Leeds Community Healthcare and private care agencies and care homes) and hospice settings over a period of three months, October to December 2021.

Healthwatch Leeds is a partner in this project and its role was to assist in the development of the surveys and support with writing of the report. The clinical partners within Leeds Palliative Care Network have informed the process for this work and their service level expertise has provided the context in which to interpret the findings within this report.

A total of 115 people provided feedback across all the settings. This represents about 6% of the total number of deaths registered during this time; hence the report should be read and interpreted with some caution. Please also be aware that not every respondent answered every question.

There are a few factors that should be taken into consideration when reading this report and the effect these have had on the survey.

There was a new process for the distribution of the surveys due to a change in the way death certificates have been issued during the pandemic.

In previous years the survey invitation had been handed out to relatives/carers by the service provider. This year they were distributed by Leeds Registrar's Office via email and, due to administration issues, there was a delay in sharing the surveys in the first month. To encourage responses a hard copy of the survey invitation letter was sent via the post to families who requested copies of the death certificate.

This new electronic process has been a factor in response rates being lower than in previous years and hence they are not representative of the number of deaths in each service.

We do note that there were more responses this year than last about people receiving end-of-life care in the community and about people from Black, Asian, and Minority Ethnic populations.

Another factor to consider when looking at the findings in this report is the significant impact the Covid pandemic itself has had, with lockdowns and restrictions on visiting affecting the way care and support have been provided in all settings.

At the same time, it caused a strain on all services due to increased numbers of people requiring end-of-life care with increased complexity from a reduced workforce that was also affected by Covid.

Another impact of Covid is a change in where people have died, with more people dying at home and slightly fewer people dying in care homes and hospices. The increase in the number of deaths at home continues to be experienced.

We cannot underestimate the overall impact on everyone in society of the pandemic during this challenging time.

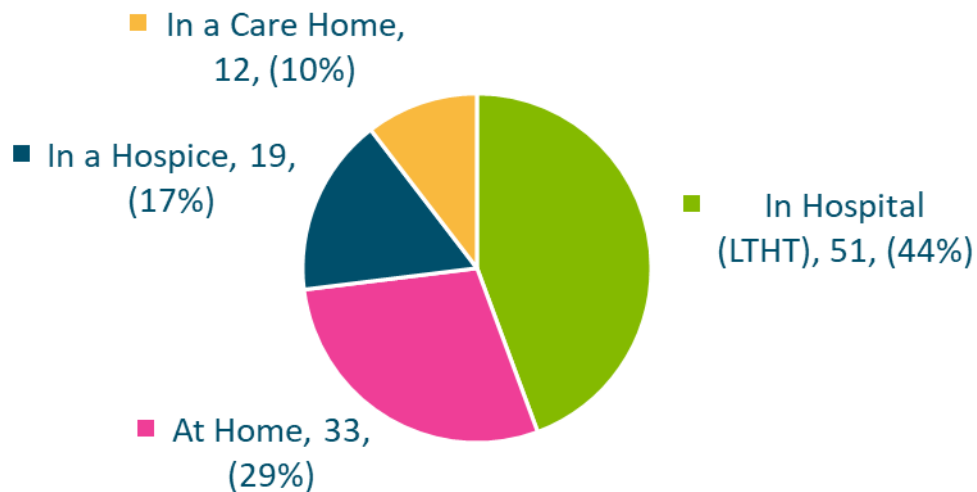
Recommendations from the findings of the survey are supplied at the end of each section for each service area and are summarised collectively at the end. These will inform future actions for improvement.

The plan of actions delivered following the 2020 Bereaved Carers report is available to read [here](#).

About our respondents

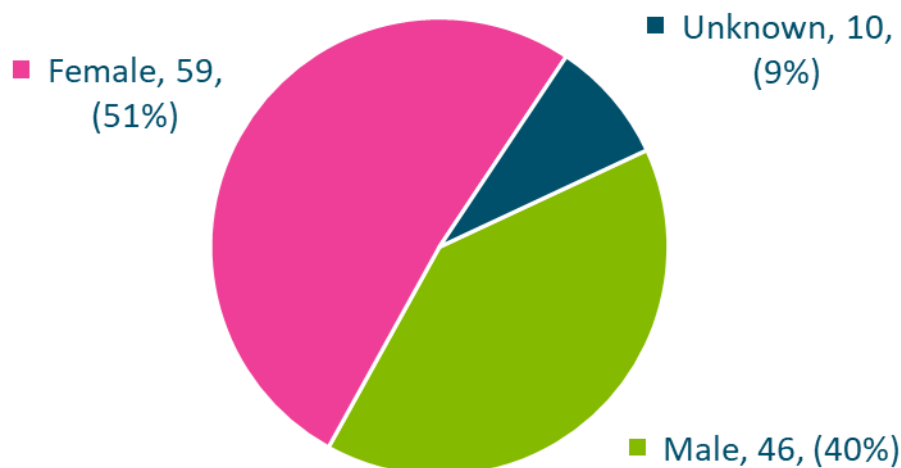
In total, we got 115 responses to our survey. The single largest group of respondents (51 people) said their relative / friend had died in hospital.

A summary of where our respondents' friends / relatives were cared for

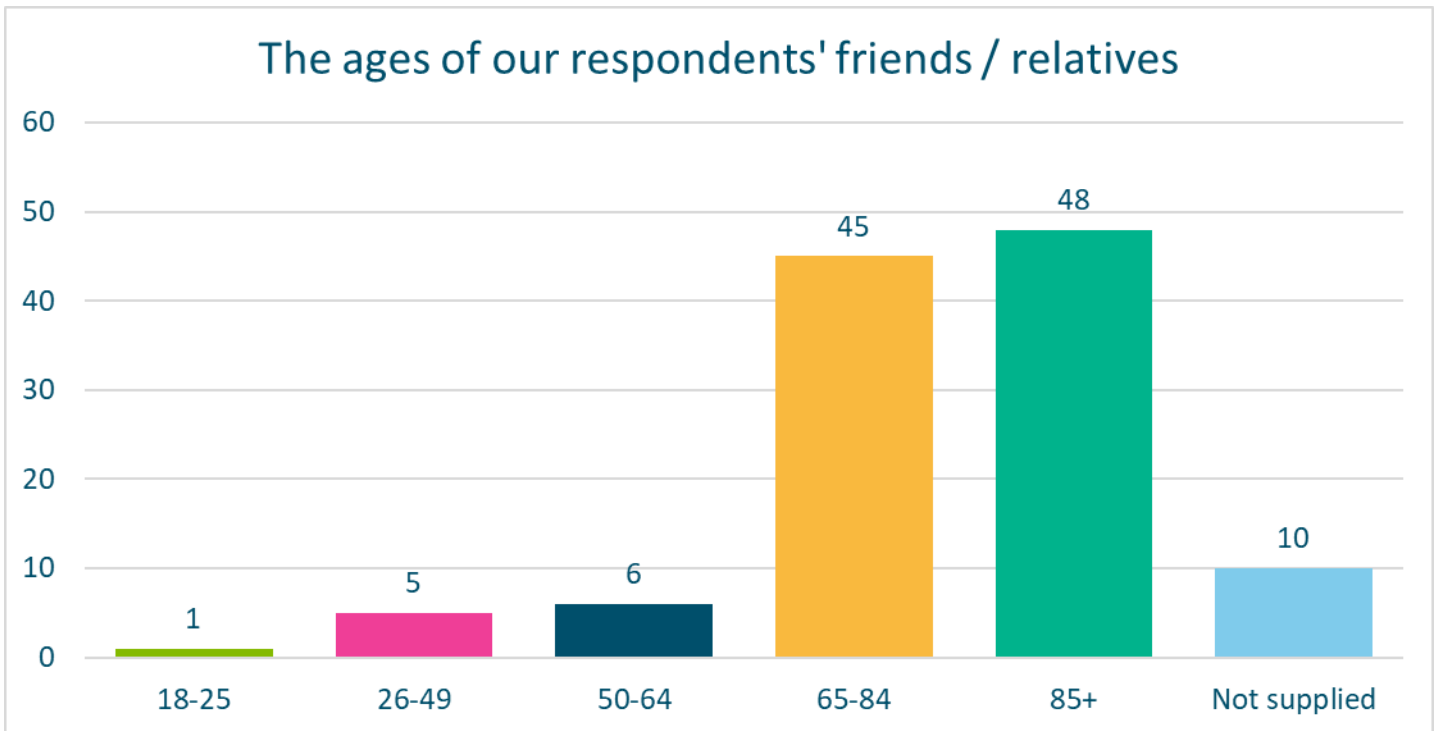


More respondents told us about a female friend / relative (59 people) than a male friend / relative (46 people). (10 people did not supply their deceased friend / relative's gender.)

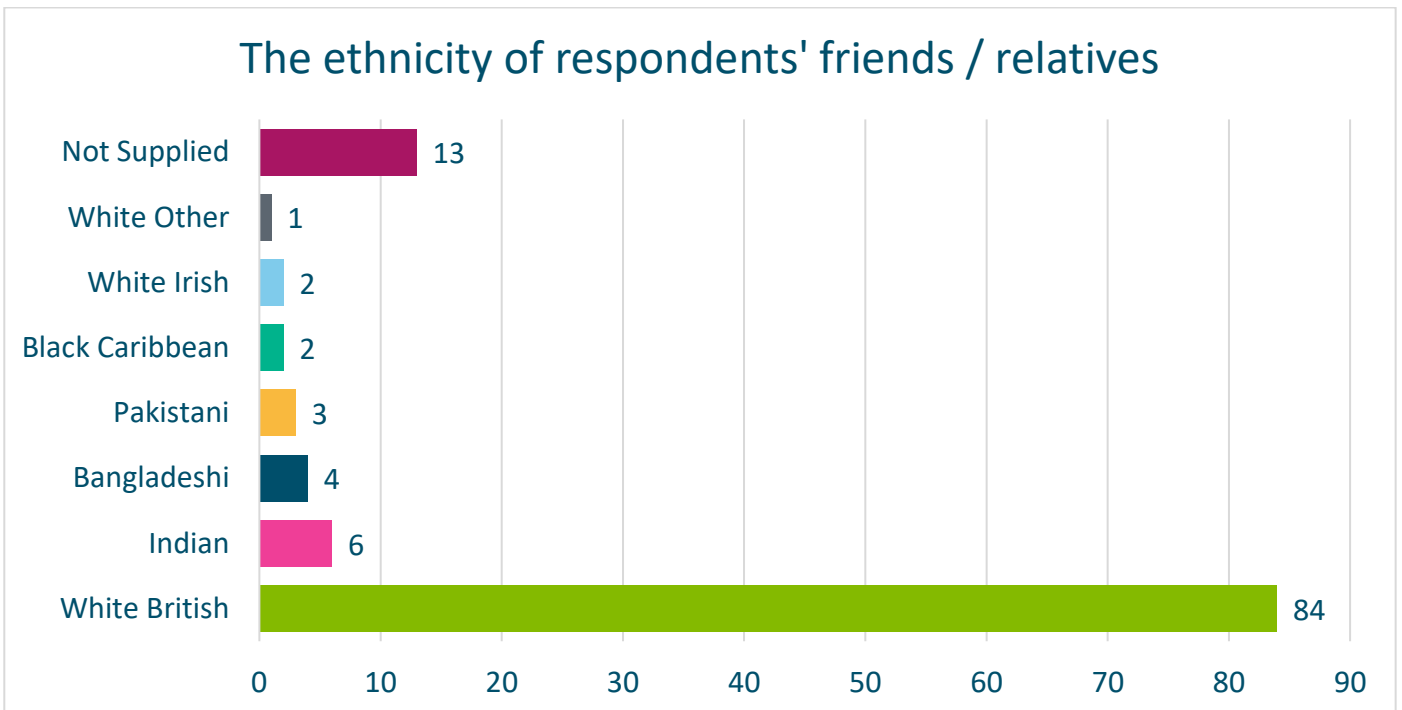
What was your relative / friend's gender?



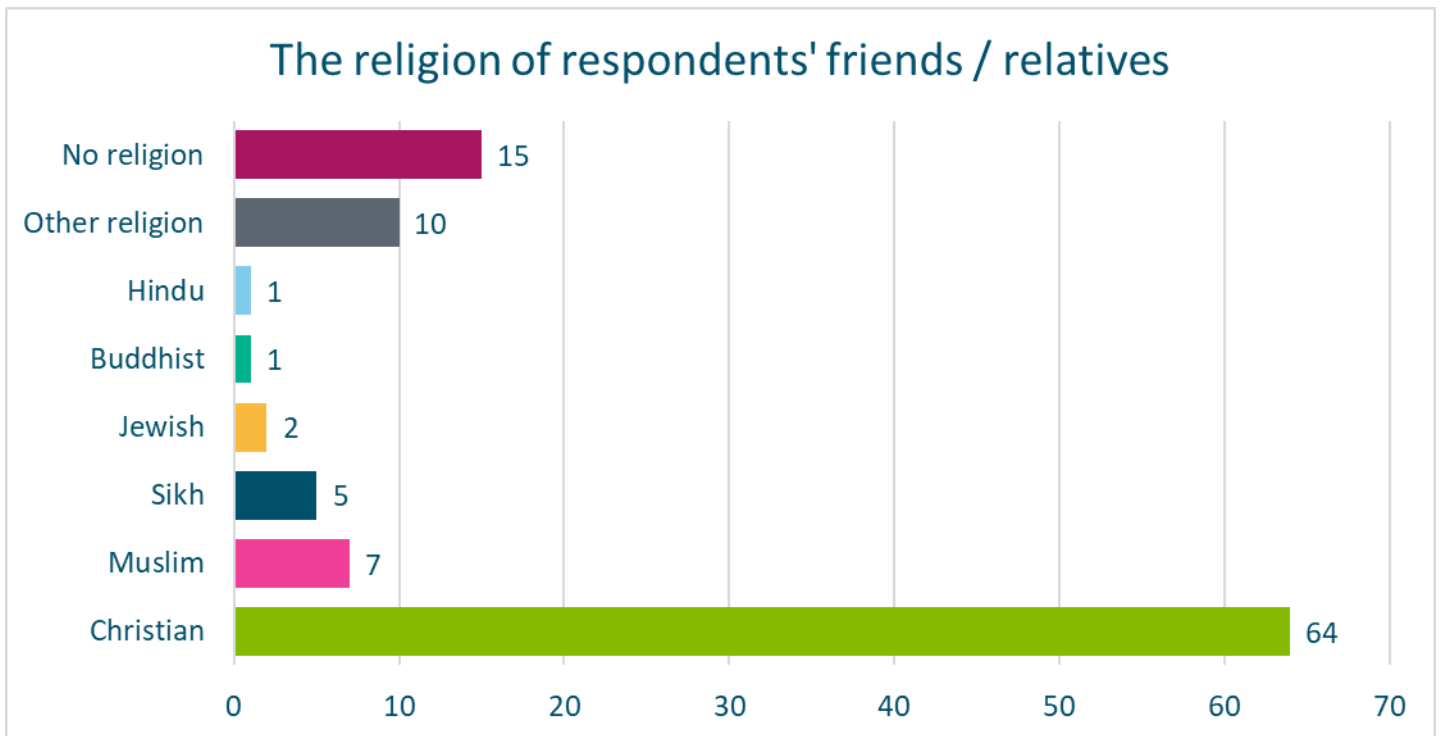
In most cases, our respondents' deceased friend / relative was aged 65 or over.



Most of our respondents told us about a friend / relative who was White British.



Most respondents told us about a friend / relative who was Christian.

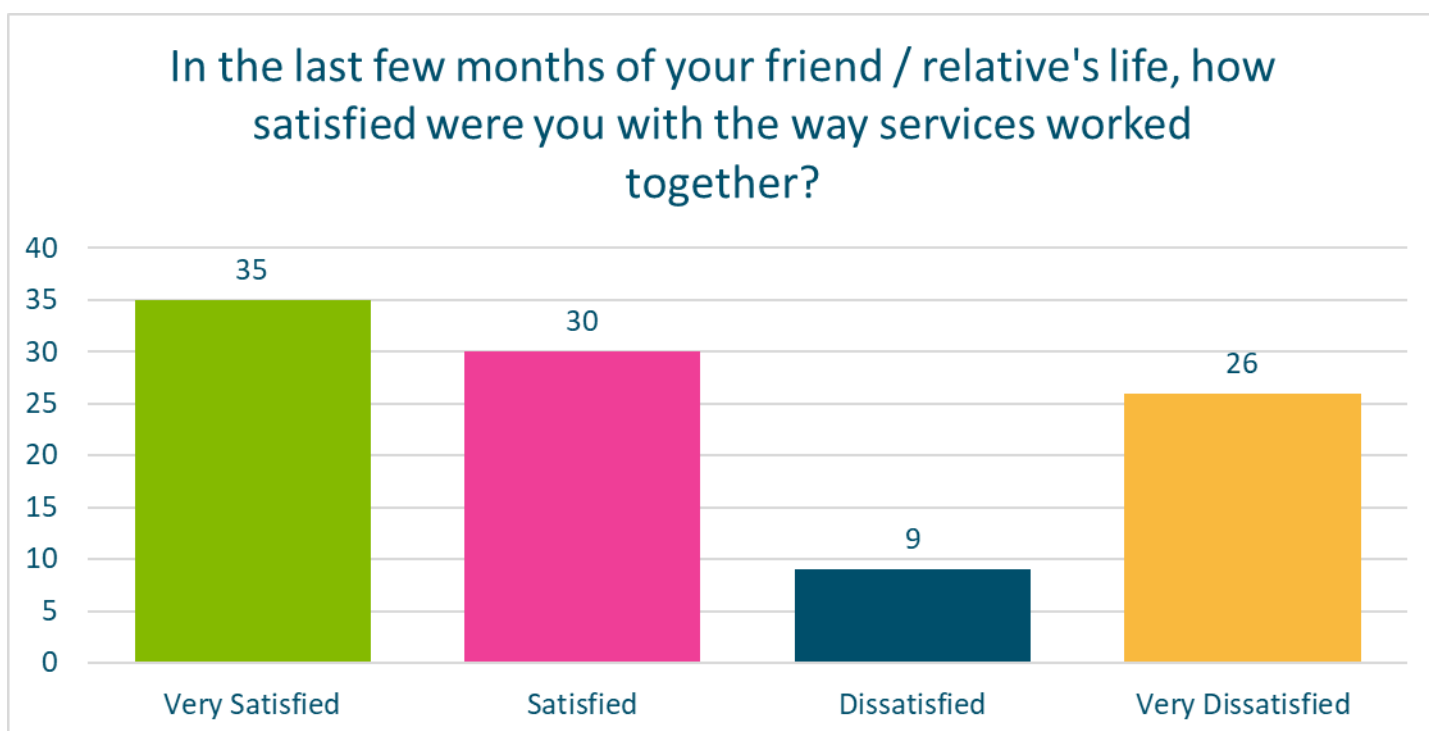


In the case where respondents had other religions, respondents indicated that they were Methodist, Roman Catholic, agnostic, Morman, Baptist, Jehovah's Witness, or humanist.

Citywide questions

Two questions in the survey asked people about their friend / relative's experiences in the last months of their life. The results for these questions across all services are given below; they are also given in more detail in the service-by-service sections of the report.

Of the 100 people who answered the following question, 65% were satisfied or very satisfied with the way services worked together during the last weeks and months of their friend or relative's life.



Of the 91 people who answered the following question, 66% had the chance to discuss their friend or relative's wishes for their care.

In the last few months of your friend / relative's life, did you or they have the opportunity to discuss their wishes about care and treatment?



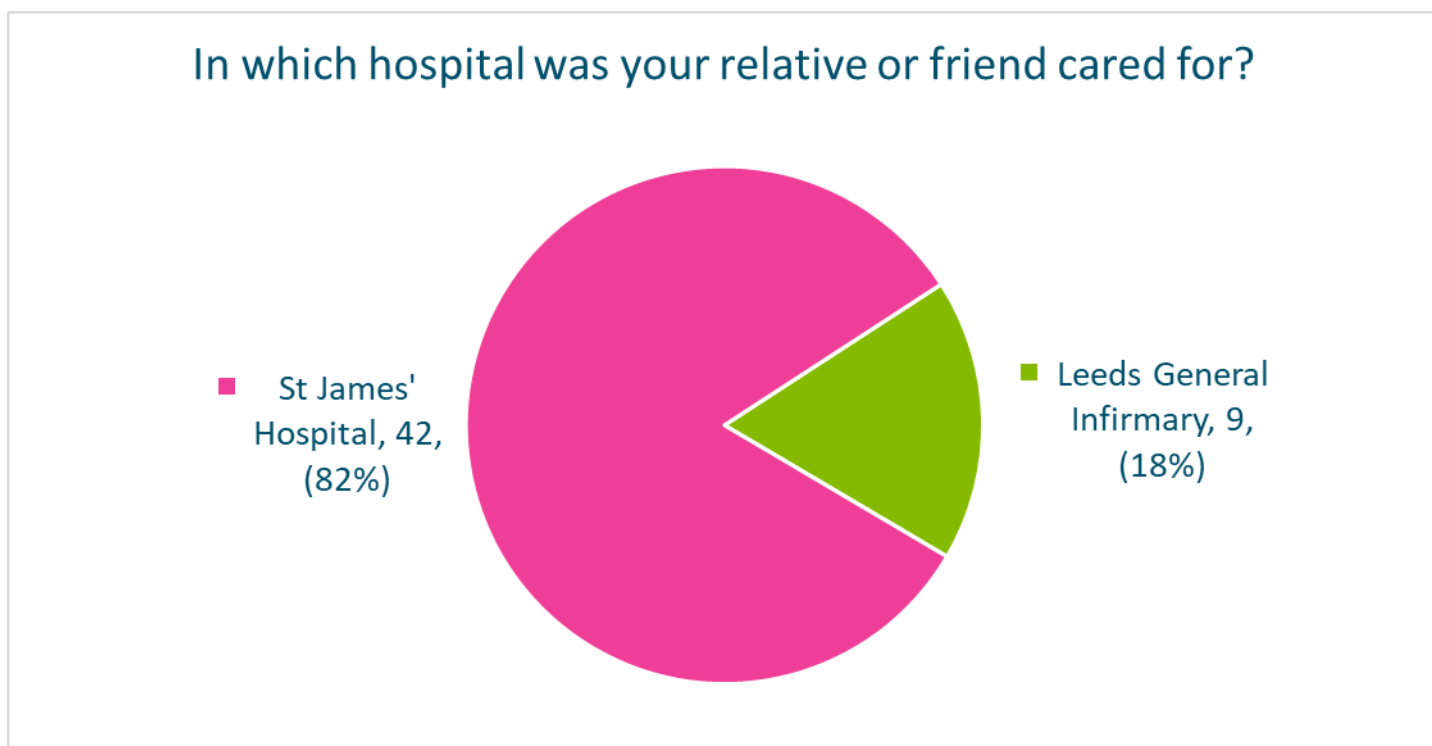
Reflections from partners

Based on the findings above, the Bereaved Carers working group partners have agreed the following recommendations:

- Use citywide forums to widely disseminate findings of this report.
- Providers to consider ways they can continue improving how they work collaboratively.

People who died in hospital

In total, we got 51 responses from people whose relative/friend was cared for in hospital. Of these, the majority – 42 people - had been cared for in St James' Hospital. 9 were cared for at Leeds General Infirmary.



Respondents also indicated on which ward their friend or relative was cared for. For a list of wards, please refer to Appendix 3.

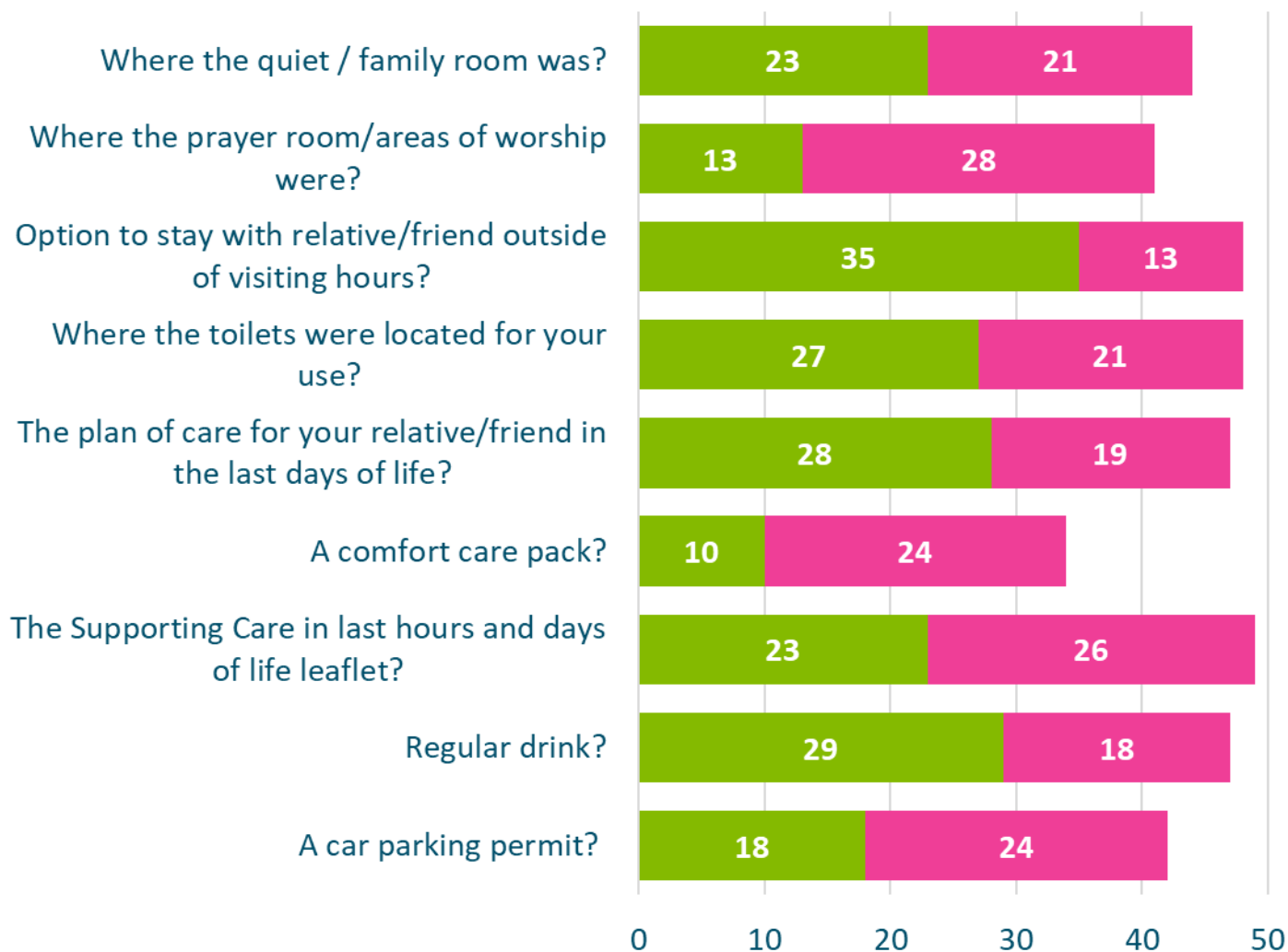
Practical support and information

We asked people what kind of practical support and information they had received in the last weeks and days of their friend / relative's life.

Their responses were as follows. Please note that the graphic below excludes responses where the person indicated the question wasn't relevant to them.

Were you offered information or told about the following?

■ Yes ■ No



Specific aspects of care

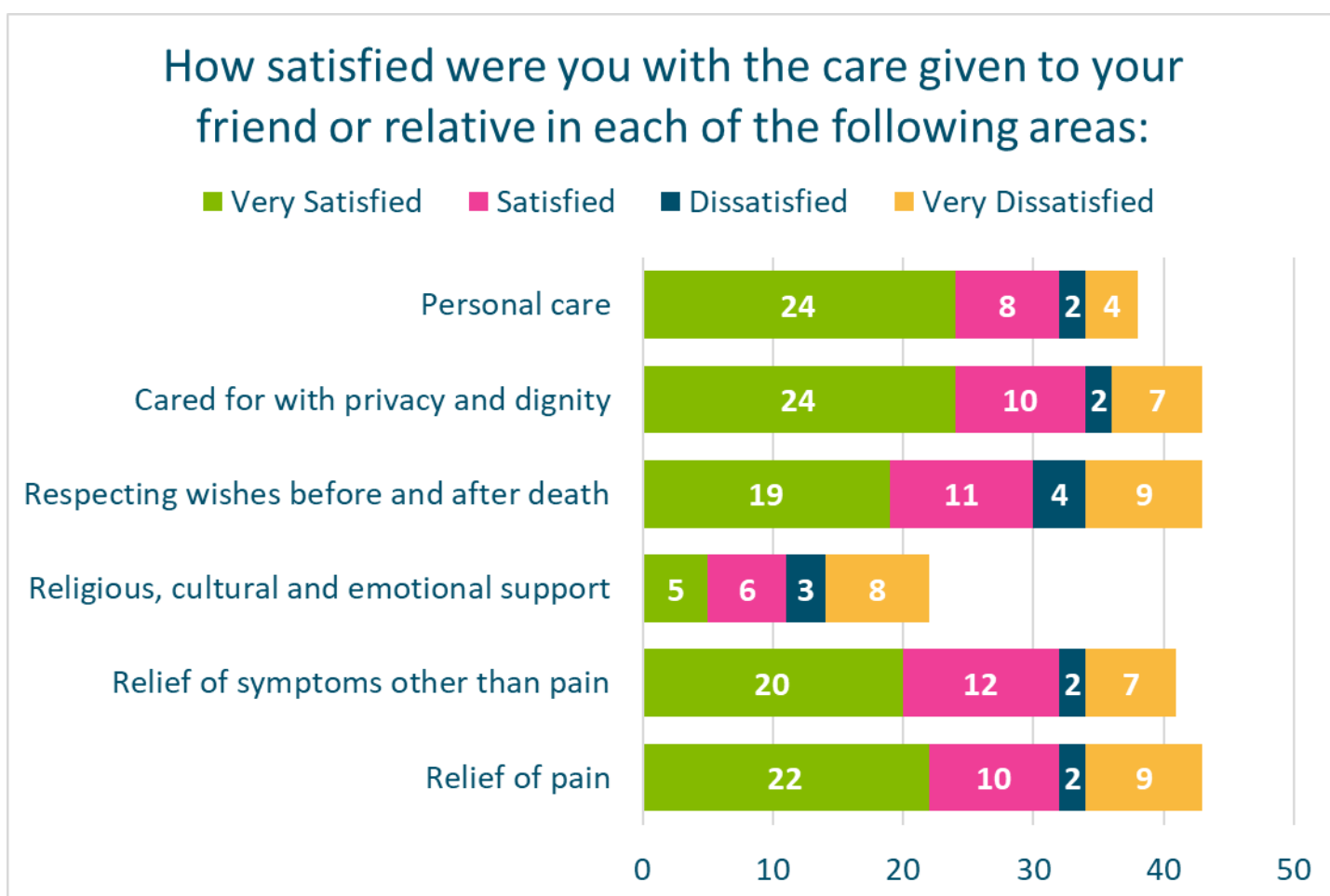
We asked the respondents to rate their level of satisfaction with specific aspects of their friend / relative's care.

Overall there were high levels of satisfaction with most of the areas of care. The highest levels of satisfaction were for personal care provided to their friend or relative, as 84% of respondents were very satisfied or satisfied with this. In the other areas of care as listed in the graph below, between 74% and 79% of respondents were very satisfied or satisfied. The only area with a very low satisfaction rating of 50% was

religious and cultural support, however only 22 of the respondents rated their satisfaction levels with this question.

The numbers of people saying they were dissatisfied or very dissatisfied with an area of care ranged from 16% for personal care, to 30% for respecting wishes.

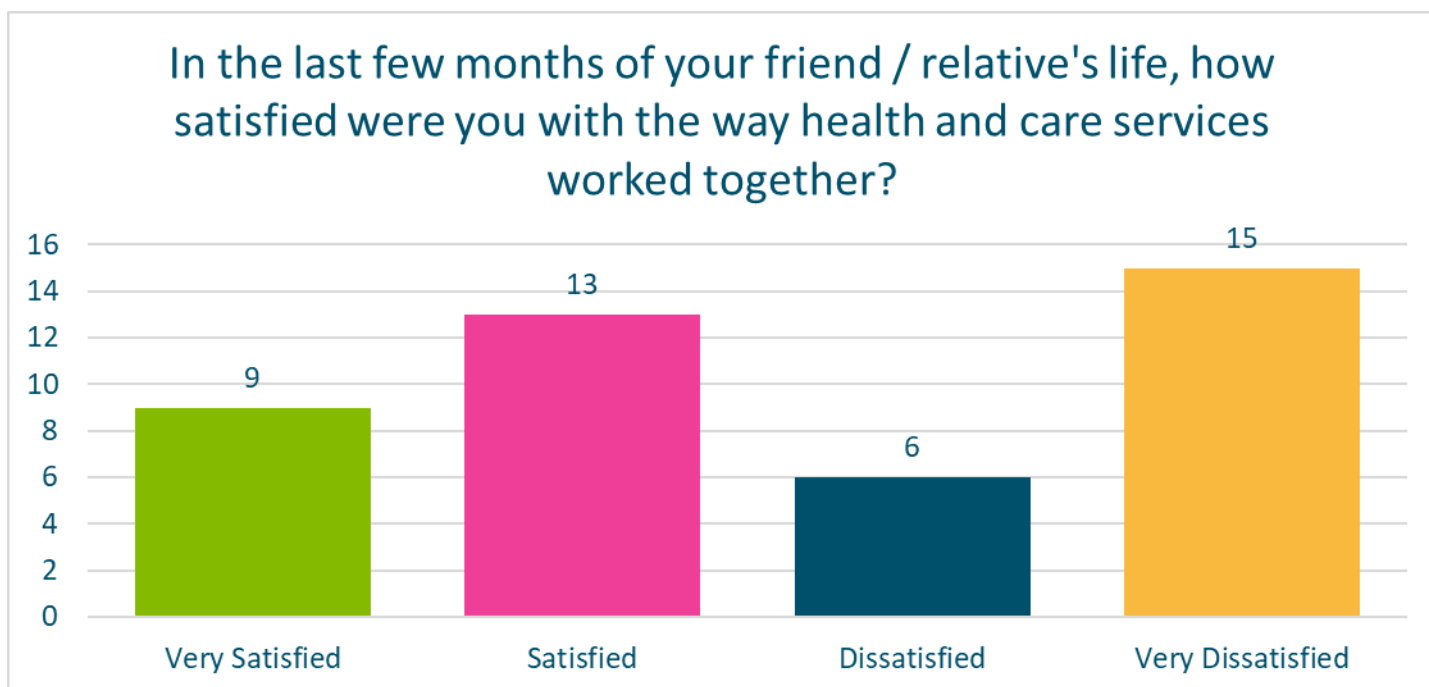
Please note that the graphic below excludes responses where the person indicated the question wasn't relevant to them.



Services working together

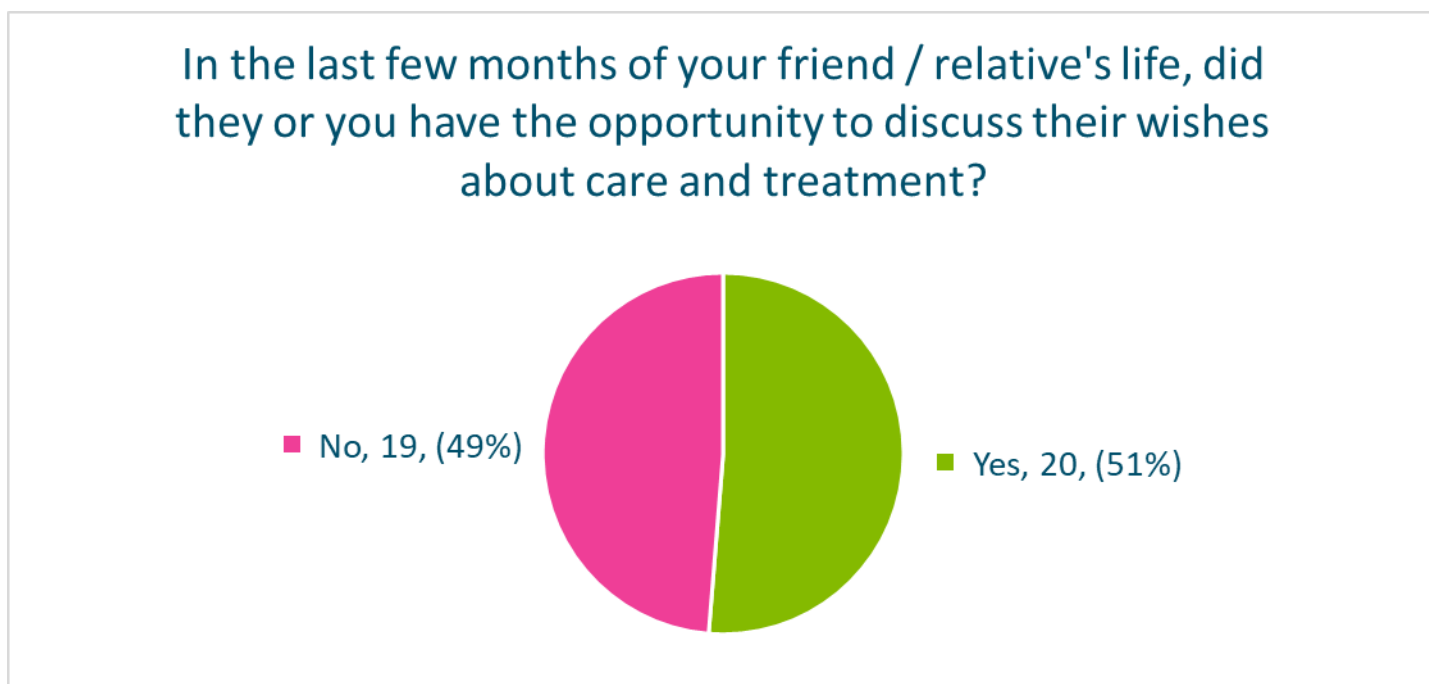
We asked respondents how satisfied they were with how health and care services worked together in the last few months of their relative or friend's life. 51% of the 43 people who answered this question said they

were satisfied with the way health and care services had worked together.



Discussing wishes and being involved

Just over half of the respondents had the opportunity to discuss their relative or friend's wishes about care and treatment. It is important to note that these questions may cover multiple services and have been reported on as city wide response earlier in the report.



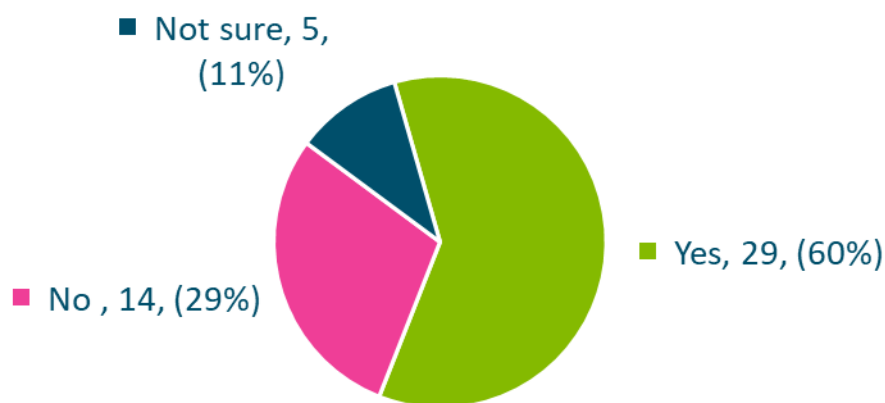
Just over half said they had been sufficiently involved in their friend / relative's care.

Do you feel that you or your relative / friend were as involved in the care as you or they would have wanted to be?



Dying in the right place

Did you feel that your friend / relative died in the right place?



29 respondents said they believed their friend / relative had died in the right place.

14 people told us that they believed hospital hadn't been the right place for their relative or friend to die.

Of these 14 people, all said they hadn't been as involved in their friend / relative's care as they would have wanted. 4 said they had had the chance to discuss their friend / relative's wishes before their death.

All 14 were dissatisfied or very dissatisfied with the way services had worked together.

What worked well and what could have worked better?

41 respondents commented on what the hospital had done well when caring for their friend / relative at the end of their life, and 39 commented on what the hospital could have done better.

23 of the 41 respondents who commented on what went well referred to the compassion, kindness and respect staff had shown them and their friend / relative.



“The 3 palliative care nurses were so kind to us during our Mum's last days and hours. They supported us really well and answered all our questions in a gentle but accurate way.”

“The hospital asked if there were any close relatives who would like to visit which I thought was very kind and respectful.”

“The hospital doctors and nurses were great [...] They were very caring, and this was what we found most impressive.”

“The staff were considerate, thoughtful caring and friendly. Thank you to all the amazing staff for the kindness and respect towards my father and making his last few days comfortable.”

“Dad had dementia, so he did not understand what was happening and why things were done, and he was at times slightly aggressive, and the staff dealt with it so calmly.”



8 of the 41 respondents said that the way staff kept in touch with them about their friend / relative had been a positive part of their experience.



“The palliative care team spoke to us daily and their recommendations were followed in full.”

“The doctors spent a lot of time on the phone explaining [my relative’s] condition and treatment.

We felt they were very patient and considerate.”

“There was full disclosure from the 2 surgeons performing the procedure and subsequent events. The ITU consultant gave a thorough and honest outlook of the possibilities to come so that we could make an informed decision and choose quality of life rather than prolonging a life which had no possibility of recovery.”

“It was quite difficult as I live far away and don't drive but the staff were great and kept me updated all the time. I couldn't have asked for anything more. I struggled to look after him before he went to hospital and the hospital staff did an excellent job at doing this.”



Of the 39 people who told us what could have been better, 11 commented that they would have liked the hospital to keep them better informed about their friend / relative.



“Prior to being end of life, communication with the medical staff was poor. Patients’ [relative] spent 2 days trying to talk to someone and phone calls were not returned.”

“I wish that I had been told a little earlier that my father was end of his life. I rushed to the hospital only to be told he had just passed away.”

“We were constantly told he was not dying. They used the actual words, 'he is not dying'. So, to receive a phone call at 11:10pm telling us he had passed away has been very traumatic. We were denied the right to see him, and have our final moments with him, and he was denied the ability to die surrounded by people who cared about him.”



9 people told us that restrictions on visiting had made their and their friend / relative’s experience harder.



“Covid restrictions were the biggest obstacles but to not allow a visitor or visitors was inhumane. We had all recently had covid, so we were not putting mum or staff at risk, and she was so frightened.”

“I had asked to be present at several times [...] and was told that COVID would not make this possible. As someone who is fully vaccinated and performing regular lateral flow, I feel this was a missed opportunity to provide a wonderful old lady the support that she desperately wanted/needed.”



6 people said that the staff could have been more compassionate and respectful.

14 people offered no information about what could have been done better.

Reflections from partners

“The survey responses and comments show much of the care provided was considerate, kind and respectful, however, there were some experiences where the care was not up to this high standard. Involving relatives and friends and allowing visiting were areas for improvement. We recognise that the COVID-19 restrictions in place at the time may have had a significant impact on communication with families.”

Recommendations from partners

“Embed the [SUPPORT Campaign](#) for relatives of dying patients. This includes the offer of car parking permits, comfort care packs, toilet/shower facilities, family/prayer rooms, information and updates about care and out of hours visiting.

Reinforce the importance of keeping families up to date about changes in condition/plan of care and the importance of delivering compassionate care at all times within all our education sessions.

Share the survey results with colleagues in LTHT”

People who died at home

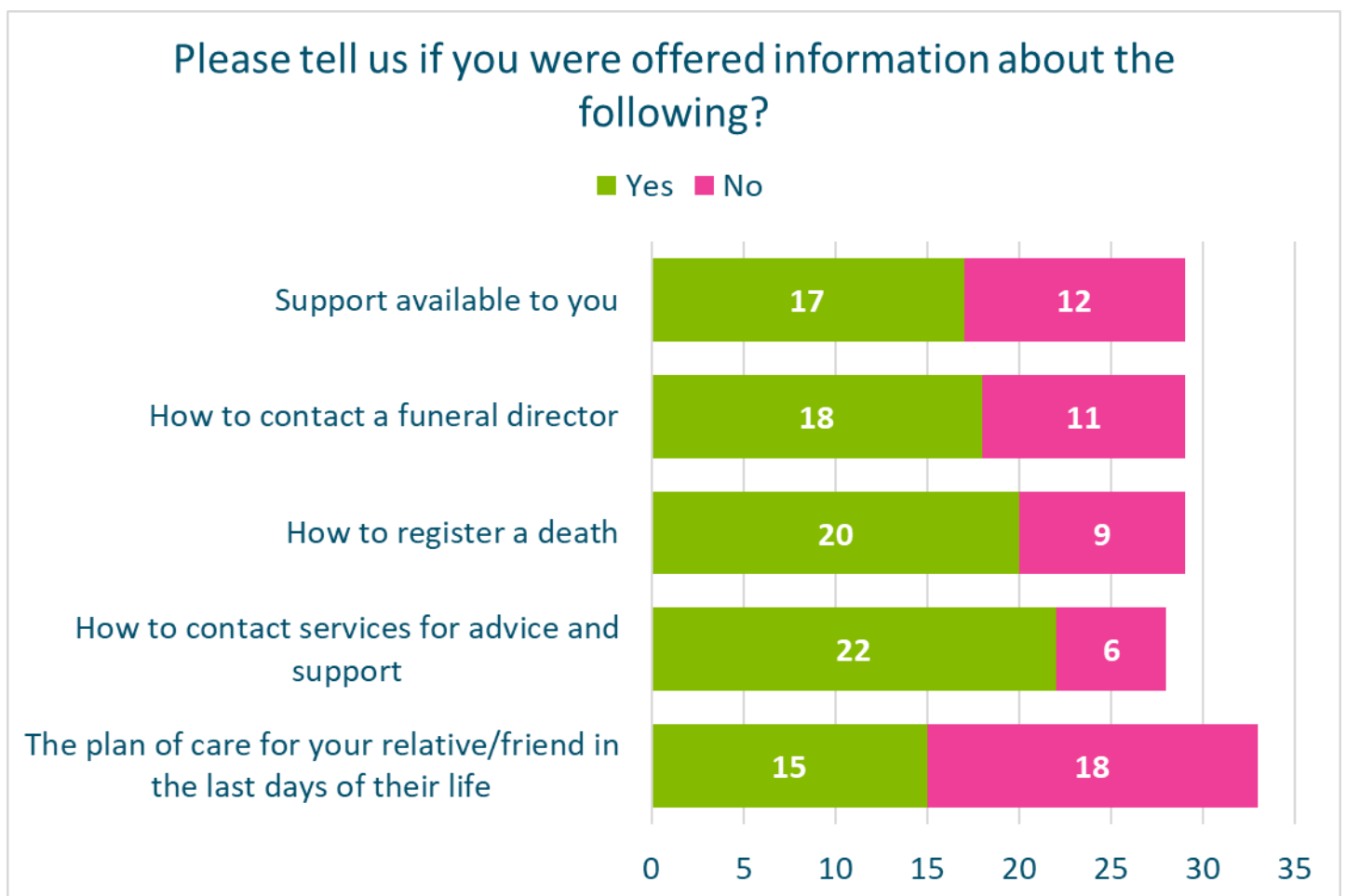
About our respondents

33 people whose friend / relative died at home responded to our survey.

Their friends / relatives were registered with a variety of GP practices (for a full list, please refer to Appendix 2).

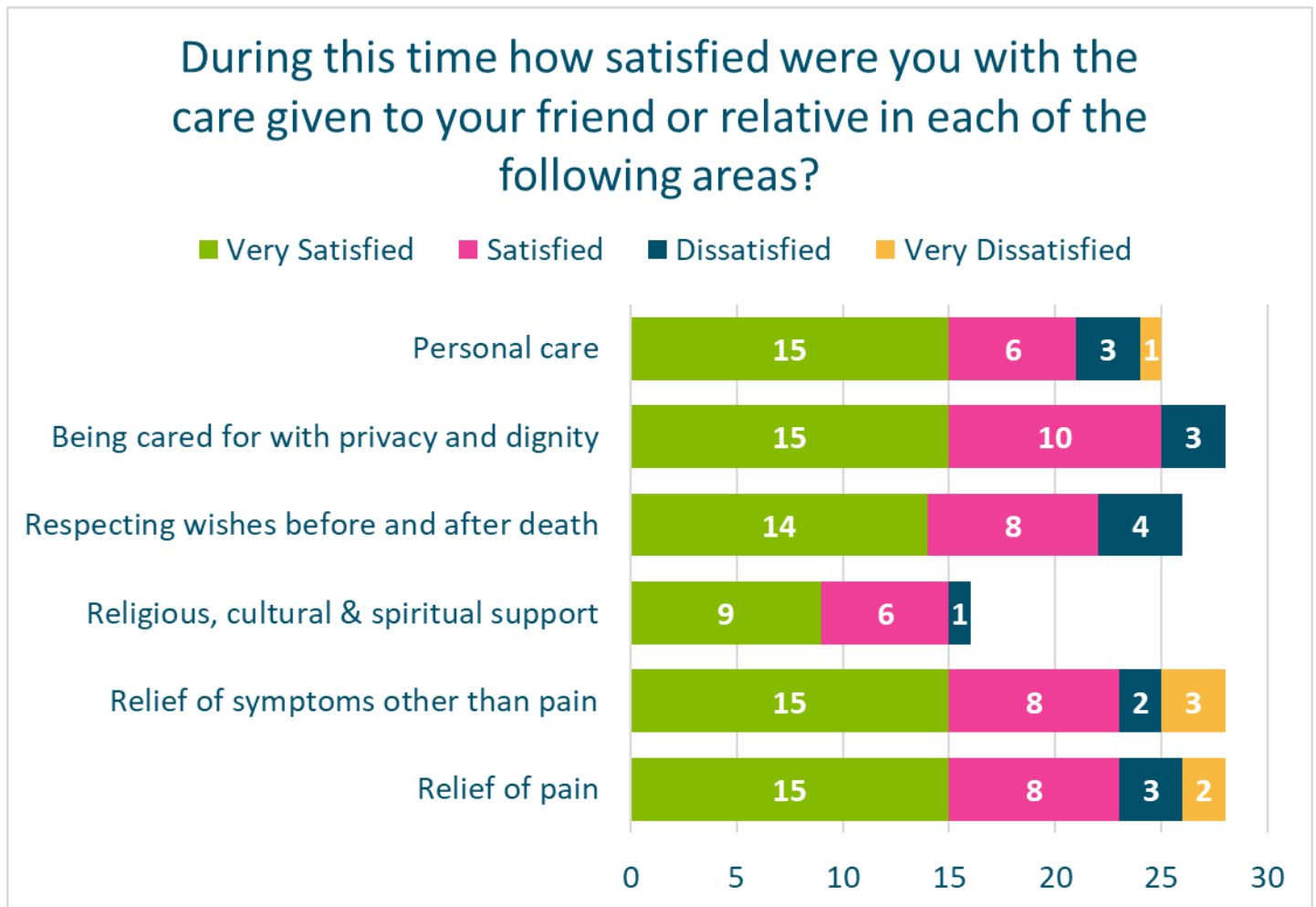
Practical support and information

We asked the respondents about the information they had been provided by services. With the exception of the plan of care, in most cases, most respondents said they had received the relevant information. Please note that the graphic below excludes responses where the respondent indicated the question wasn't relevant to them.



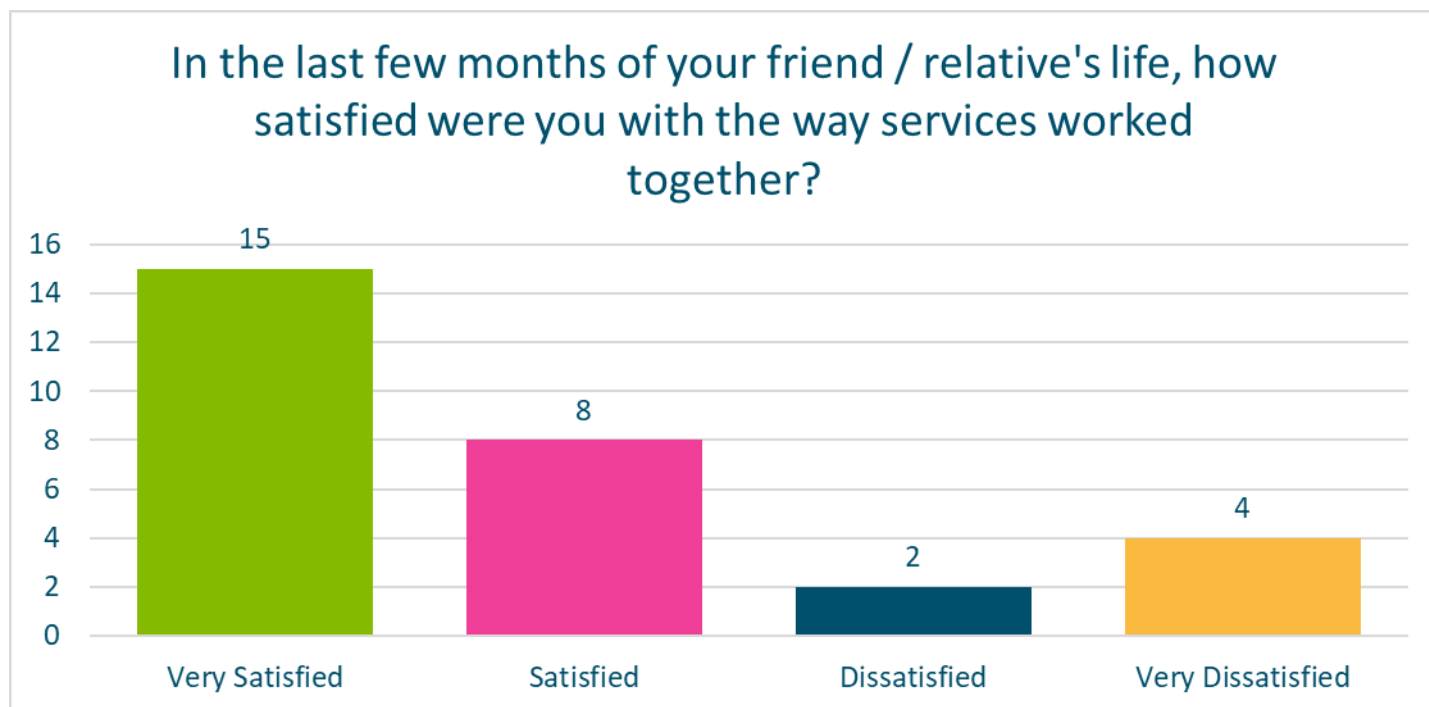
Specific aspects of care

We asked the respondents about specific aspects of their friend / relative's care. In all cases, respondents indicated they were satisfied or very satisfied with the care provided. The following chart excludes responses where the respondent indicated the question wasn't relevant, or that they were unsure or couldn't remember.



Services working together

Most people were satisfied with the way services worked together in the last weeks and months of their friend / relative's life.



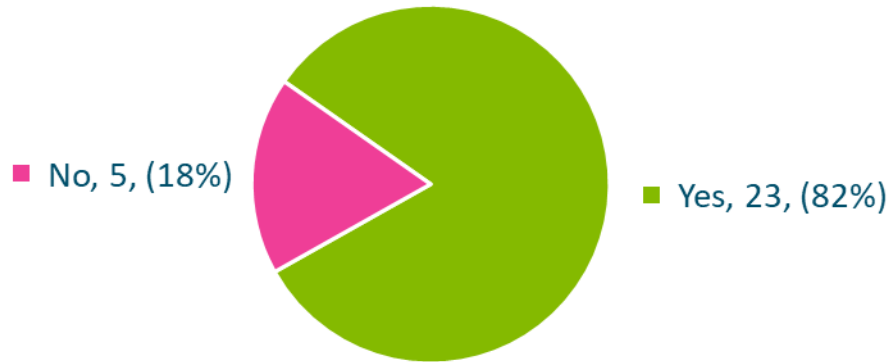
Discussing wishes and being involved

Most people said they or their friend / relative had the opportunity to discuss their wishes about care and treatment in the weeks and months before their death; just fewer than a quarter did not.



Most people felt they or their friend / relative were as involved in their care as they wanted to be.

Did you feel that you or your relative / friend were as involved in the care as you or they would have wanted?



Dying in the right place

30 people told us whether they thought their friend / relative had died in the right place. 93% told us they felt their friend or relative had.

Did you feel that your friend / relative died in the right place?



What worked well and what could have worked better?

25 respondents commented on what worked well for their friend / relative when they were in the last stages of their life at home, and 26 commented on what could have been done better.

9 of the 25 respondents who told us what went well referred to the kindness and compassion displayed by the staff.



“The staff were very kind, caring and compassionate, they also understood her needs. E.g., made hand gestures close by to let her know what they were going to do, this helped her cooperate with them as she was partially sighted. They went above and beyond with their caring duties.”

“Respectful, kind, compassion. Every service offered and made available offered and provided without any prompting from family. We could not have been more supported to assist us in helping keep and care for mum at home, within our family. Our health and needs were also a priority to all who visited and supported us. Wonderful care and service up until the very end. Thank you”



Of the 25 respondents who told us about positive aspects of their experience, 6 volunteered that the way staff kept in touch with family had made a difference.



“We had a dedicated GP from the surgery who visited my mother-in-law once a week, even if it was for 5 minutes. If he was unable to come, he would have a conversation over the phone to ask how she was doing and if we needed any support.”

“The neighbourhood team were very caring and compassionate. They were just a phone call away and advised appropriately.”



6 praised services' organisation and efficiency.



“Prompt and timely intervention initiated by GP the contact made by district nurses. Provision of nursery equipment (bed, slide sheet, mattress), equipment services communicated well. Professional and timely provision of pain relief (day services).”

“The surgery had quickly arranged for help from the end-of-life care team. We had a dedicated GP from the surgery who visited my mother-in-law once a week, even if it was for 5 minutes.”



5 identified the way the dying person's wishes were respected as a positive part of the experience.



“[You listened] to dads wishes and did your best to make sure he had what he needed”

“My mum out of her own choice did not want to share everything about her current status with us as she was worried that we would be concerned, sad/upset. The team respected her wishes and choices but also encouraged her to share her thoughts and feelings with us.”



Of the 26 people who told us what had not worked so well, 6 suggested that communications between services and family members could have been better. They said that they wanted more information about what to expect in terms of the progression of their

friend / relative's illness, but also the practicalities of how the service would work.



“Anticipated progress of disease and what to expect needed to be discussed much earlier- despite complaining of pain and tiredness my mother was not told that this was part of disease progression. We were not told of the restlessness at the end, and

this resulted in a traumatic fall and paramedic call out. Slow communication from palliative care to District nurses meant we were left to chase up end of life drugs and to explain over and over to district nursing teams what was going on as palliative care notes had not been entered and referral not been made”

“Our mum was given a morphine driver on the night of her death. [...] the carer with our mum at the time of death, woke me up and asked me to come downstairs. She did not warn me what to expect [i.e.: that mother had already died].”

“The whole process of end-of-life care and what that involves could have been explained better. What to expect and what support could be in place”

“More information about what to expect in the last few days/hours of death. We were not prepared for what happened. My dad was very confused and didn't understand why he might be more comfortable in the hospice. When he finally deteriorated it was very rapid, the palliative team were slow to put him on an infusion and I believe he was in pain throughout the entire morning while he lay dying. When he finally did get put on a drip pump the nurse

did not tell us he was so close to dying. He died within an hour. My brother had gone out and I came up to find him dead. It was a terrible shock. I think it would have been managed much better at the hospice and less distressing for us.”



4 people said that their friend / relative's experience would have been improved if the intervention had been earlier.



“I think the palliative care should have started when the doctor said so in March, but it didn't happen till June. It was a difficult time because of covid, and the doctor was retiring so this might

be where there was a delay.”



8 people didn't indicate anything that could be improved.

Reflections from partners

“The survey responses and comments show the majority of carers were satisfied with the overall care provided at the end of life, however highlights potential areas for improvement. At this time there was a significant increase in people choosing to die at home and it is reassuring that despite the increased pressure on services almost all respondents felt their loved one had died in the right place.

The survey findings and comments highlight the kindness and compassion of staff and how much patients and families value GP involvement in end of life care. Comments also reinforce the importance of care that is personalised and reflects a person's wishes.

Overall the responses suggest communication as an underlying theme for improvement. In contrast to previous years, less than half of carers felt the plan of care in the last days of life had been discussed and some responses

suggest the provision of information about available support and what to expect at home could have been improved.”

Recommendations from partners

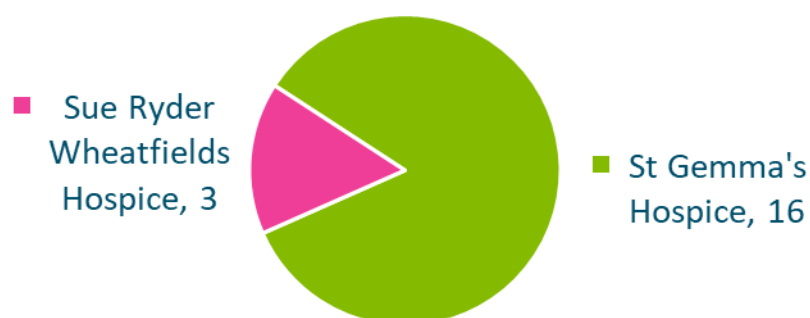
- “Share the positive feedback about the care and compassion shown to patients and carers by staff
- Share feedback with GP practices about the value of early recognition of end of life care needs and continuity of GP care and support especially in the last few weeks of life.
- Improve communication about the plan of care in terms of available support, what to expect and the use of medicines in managing common symptoms at end of life
- Promote use of the information leaflet Care in the Last Days of Life which has been adapted for use across community settings
- Improve the provision of information about care and what to do after death, including use of the leaflet When Someone Dies which has been adapted for use across community settings.”

People who died in a hospice

About our respondents

We received 19 responses from people whose friend / relative died in a hospice; most referred to St Gemma's Hospice.

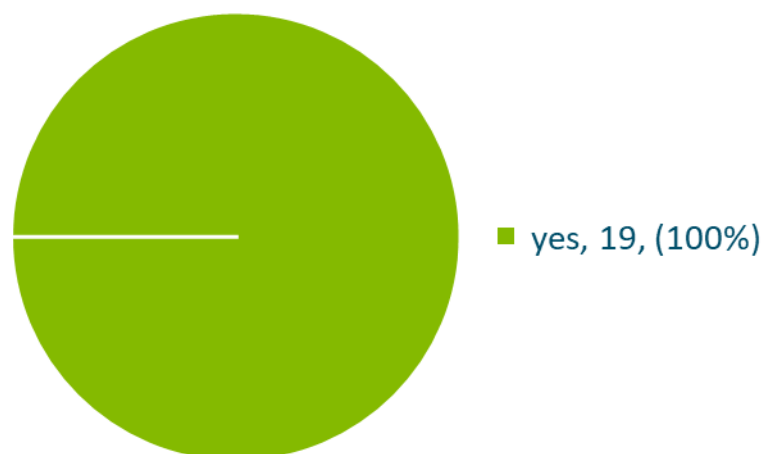
In which hospice was your friend / relative cared for?



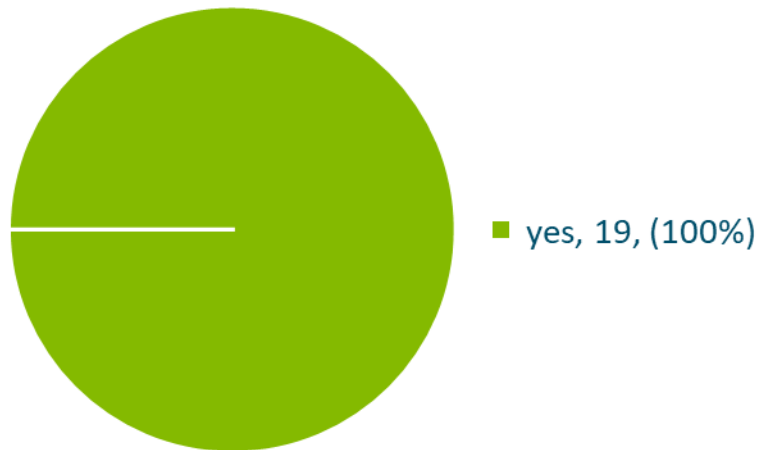
Practical support and information

We asked the respondents about their experience of the staff working in the hospice. Their responses were unanimously positive.

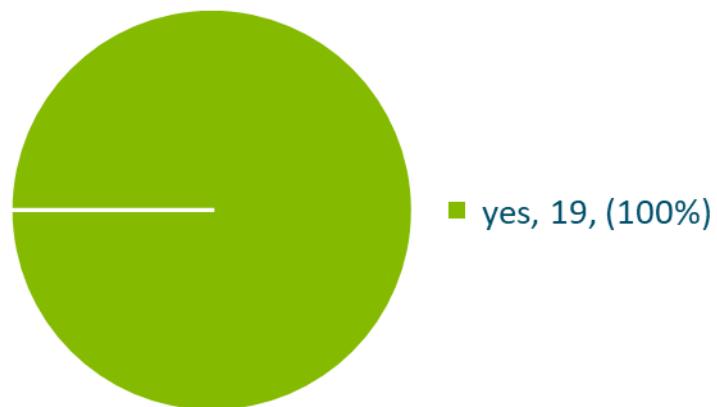
Were staff professional?



Did the staff make time for you?



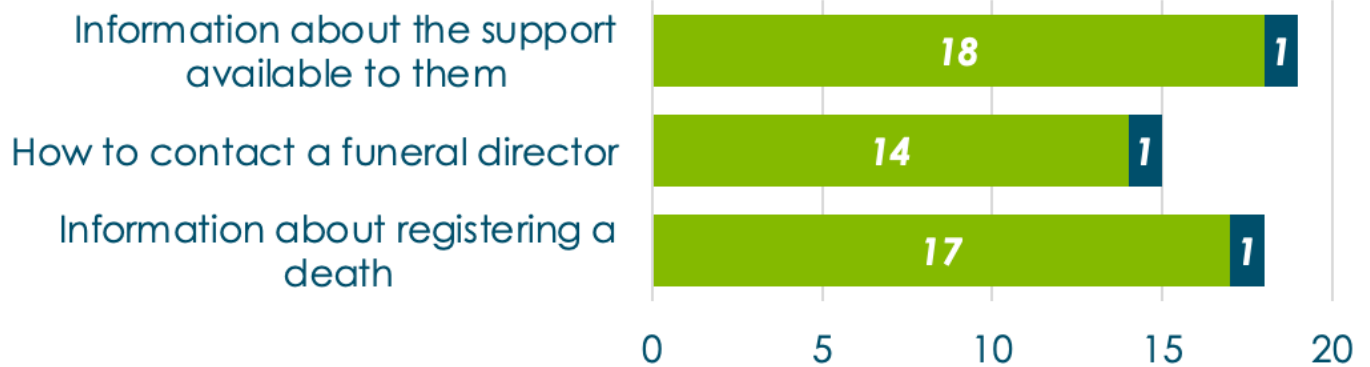
Did staff give you the opportunity to ask questions and raise concerns?



We also asked the respondents about what information they had received from the hospice. In the vast majority of cases, people had received the relevant information.

Did the hospice provide the following?

■ yes ■ no ■ unsure

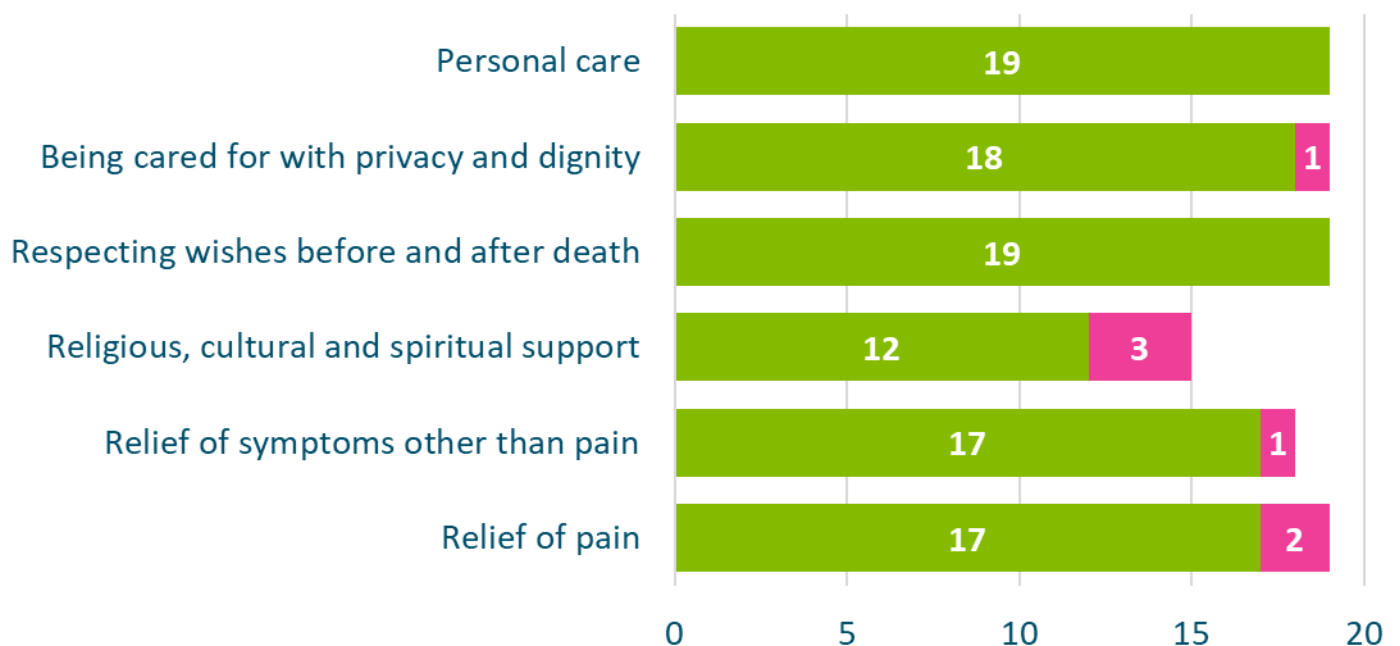


Specific aspects of care

We asked the respondents how they felt about specific aspects of their friend / relative's care. In every case, the respondents said they were either satisfied or very satisfied.

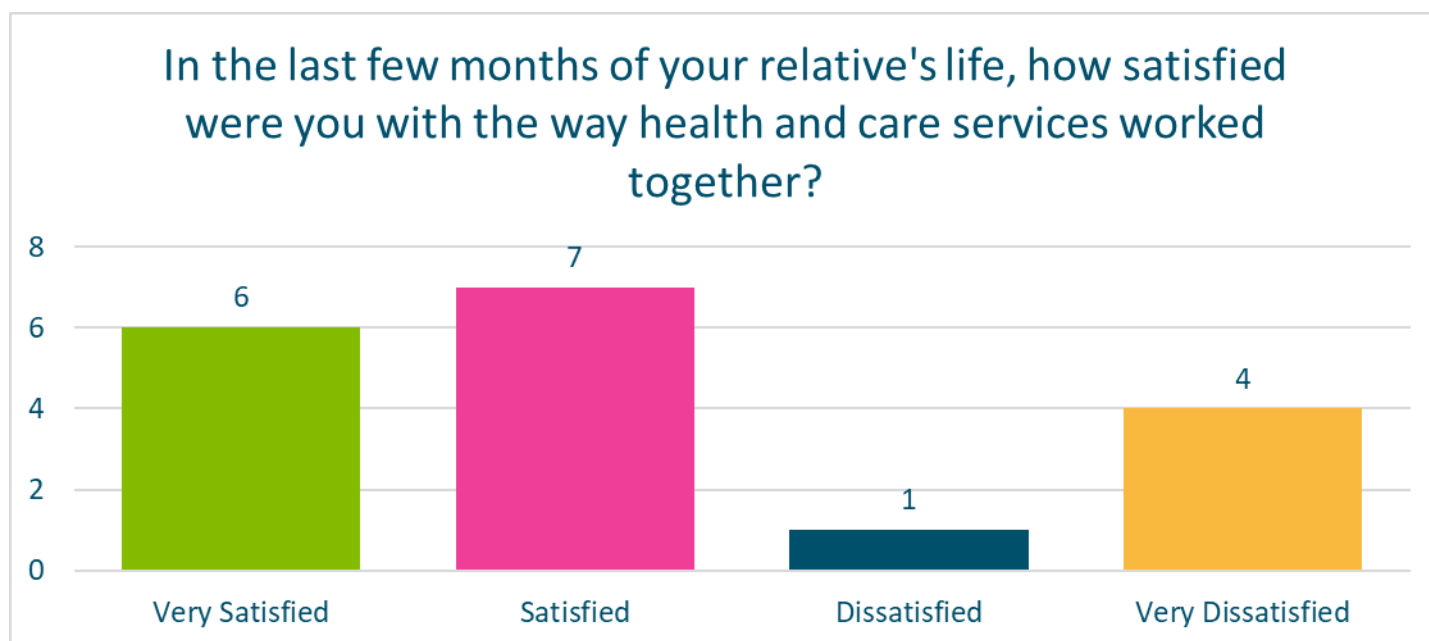
During this time how satisfied were you with the care given to your friend or relative in each of the following areas?

■ Very Satisfied ■ Satisfied ■ Dissatisfied ■ Very Dissatisfied



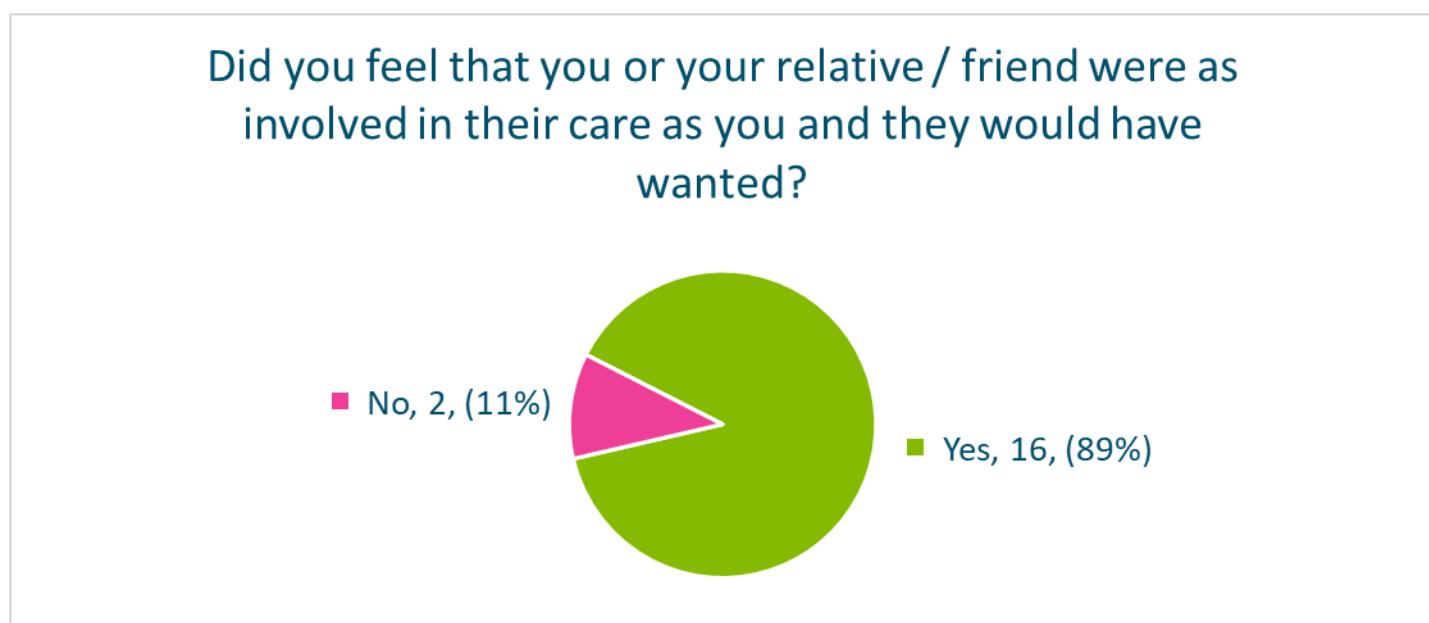
Services working together

We asked the respondents how satisfied they were with the way services worked together. Most people were satisfied or very satisfied, but it is worth noting that we received higher levels of dissatisfaction (28%) for this question compared with other questions.



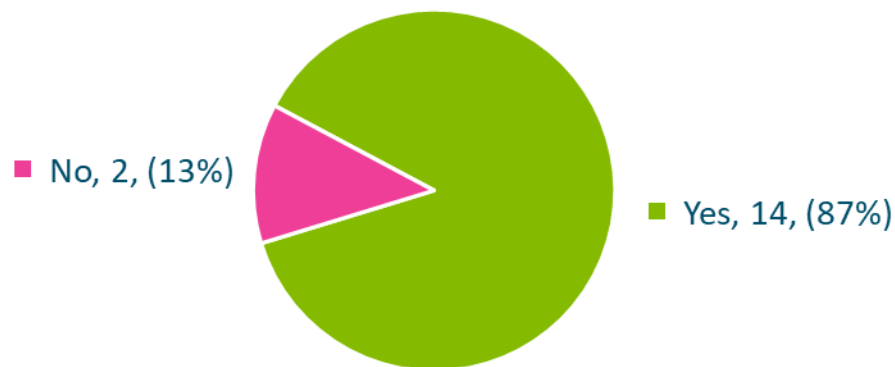
Discussing wishes and being involved

Most people felt they and their friend / relative had had as much input into their care as they wanted.



Most people had the opportunity to talk about their friend / relative's wishes for their care and treatment.

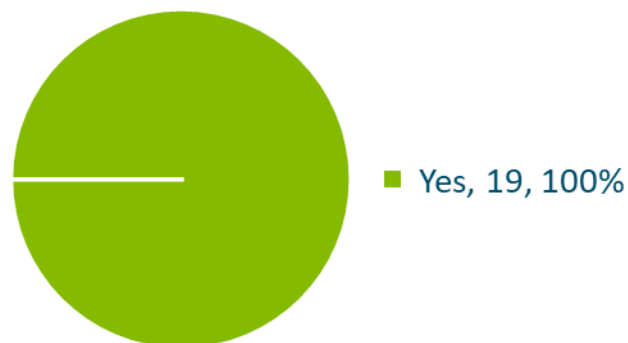
In the last few months of your friend / relative's life, did you or they have the chance to discuss their wishes?



Dying in the right place

All 19 people said they felt their friend / relative had died in the right place.

Did you feel that your friend / relative died in the right place?



What worked well and what could have worked better?

18 respondents commented on what the hospice had done well when caring for their friend / relative at the end of their life, and 15 commented on what the hospice could have done better.

12 of the 18 respondents who told us what went well credited the staff's caring attitude and professionalism.



“Your team treated him with respect and compassion but never patronised him or made him feel like he was a terminally ill and thus fragile. Dignity was always clearly very important all the way through his illness and continued in the initial moments after he'd passed away and beyond.”

“The total respect given even when my husband was unresponsive and after his death was a special comfort to me.”



Other aspects of the care people praised were the care and attention given to them as family members, and the access they were given to their friend / relative.



“St Gemma's were amazing, and I'm so pleased my dad was able to spend his final 5 weeks there, pain free, cared for and respected. I lived in his room for his last 12 days and the staff cared and looked me too. Can't praise them enough.”



12 of the 15 respondents who answered our question about what could have been better commented that nothing could have been improved. We received a couple of comments about how the care at other settings had not been satisfactory. We only received 1 comment about how hospices could improve their service:



“I appreciate how hard it is to shave someone who is unconscious, but [my relative’s] face was cut quite badly so perhaps some training in shaving patients would benefit your lovely staff.”



Reflections from partners

“It is good to see these positive comments and results from this year’s survey. Despite low response numbers in comparison with previous years, these findings are consistent with our internal feedback for patients and families.

The survey reflects high standards of personalisation of care, patients and their loved ones being involved in decision-making and high levels of satisfaction with pain and symptom management. Clearly, there are concerns about how the whole system works together around the patient, which is the focus of work happening this year across community palliative care services.

It is useful to understand the elements of care that require improvement which can provide a focus for education and training for the future.”

Recommendations from partners:

1. “Thank staff for the kindness and compassion they have shown families.
2. To review personal care competence for patients who require assistance with shaving and identify any further staff training needs.”

People who died in a care home

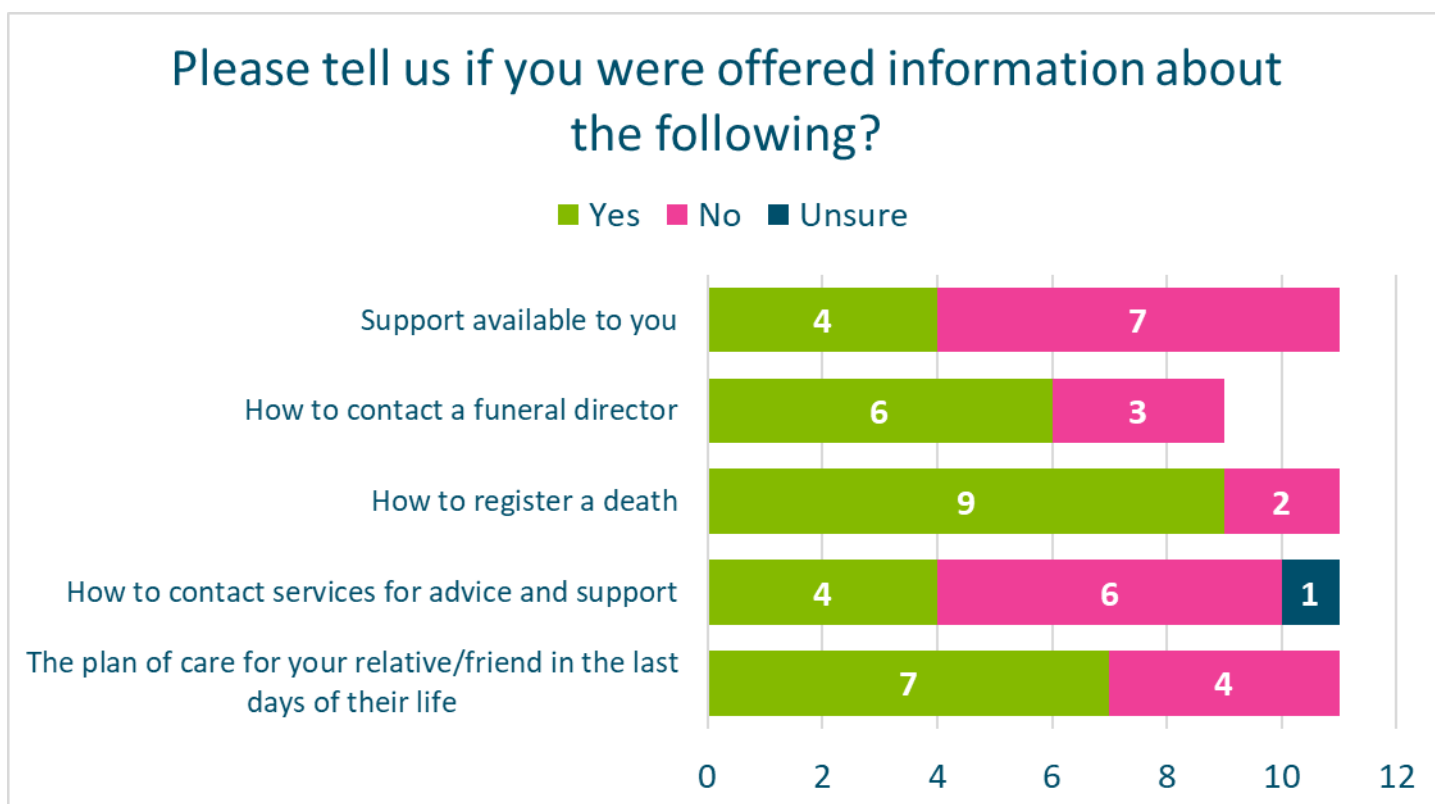
About our respondents

12 people whose friend / relative died in a care home responded to our survey. We received fewer responses about this than any other service.

Their friends / relatives had been registered with a variety of GP surgeries. For a list of these, please refer to Appendix 1.

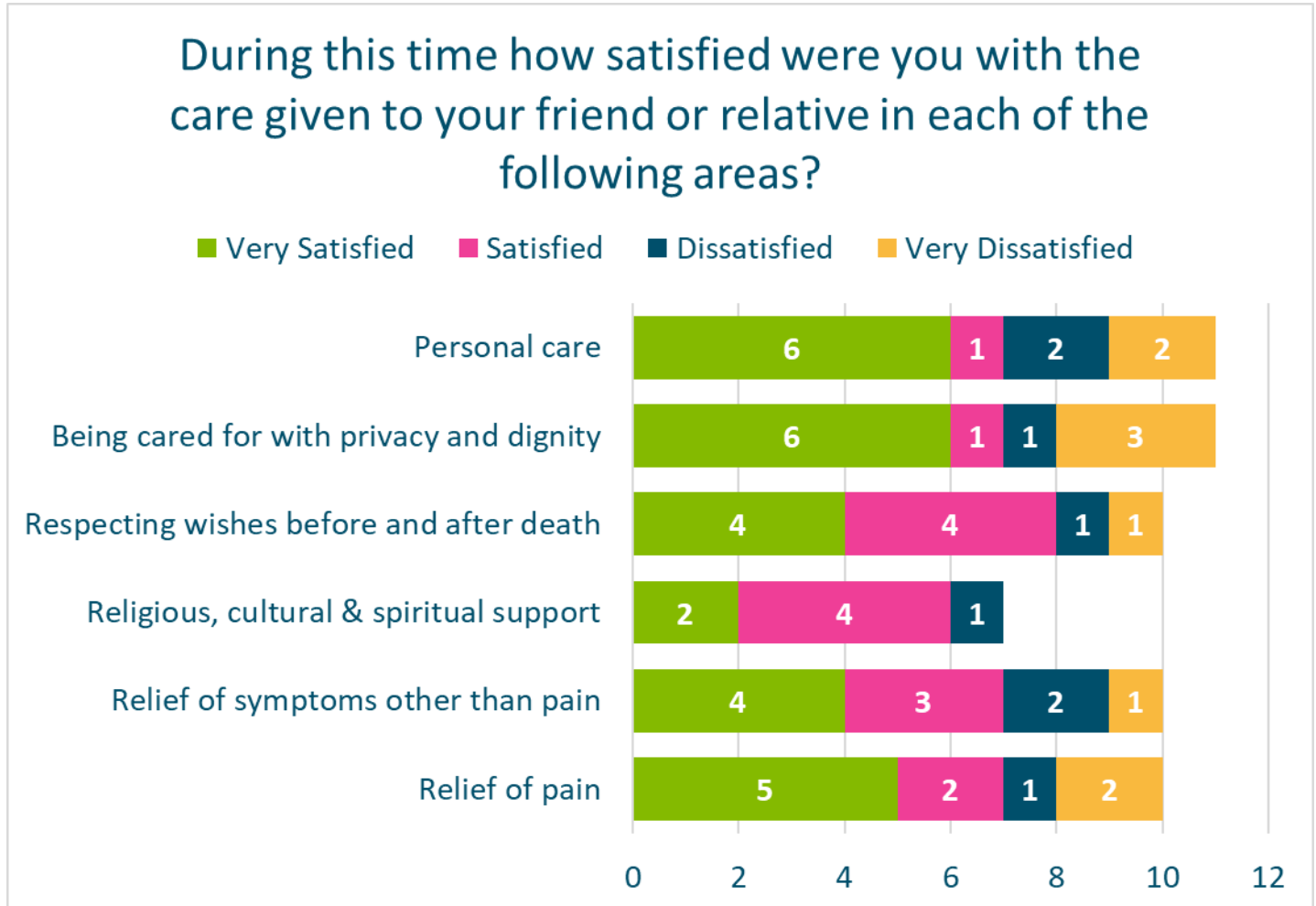
Practical support and information

We asked the respondents about the information they received from the service. In most cases, most respondents indicated that they had received the relevant information, the exceptions being information about support available to carers and information about how to contact services for support and advice.



Specific aspects of care

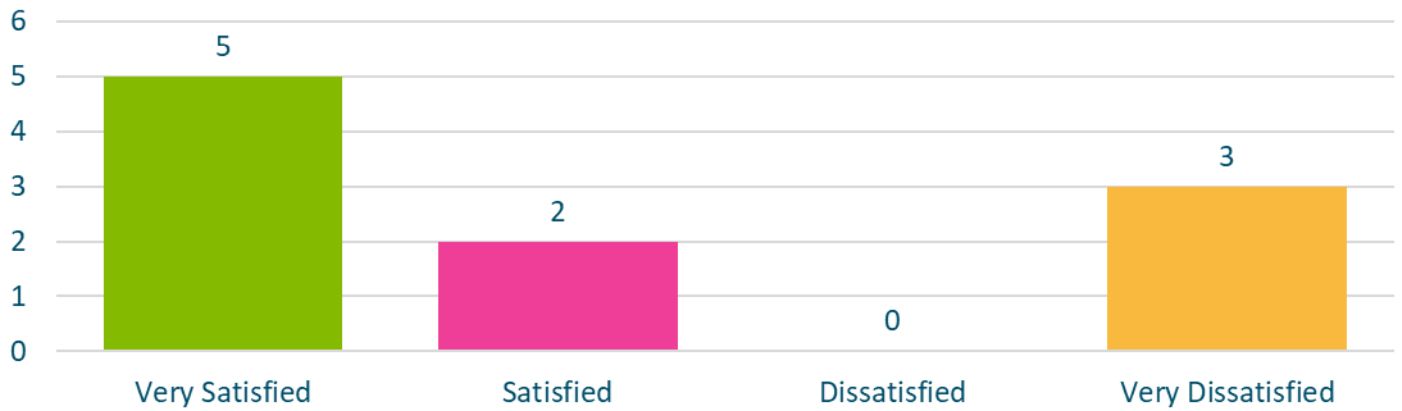
We asked respondents about how satisfied they were with specific aspects of their friend / relative's care. In each case, most respondents were satisfied or very satisfied.



Services working together

Most people said they were satisfied or very satisfied with the way services worked together in the last weeks or months of their friend / relative's life.

In the last few months of your friend / relative's life, how satisfied were you with the way services worked together?



Discussing wishes and being involved

Just over half of the respondents said they or their friend / relative had had the opportunity to discuss their friend / relative's wishes for their care and treatment in the last few months and weeks of their life.

In the last few months of your friend / relative's life, did you or they have the chance to discuss their wishes?



Just over half said they or their friend / relative were as involved in their care as they wanted to be in the last weeks and months of their life.

Did you feel that you or your relative / friend were as involved in their care as you or they would have liked?

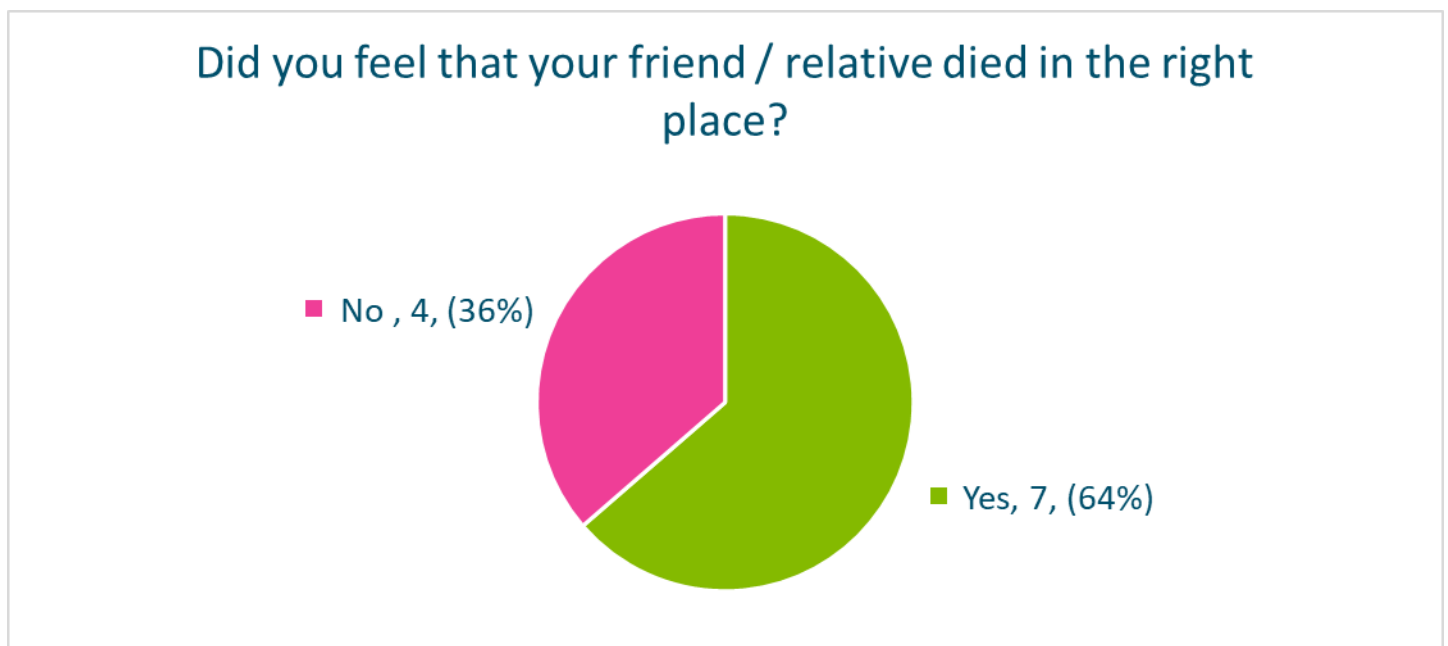


While the low response rate should be borne in mind, it may be worth noting that those respondents who said they hadn't had the opportunity to discuss their friend / relative's wishes also said they hadn't been as involved as they wanted. They were also likely to express dissatisfaction with specific areas of care:

- 3 out of 4 said they were dissatisfied or very dissatisfied with the respect and dignity shown to their friend / relative
- 3 out of 4 said they were dissatisfied or very dissatisfied with their friend / relative's personal care
- 3 out of 4 were very dissatisfied with the way services worked together.
- 3 out of the 4 also believed their friend / relative hadn't died in the right place.

Dying in the right place

7 out of the 11 people who commented said they felt their friend / relative had died in the right place.



What worked well and what could have worked better?

10 respondents told us what had worked well during their friend / relative's time in a care home, and 8 told us what could have been better.

Of the 10 respondents who told us what worked well, 5 praised the staff for their kindness and compassion. Some people felt that the way staff had kept in touch with them had been an aspect of their kind, caring attitude.



“[Care home] staff, from managers to caring staff to domestic helpers were friends to my mother from her arrival and she was prepared after leaving her own home and living independently until 90 years old without needing to have your help.”

“[Care home] were fantastic in caring for our aunt, they assured us that she would not be alone at the end if we could not be there.”

“We were kept informed by the home and the GP service especially as mum deteriorated - everyone involved was patient, kind and available to discuss what was happening and to answer any queries we had - we understand that covid has made everything so much more difficult but in spite of this we were never left wondering what was going on with mum - we're really grateful for that”



A further 2 people specifically praised the way the home had kept them informed as family members.



“Kept us informed of what was happening and the treatment being given - everyone involved was incredibly good.”

“I was contacted at the right time when she was actually dying, and they provided time and space in the room with her once she was gone.”



On the other hand, of the 8 people who shared what would have made their friend / relative's experience better, 2 talked about keeping family members better informed.



Making people more aware that she was dying..... no one actually said this was the case.”



2 people said that procedures after the person died could have been improved to make families' experiences better at a stressful time.



“The doctors practice were very slow issuing the cause of death, I had to chase them all the time. Said they didn't have the death cert from the coroner when they did, just didn't look.”

“Have a GP involved so we didn't get the delays with the coroner after she passed.”



3 people said nothing could have been done better for their friend / relative.

Reflections from services which support care homes

“The survey responses and comments suggest the majority of carers were satisfied with the overall care provided at the end of life. The number of responses was particularly low, compared to other settings, however some potential areas for improvement have been highlighted.”

Recommendations from partners:

1. “Based on the findings of this report, it is recommended that the findings are shared through citywide forums and services work with care homes to understand people's experience and identify where improvements could be made in the following areas:

Provision of information about:

- Who to contact for care and support
- Support available to carers

How services work together in the months before a person's death

Communication with families about:

- their loved one's wishes
- how these can be supported
- family involvement in their loved one's care.

2. Thank staff for the kindness and compassion they have shown families and reiterate how important this is to their experience of the service."

Summary of Recommendations

Below is a summary of the recommendations partners have set, based on the findings of this report. These recommendations will ultimately form the basis for an action plan, which will be publicly available [here](#).

Hospitals

Embed the [SUPPORT Campaign](#) for relatives of dying patients. This includes the offer of car parking permits, comfort care packs, toilet/shower facilities, family/prayer rooms, information and updates about care and out of hours visiting.

Reinforce the importance of keeping families up to date about changes in condition/plan of care and the importance of delivering compassionate care at all times within all our education sessions.

Share the survey results with colleagues in LTHT

Services at home

- Share the positive feedback about the care and compassion shown to patients and carers by staff
- Share feedback with GP practices about the value of early recognition of end of life care needs and continuity of GP care and support especially in the last few weeks of life.
- Improve communication about the plan of care in terms of available support, what to expect and the use of medicines in managing common symptoms at end of life

- Promote use of the information leaflet *Care in the Last Days of Life* which has been adapted for use across community settings
- Improve the provision of information about care and what to do after death, including use of the leaflet *When Someone Dies* which has been adapted for use across community settings.

Hospices

1. Thank staff for the kindness and compassion they have shown families.
2. To review personal care competence for patients who require assistance with shaving and identify any further staff training needs.

Care homes

1. Based on the findings of this report, it is recommended that the findings are shared through citywide forums and services work with care homes to understand people's experience and identify where improvements could be made in the following areas:

Provision of information about:

- Who to contact for care and support
- Support available to carers

How services work together in the months before a person's death

Communication with families about

- their loved one's wishes
- how these can be supported

- family involvement in their loved one's care.
2. Thank staff for the kindness and compassion they have shown families and reiterate how important this is to their experience of the service.

Next Steps

The report will be shared with Leeds Palliative Care Network and will also be shared by each individual organisation locally through their clinical governance and quality assurance structures.

The report will also be made publicly available via Healthwatch Leeds and Leeds Palliative Care Network website.

All providers will agree the next steps to be taken in response to the recommendations from this report. We will work collectively to monitor progress and plan ongoing bereaved carers' surveys with the aim of addressing accessibility and low response rates from marginalised communities.

There will be a review of the content and future distribution of the survey to ensure the issues which are important to dying patients' families are being assessed.

Thank you

We would like to thank all the relatives and friends who took the time to respond to this survey and share their feedback during a very difficult time for them. This feedback is important in helping to shape services and ensure any issues are addressed when needed.

Appendices

Appendix 1: GP practices & care home respondents

We asked respondents who's friend / relative died in a care home which GP surgery the deceased person was registered with. Their responses were as follows:

- Laurel Bank Surgery
- Drighlington Medical Centre
- Windmill Health Centre
- Meanwood Health Centre
- Manor Park Surgery
- Chapeltown Family Surgery
- West Leeds Family Practice
- Robin Lane Health and Wellbeing Centre
- Manor Park Surgery
- Morley Health Centre
- Lingwell Croft Surgery
- Kirkstall Lane Medical Centre

Appendix 2: GP practices & people who died at home

We asked respondents whose friend / relative died at home to tell us which GP surgery the deceased person was registered with. Their responses were as follows:

- Abbey Grange Medical Practice
- Aire Valley Surgery
- Alwoodley Medical Centre (3 respondents)
- Chapeltown Family Surgery
- City View Medical Practice
- Garforth Medical Practice (2 respondents)
- Gibson Lane Practice (3 respondents)
- Hawthorn Surgery
- High Field Surgery
- Hyde Park Surgery (2 respondents)

- Leigh View Medical Practice
- Lingwell Croft Surgery
- Manor Park Surgery
- Manston Surgery
- Meanwood Health Centre
- Oulton Surgery (2 respondents)
- Robin Lane Health and Wellbeing Centre (2 respondents)
- South Bank Surgery (formerly Whitfield Practice)
- St Martins Practice
- Street Lane Practice
- Sunfield Medical Centre
- Vesper Road Surgery
- West Leeds Family Practice
- Windsor House Group Practice

Appendix 3: Hospital Wards

We asked people whose friend / relative died in hospital for the ward where the deceased person was located. Their answers were as follows:

- J10 (2 responses)
- J11 (2 responses)
- J12 (3 responses)
- J14
- J15
- J16 (2 responses)
- J17
- J19 (4 responses)
- J21
- J27 (2 responses)
- J28 (2 responses)
- J30
- J31
- J42 (2 responses)
- J50
- J53 / J54 (ICU)

- J8
- J84
- J88
- J92
- J94
- J97

Appendix 4: Relief of pain & other symptoms

In total, 100 people responded to the question about relief of pain and 98 responded to the question about management of other symptoms.

The breakdown of their responses is as below:

Place of Death	Pain	%	Other symptoms	%
Care Home	7/10	70%	7/10	70%
Hospital	32/43	74%	32/41	78%
Hospice	19/19	100%	19/19	100%
Home	23/28	82%	23/28	82%
Total	81/100	81%	81/98	82.6%

Appendix 5: The survey

The following wording was used to introduce each version of the survey:

This survey will take around 5/10 minutes to complete.

On behalf of the Leeds Palliative Care Network, we would like to extend our sincere condolences to you and your family at this time.

Providing high quality care to people at the end of their lives is really important to us. We value hearing from families and those close to our patients and your thoughts help us to continue to improve how we provide this care and support.

We understand that this may be a difficult time for you and it could be upsetting to think about giving feedback. If you do feel able to participate and choose to take part in this survey we want to assure you that all responses are anonymous.

Any information we receive will be used to improve care at the end of life across Leeds.

Results of the survey will be available in summer 2022 on the Leeds Palliative Care Network website and the Healthwatch Leeds website.

Please complete the survey by the end of January 2022

For those whose friend / relative died in hospital

1. Please tell us when your loved one died (month and year)*

2. Please tell us where your relative or friend was cared for in their last days of life?*

 - At home
 - In hospital (LTHT)
 - In a hospice
 - In a care home
 - At The Mount (LYPFT)

3. Please tell us which hospital they were cared for in.*

 - Leeds General Infirmary
 - St James' University Hospital
 - Chapel Allerton Hospital
 - Wharfedale Hospital
 - Seacroft Hospital

4. Please tell us which ward your relative/friend was cared for in the last days of their life.* (Dropdown list)

5. Please tell us if you were offered the following* (options: Yes, No, Not sure / can't remember, N/A)

- Regular drinks
- Car parking permit
- The supporting care in the last hours and days of life information leaflet
- Comfort care pack which might have included toiletries, pen/notebook (this is usually only offered for overnight or longer stays)

6. Please tell us if you were offered information about the following* (options: Yes, No, Not sure / can't remember, N/A)

- The plan of care for your relative/friend in the last days of their life
- Where toilets were located for your use
- Option to stay with relative/friend outside visiting hours
- Where the prayer room/areas of worship were
- Where the quiet/family room was

7. Do you feel that your relative or friend died in the right place?* (options: Yes, No, Not sure)

8. During this time how satisfied were you with the care given to your friend or relative in each of the following areas. (Please tick one box per row).* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)

- Relief of pain
- Relief of symptoms other than pain (e.g. nausea, restlessness)
- Religious, cultural & spiritual support
- Respecting wishes before and after death
- Being cared for with privacy and dignity
- Personal care e.g. help with washing/going to the toilet/change of position

9. In the last few months of your relative/friends life, how satisfied were you with the way health and care services worked together? e.g. GP, Community Nurse, Homecare etc.* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)

10. In the last few months of your relative/friends life, did they or you have the opportunity to discuss their wishes about care and treatment?* (options: Yes, No, Not sure / can't remember, N/A)

11. Did you feel that you or your relative/friend were as involved in the care as you or they would have wanted to be?* (options: Yes, No, Not sure / can't remember, N/A)

12. Please tell us anything that you feel we did well when providing end of life care for your relative/friend.

13. Please tell us anything that you feel we could have done better when providing end of life care for your relative/friend.

14. Please use the space below to tell us anything else about your experience that you have not already told us about.

Equality Monitoring Form (optional)

Can you please complete this section with your relative/friend's information. By filling in this equality monitoring section you will help us ensure that we get feedback from all our communities. Filling in this section is optional.

What was your relative/friend's gender?

- Male
- Female
- Other (please state)

What was your relative/friend's age when they died?

- 18-25
- 26-49
- 50-64
- 65-84
- 85+

What was your relative/friend's religion?

- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Sikh
- No religion
- Other (please state)

Please could you indicate which ethnic group in your opinion they belonged to:

- White British
- White Irish
- Gypsy or Traveller
- Other White
- White and Black Caribbean
- White and Black African
- White and Asian
- Other Mixed
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Other Asian
- Black African
- Black Caribbean

- Other Black
- Arab
- If any other ethnic background, please state

Thank you for taking part in this survey. If you would like information about how raise any concerns or make a complaint please contact Healthwatch Leeds on 0113 8980035 or email: info@healthwatchleeds.co.uk

For those whose friend / relative died at home:

1. Please tell us when your loved one died (month and year)*
2. Please tell us where your relative or friend was cared for in their last days of life?*

 - At home
 - In hospital (LTHT)
 - In a hospice
 - In a care home
 - At The Mount (LYPFT)

3. Please tell us the name of your relative/friend's GP Practice*
(dropdown list)
4. Please tell us if you were offered information about the following*
(options: Yes, No, Not sure / can't remember, N/A)

 - The plan of care for your relative/friend in the last days of their life
 - How to contact services for advice and support
 - How to register a death
 - How to contact a funeral director
 - Support available for you

5. Do you feel that your relative or friend died in the right place?*
(options: Yes, No, Not sure)

6. During this time how satisfied were you with the care given to your friend or relative in each of the following areas. (Please tick one box per row).* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
- Relief of pain
 - Relief of symptoms other than pain (e.g. nausea, restlessness)
 - Religious, cultural & spiritual support
 - Respecting wishes before and after death
 - Being cared for with privacy and dignity
 - Personal care e.g. help with washing/going to the toilet/change of position
7. In the last few months of your relative/friends life, how satisfied were you with the way health and care services worked together? e.g. GP, Community Nurse, Homecare etc.* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
8. In the last few months of your relative/friend's life, did they or you have the opportunity to discuss their wishes about care and treatment?* (options: Yes, No, Not sure / can't remember, N/A)
9. Did you feel that you or your relative/friend were as involved in the care as you or they would have wanted to be?* (options: Yes, No, Not sure / can't remember, N/A)
10. Please tell us anything that you feel we did well when providing end of life care for your relative/friend.
11. Please tell us anything that you feel we could have done better when providing end of life care for your relative/friend.

12. Please use the space below to tell us anything else about your experience that you have not already told us about.

Equality Monitoring:

as above

For those whose friend / relative died in a hospice

1. Please tell us when your loved one died (month and year)*

2. Please tell us where your relative or friend was cared for in their last days of life?*

 - At home
 - In hospital (LTHT)
 - In a hospice
 - In a care home
 - At The Mount (LYPFT)

3. Please tell us which hospice they were cared for in. (*dropdown list**)

4. During this time do you feel that the staff* (options: Yes, No, Not sure / can't remember, N/A)

 - Were professional
 - Made time for you
 - Gave you the opportunity to ask questions and raise concerns

5. Please tell us if you were offered information about the following* (options: Yes, No, Not sure / can't remember, N/A)

 - How to register a death
 - How to contact a funeral director
 - How to access support for you

6. Do you feel that your relative or friend died in the right place?*(
options: Yes, No, Not sure)
7. During this time how satisfied were you with the care given to your friend or relative in each of the following areas. (Please tick one box per row).* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
- Relief of pain
 - Relief of symptoms other than pain (e.g. nausea, restlessness)
 - Religious, cultural & spiritual support
 - Respecting wishes before and after death
 - Being cared for with privacy and dignity
 - Personal care e.g. help with washing/going to the toilet/change of position
8. In the last few months of your relative/friends life, how satisfied were you with the way health and care services worked together? e.g. GP, Community Nurse, Homecare etc.* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
9. In the last few months of your relative/friend's life, did they or you have the opportunity to discuss their wishes about care and treatment?*(
options: Yes, No, Not sure / can't remember, N/A)
10. Did you feel that you or your relative/friend were as involved in the care as you or they would have wanted to be?*(options: Yes, No, Not sure / can't remember, N/A)
11. Please tell us anything that you feel we did well when providing end of life care for your relative/friend.

12. Please tell us anything that you feel we could have done better when providing end of life care for your relative/friend.
13. Please use the space below to tell us anything else about your experience that you have not already told us about.

Equality Monitoring:

as above

For those whose friend / relative died in a care home:

1. Please tell us when your loved one died (month and year)*
2. Please tell us where your relative or friend was cared for in their last days of life?*

 - At home
 - In hospital (LTHT)
 - In a hospice
 - In a care home
 - At The Mount (LYPFT)

3. Please tell us the name of your relative/friend's GP Practice*
(dropdown list)
4. Please tell us if you were offered information about the following*
(options: Yes, No, Not sure / can't remember, N/A)
 - The plan of care for your relative/friend in the last days of their life
 - How to contact services for advice and support
 - How to register a death
 - How to contact a funeral director
 - Support available for you

5. Do you feel that your relative or friend died in the right place?*
(options: Yes, No, Not sure)
6. During this time how satisfied were you with the care given to your friend or relative in each of the following areas. (Please tick one box per row).* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
- Relief of pain
 - Relief of symptoms other than pain (e.g. nausea, restlessness)
 - Religious, cultural & spiritual support
 - Respecting wishes before and after death
 - Being cared for with privacy and dignity
 - Personal care e.g. help with washing/going to the toilet/change of position
7. In the last few months of your relative/friend's life, how satisfied were you with the way health and care services worked together? e.g. GP, Community Nurse, Homecare etc.* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
8. In the last few months of your relative/friend's life, did they or you have the opportunity to discuss their wishes about care and treatment?*
(options: Yes, No, Not sure / can't remember, N/A)
9. Did you feel that you or your relative/friend were as involved in the care as you or they would have wanted to be?* (options: Yes, No, Not sure / can't remember, N/A)
10. Please tell us anything that you feel we did well when providing end of life care for your relative/friend.

11. Please tell us anything that you feel we could have done better when providing end of life care for your relative/friend.
12. Please use the space below to tell us anything else about your experience that you have not already told us about.

Equality Monitoring:

as above

For those whose friend / relative died in The Mount:

1. Please tell us when your loved one died (month and year)*
2. Please tell us where your relative or friend was cared for in their last days of life?*

 - At home
 - In hospital (LTHT)
 - In a hospice
 - In a care home
 - At The Mount (LYPFT)

3. Do you feel that your relative or friend died in the right place?*(options: Yes, No, Not sure)
4. During this time how satisfied were you with the care given to your friend or relative in each of the following areas. (Please tick one box per row).* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)

 - Relief of pain
 - Relief of symptoms other than pain (e.g. nausea, restlessness)
 - Religious, cultural & spiritual support
 - Respecting wishes before and after death

- Being cared for with privacy and dignity
- Personal care e.g. help with washing/going to the toilet/change of position

5. In the last few months of your relative/friend's life, how satisfied were you with the way health and care services worked together? e.g. GP, Community Nurse, Homecare etc.* (options: Very Satisfied, Satisfied, Dissatisfied, Very Dissatisfied, Not sure/can't remember, N/A)
6. In the last few months of your relative/friend's life, did they or you have the opportunity to discuss their wishes about care and treatment?* (options: Yes, No, Not sure / can't remember, N/A)
7. Did you feel that you or your relative/friend were as involved in the care as you or they would have wanted to be?* (options: Yes, No, Not sure / can't remember, N/A)
8. Please tell us anything that you feel we did well when providing end of life care for your relative/friend.
9. Please tell us anything that you feel we could have done better when providing end of life care for your relative/friend.
10. Please use the space below to tell us anything else about your experience that you have not already told us about.

Equality Monitoring:

as above



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