



Leeds Palliative
Care Network

Your
healthwatch
Leeds

Bereaved Carers Survey about End of Life Care in Leeds

People's experiences of end of life care and support for their loved ones in hospices, hospitals, in their own homes and care homes

January to March 2020

Your independent watchdog ensuring people's voices are at the heart of shaping health and care services in Leeds.

Contents

Page 3-5	Summary
Page 6	Background
Page 6	Why we did it
Page 6-7	What we did
Page 7-31	What we found
Page 31-33	Our Messages/Recommendations
Page 33-34	Service Provider Response
Page 34	Next Steps/Acknowledgements
Page 35-37	Appendices

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/friend in a hospital, community (including GP surgeries, Leeds Community Healthcare and private care agencies and care homes) and hospice settings. A total of 225 people provided feedback across all the settings.

It is important to note that on 11th March, the World Health Organisation announced that COVID-19 had become a global pandemic. At this time there were huge changes taking place in healthcare settings across the country both in hospital and the community. This means the survey was not handed out to relatives during the final days of the survey (23rd-31st March) in hospital or community settings but were still given out in hospices

Key Findings

Overall there were high levels of satisfaction across all services, with care in hospices being rated most highly. The vast majority of people felt their friend/relative had died in the right place. Many people told us they had valued the kindness and compassion of staff and excellent care that had been provided to their friend/relative in their final days.

Hospices

- 92 responses were received from the hospice setting
- Almost all respondents (99%) felt their relative/friend had died in the right place.
- Every respondent expressed satisfaction with the care provided.
- People talked highly of the staff and their professionalism.
- The feedback was very positive, with staff kindness and compassion and the high standard of care valued by many.

Hospitals

- 104 responses were received from the hospital setting
- The majority of respondents (85%) felt their relative/friend had died in the right place.
- There were high levels of satisfaction in most areas of care.
- There was praise for the kindness and compassion shown by staff.
- Some people felt the care was not as good as it could be. However when it was known that the treatment was not working and the patient was dying, there was an improvement in the level of support and care for the patient and their family
- The lack of privacy on wards was a concern for some.
- Respondents felt information about practical issues could be better, e.g. parking charges and access to toilet facilities.

Community

- 34 responses were received from community settings
- Most respondents (97%) felt that their friend/relative had died in the right place.
- Most people had the opportunity to discuss their wishes about care/treatment, where this had been appropriate.
- There were mixed responses about the level of information people were given about other services.
- There was praise for the level of care given at the end of life and the kindness of staff.

Key Recommendations / Messages

Hospices

As the findings indicate high levels of satisfaction, there are no recommendations for hospices other than to continue with the good level of care and support that is currently being provided.

Hospitals

- Continue to provide end of life training for staff to ensure there is a consistent approach across all services.
- To embed the principles of the SUPPORT campaign to ensure families of dying patients are consistently asked about their needs and given information about care available for them. For example, updates about care, car parking permits, overnight accommodation/comfort care packs, location of prayer rooms, location of toilets, drinks and a private space away from the bedside.
- If a dying patient wishes to be cared for in a side room and one is not available, the reasons for this should be communicated to the patient and their family.
- Processes for dealing with administrative issues following bereavement to be reviewed to ensure the individual needs of bereaved families are being met.

Community

- Current end of life care information provided to patients and families to be reviewed across community providers (primarily Leeds Community Healthcare Trust, Primary Care and Care Homes) to ensure consistent information is offered and available; including information about the support available out of hours. This could be delivered through a single leaflet or information point.
- All providers to continue working together to support consistency of end of life care across community settings.

Background

Since 2015, through a partnership approach, Leeds has been running an annual survey of bereaved relatives' experiences of care in the last days of life.

The survey has been developed over the past few years by stakeholders from Leeds Palliative Care Network with the involvement of Healthwatch Leeds to assess the care delivered to patients and their families in the following care settings: Leeds Teaching Hospitals NHS Trust (LTHT), St Gemma's Hospice, Sue Ryder Wheatfields Hospice, and at home or in residential care homes for people being cared for by local GP's, Leeds Community Healthcare NHS Trust (LCH) and other private care providers. The survey provides feedback from the perspective of bereaved relatives. Since 2015 the survey has been redesigned, making it shorter, user-friendly and with more focused questions, taken from the themes that were highlighted by the Salter, Wood, and Sue Ryder Care 2013 report. This report looked at what was important to people at the end of life.

Why we did it

We wanted to help Leeds Palliative Care Network to understand people's experience of the quality of care their relative/friend received in the last days or hours of life. We wanted to look at experiences across different health care settings in Leeds, including hospitals, hospices, care homes and people's own homes.

What we did

The surveys were reviewed based on previous year's findings and each organisation developed their own processes for providing the survey to the bereaved relatives for adult deaths between 1st January and 31st March 2020. In each setting a paper copy of the survey was offered to the relative/nominated contact with the medical certificate of cause of death. The survey also contained information about how to access it online.

The completed surveys were submitted via post or online to Healthwatch Leeds. As part of this process, Healthwatch Leeds could

feed back to the individual provider about any comments that they felt needed immediate attention or if individual staff members were mentioned in a positive way.

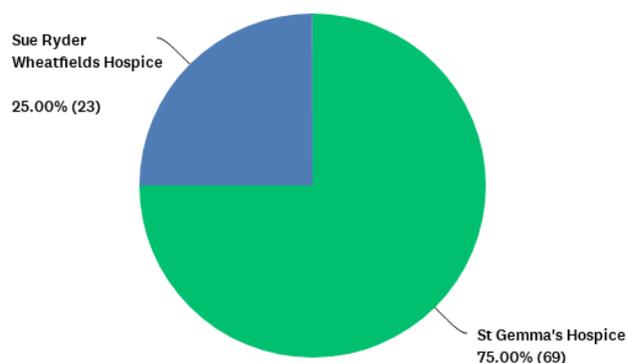
The surveys were analysed and this report produced by Healthwatch Leeds. A total of 230 people provided feedback across all the settings.

What we found - Hospices

150 deaths occurred in the hospices during 1st January-31st March 2020, 87 in St Gemma's and 63 in Wheatfields. 150 surveys were given out and a total of 69 were received back from St Gemma's (79% response rate) and 23 from Wheatfields (36.5% response rate)

92 people provided feedback about their experience of end of life care for a loved one in a hospice. Of those, 69 (75%) gave feedback about St Gemma's Hospice and 23 (25%) provided feedback about Wheatfield's Hospice.

Please tell us where your relative or friend was cared for in their last days and hours of life?



91 people told us about whether they felt their relative/friend died in the right place. Out of those, 90 (99%) felt it had been the right place for their relative/friend to die and 1 person responded that they did not know if it had been the right place.

44 respondents provided further comments about this and all were positive. Three key themes emerged from the comments. These were the high standard of care received at the hospices, the kindness and compassion of the staff and this being the place where their relative/friend had wanted to die.

“It was her request to pass away in St Gemma’s so we were very happy that she managed to get a bed and have her last wish granted”.

“It was where she wanted to be and everyone was so kind”.

About the Care

Respondents were asked to rate their satisfaction levels with the care provided in the following areas:

- 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

The responses rated the care as overwhelmingly positive for all areas, with almost all rating the care as very satisfactory or satisfactory. Nobody stated they were dissatisfied with any of the care they had received. There were some neutral responses for respecting wishes before and after death and religious and cultural support. There was also a high number of “not applicable” responses to the cultural and religious support question.

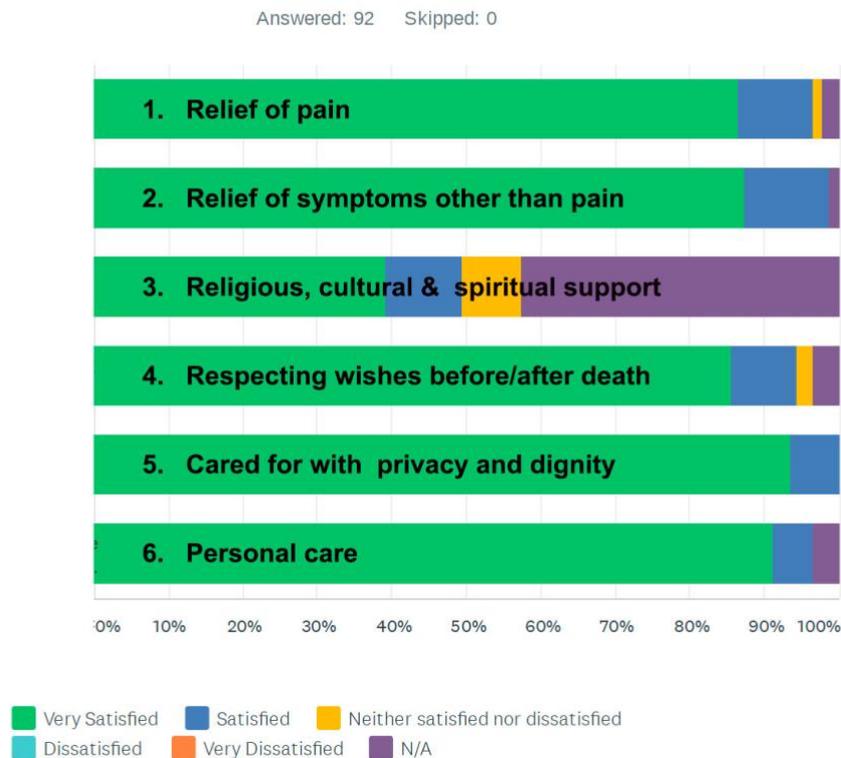
Many of the comments reflected people’s positive experiences, especially in relation to the kindness and compassion shown by the staff. People felt they were listened to and treated with dignity and respect and their loved ones had been well cared for.

“The compassion shown by everyone was above and beyond what we expected”

“Dad’s wishes were respected at all times and his care was exemplary”

The graph below lists the responses for the different areas of care.

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



About the staff and information provided

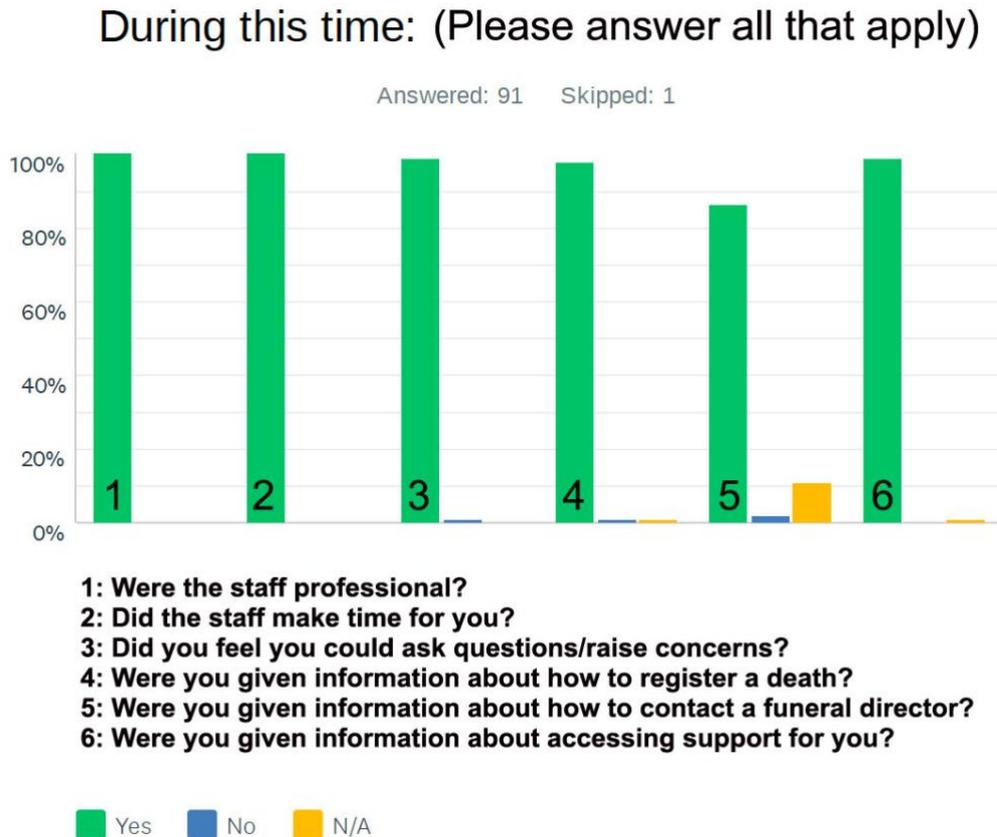
Respondents were asked about their experience of the staff and the information that was provided to them. Questions were asked in the following key areas:

- Professionalism of staff
- Time and availability of staff
- Ability to ask questions of staff
- Information about registering a death
- Information about funeral directors
- Information about accessing support

The vast majority of responses were positive, especially in the relation to staff professionalism and people feeling able to talk to staff and ask questions. Only 1 respondent felt that they had not been able to ask questions or raise concerns.

The vast majority of people also felt that they had been given information in relation to registering a death, funeral directors and accessing support for themselves. Only 1 person told us they were not given information about registering a death and 2 stated that they had not been given information about funeral directors. A few selected the not applicable option for some of the questions.

The graph below sets out the responses for each question.



What worked well and what could have been better

Respondents were asked about what had worked well and what could have been done better. Of the 72 people that responded to this question, each one gave positive feedback about their experiences. Many people talked about the kindness and compassion that they and their loved ones were shown as well as the high level of care that they received. People talked about the calm surroundings and homely environment as a real positive and a few commented on how much better it was than a clinical hospital environment.

“Overall, the care was excellent. My mother seemed to relax the moment she entered the hospice. The care was in stark contrast (much better) than she had received in hospital”.

“All staff were supremely competent, carry out their tasks, but they also shared their “human” sides and always had time for us. I will always remember this”.

Out of the 72 respondents, only 7 people suggested areas for improvement. Some of the issues mentioned included having tokens for the coffee machine instead of £1 coins, others talked about minor admin errors. Someone felt that, while the care was “amazing”, there could possibly be more psychological support, especially for younger patients. One person talked about the lack of support for the family to deal with their grief and this had been made worse due to the impact of covid. Two people had concerns with specific members of staff, which have been taken up directly with St Gemma’s hospice..

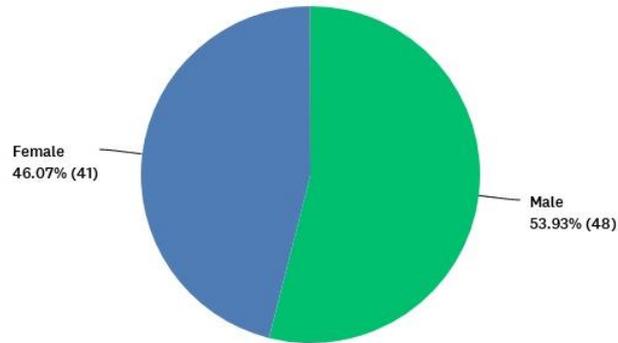
“Levels of care and kindness were amazing! Maybe patients in some cases, particularly younger patients, need more psychological support coming to terms with terminal illness”.

“We haven’t had any support for our grief, but doesn’t help that covid 19 happened after we lost my mum, really struggling at the moment”.

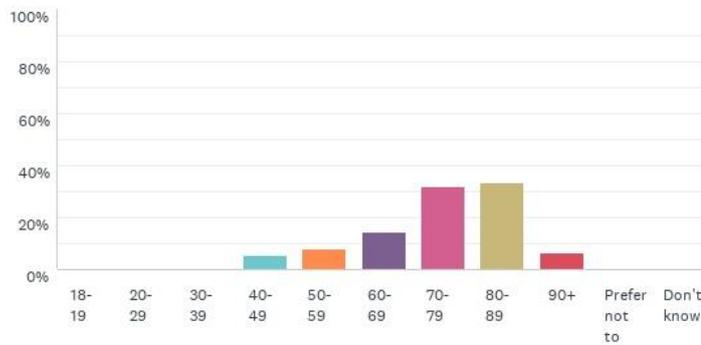
Equality Monitoring

Below is breakdown of the age, gender, ethnicity and religious group of those who had died at the hospices and on whose behalf the surveys had been completed. As can be seen, there was a fairly even split between male and female and the majority of people were aged between 70 and 89. The vast majority were from a white British or white Irish background with only 1 person selecting Black/Black British Caribbean and nobody selecting any other BAME group. For religion, Christian was selected by the greatest number of people, with no religion being the second highest group.

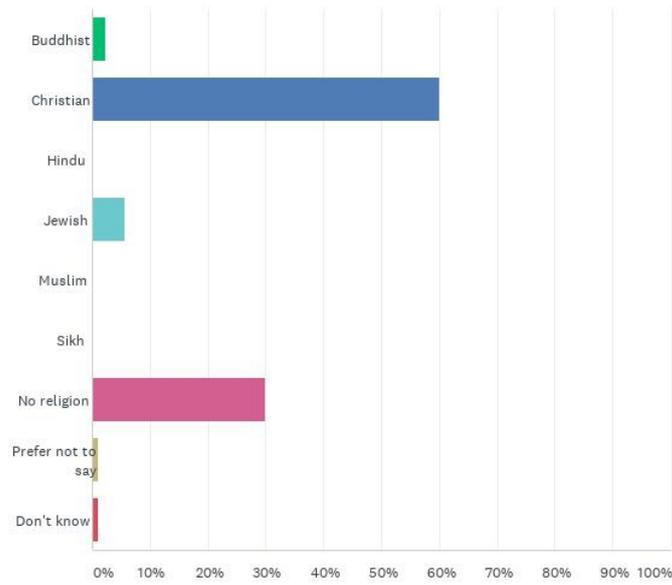
What was your relative/friend's gender?



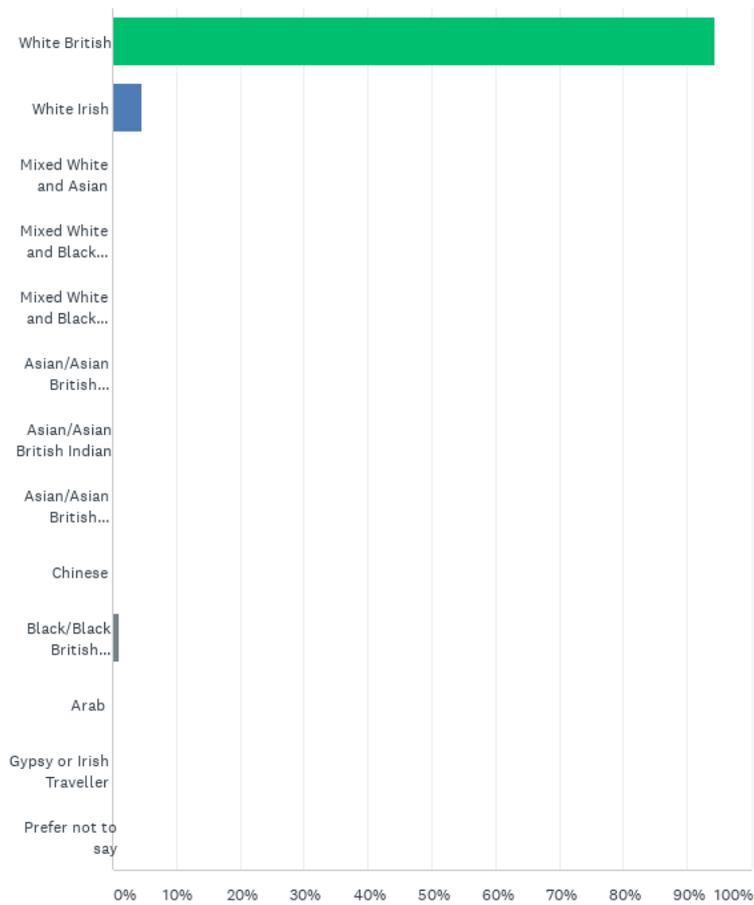
What was your relative/friend's age when he/she died?



What was your relative/friend's religion?



Please could you indicate which ethnic group in your opinion he/she belonged to:

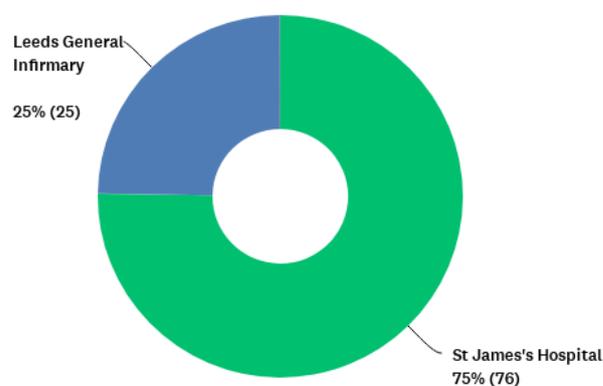


What we found - Hospitals

847 deaths occurred in the hospitals during 1st January-31st March 2020
476 surveys given out and 104 responses were received. This gives a response rate of 22%.

104 people provided feedback about their experience of end of life care for a loved one in a hospital setting in Leeds. Out of those that responded to this question, 75% told us that their relative/friend had died in St James' Hospital and 25% in Leeds General Infirmary.

Please tell us which hospital your relative or friend was cared for in their last days of life?



104 people told us about whether they felt their relative/friend had died in the right place. Out of those, 88 (85%) felt it had been the right place for their relative/friend to die; 15 (14%) felt it had not been the right place; and 1 person responded that they did not know if it had been the right place.

14 people provided further comments on this topic. Out of those, 13 had said that their relative/friend had not died in the right place. 7 commented that their relative/friend had wanted to die at home or in a hospice. 4 went on to acknowledge that there had not been enough time to move them, they had been too ill or had died suddenly. 3 comments related to a side room not being available and 1 commented that their relative should have been cared for on a different specialty ward. Two people mentioned that the person was not cared for very well and 1 comment said the environment was poor.

“I would have liked him to have been in a hospice or a quieter ward BUT it all happened quite quickly and while the pandemic problems were growing so I definitely have no complaints about where he died”

About the Care

Respondents were asked to rate their satisfaction levels with the care provided in the following areas:

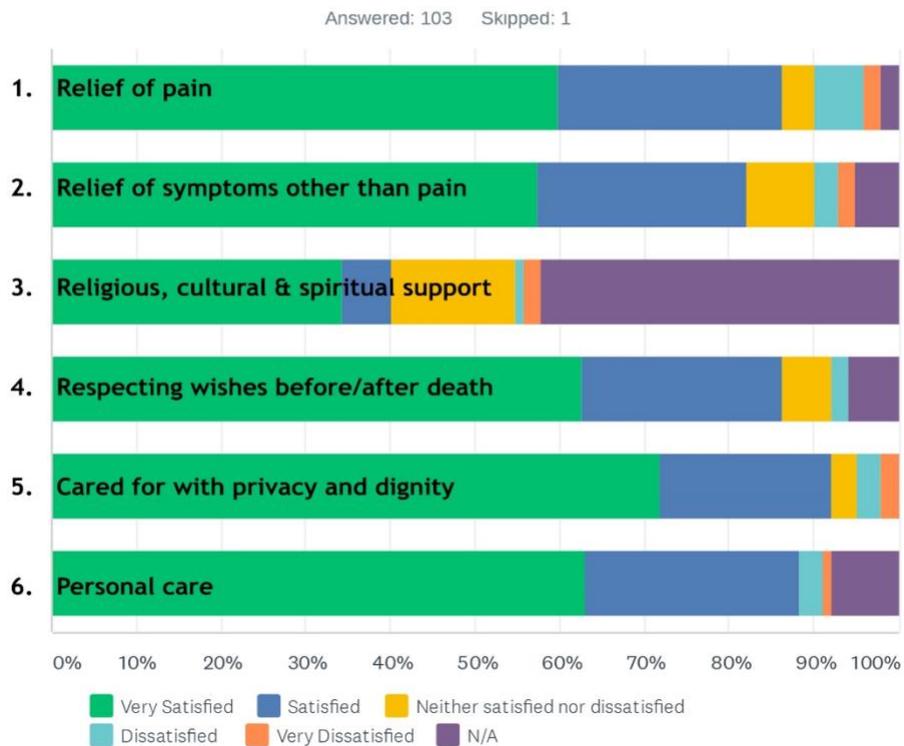
- Relief of pain
- Relief of symptoms other than pain (e.g. nausea, restlessness)
- Religious, cultural & spiritual support
- Respecting wishes before and after death
- Being cared for with privacy and dignity
- Personal care, e.g. help with washing / going to the toilet / change of position

Overall there were high levels of satisfaction with most of the areas. The highest levels of satisfaction were in the area of being cared for with privacy and dignity, as 95% of respondents had said they were very satisfied or satisfied with this. In the other areas listed above, between 82% and 88% of respondents were very satisfied or satisfied. The only area with a very low satisfaction rating of 40% was religious and cultural support, however over 42% also said this question was not applicable and a further 15% said they were neither satisfied nor dissatisfied.

The numbers of people saying they were dissatisfied or very dissatisfied with an area of care were low, ranging from 8% for relief of pain to 2% for respecting wishes before and after death. While the numbers are low, it is important to recognise that 27 people expressed some level of dissatisfaction across all the above areas of care in the hospitals.

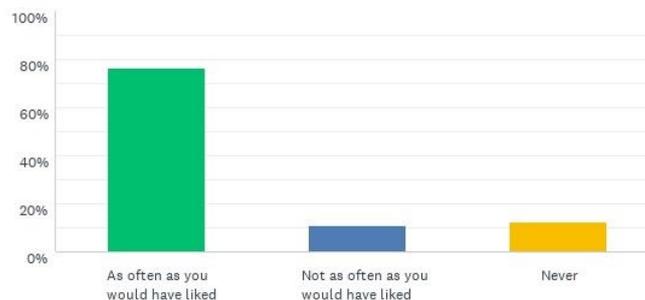
The graph shows the responses for each area.

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



People were asked if they had been offered a drink while visiting their relative/friend in hospital. Out of the 102 people that responded to this question, 78 (76%) said they were offered a drink as often as they wanted, 11 (11%) said not as often as they would have liked and the remaining 13 (13%) said they had never been offered a drink.

Were you offered a drink?



About the staff and information provided

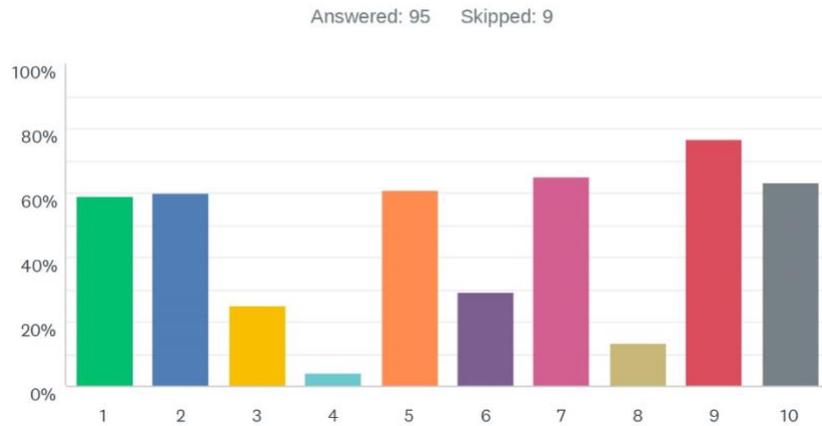
Respondents were asked to tell us if they had received certain information. 95 people responded to this question and were able to select as many options as they wanted to. Below is a list of the areas which were enquired about, and the figures in brackets show the number of people who had been given information about that topic.

- Where to obtain food and drink (56)
- Car parking permit (if applicable) (57)
- Shower / bathroom for your use (24)
- Prayer room / areas of worship (4)
- Quiet / family room (58)
- Overnight accommodation (28)
- Option to stay with your relative / friend outside of visiting hours (62)
- Comfort care pack (which might have included toiletries, pen / notebook) (13)
- Updates on your relative or friend's condition (73)
- Where toilets were located for your use (60)

It is important to note that not every area would be relevant for everyone and therefore the data only tells us where people received information, but not where it was not received or where it was not relevant.

The graph below highlights the areas that people told us they received information about.

Were you offered information about any of the following?



1. Where to obtain food and drink
2. Car parking permit (if applicable)
3. Shower / Bathroom for your use
4. Prayer room / areas of worship
5. Quiet/Family room
6. Overnight accommodation
7. Option to stay with your relative/friend outside of visiting hours
8. Comfort care pack (which might have included toiletries, pen/notebook)
9. Updates on your relative or friend's condition
10. Where toilets were located for your use

What worked well and what could have been better

We asked people to tell us what had worked well and what could have been better. A total of 78 people commented on this question, of which 53 told us about what had worked well, 11 told us what could be improved and 14 people gave feedback on what had worked well and what could be improved. Almost all of those that spoke about what had worked well talked about the kindness and compassion of the staff and the high level of care received. Many people felt their relative/friend had been treated with dignity and respect and they, as family, had been treated with kindness and care during a difficult period. Some respondents also mentioned the fact that they had been kept well informed throughout as an important factor.

“The treatment my wife and I received was caring, loving and nursing at its best, thank you St James’ for everything”.

“The ward was really good at keeping the family informed of my relatives’ condition”.

“In the last few days of life all staff went above and beyond caring not only for mum but relatives as well”.

Where people felt things could have been better included the care and treatment received, before recognition and a discussion that their relative/friend was dying, the lack of privacy and dignity when the person had died on a ward and sometimes a lack of compassion from staff. Others talked about practical things that could have made it easier for them such as knowing about parking permits earlier on and having better access to toilet facilities, especially out of hours. Some also mentioned delays in paperwork following bereavement being an issue for them.

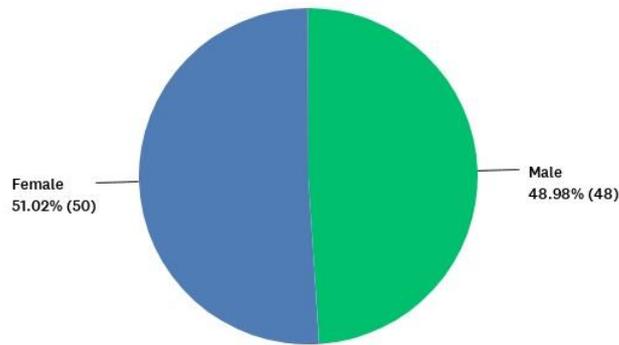
“I was really upset that there wasn't a room for my husband during his final hours and that he died on the ward with a curtain drawn around the bed. I felt this wasn't dignified for him or myself and family who stayed with him”.

“I felt a lack of compassion from some staff and they didn't seem too interested in the tasks they performed or if it was done to the best of their abilities”.

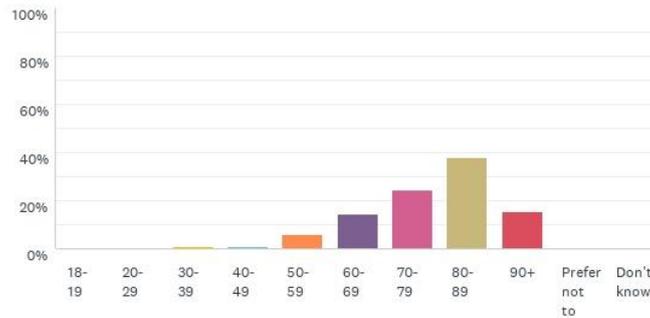
Equality Monitoring

Below is breakdown of the age, gender, ethnicity and religious group of those who had died at the hospitals and on whose behalf the surveys had been completed. As can be seen, there was an almost even split between male and female patients and the majority of people were aged 60 upwards when they died. 98% of people were from a white British or white Irish background. Only 2 people selected Black/Black British Caribbean and nobody selected any other BAME group. For religion, Christian was selected by the greatest number of people (80%), with no religion being the second highest group (19%) and 1 person selected Jewish.

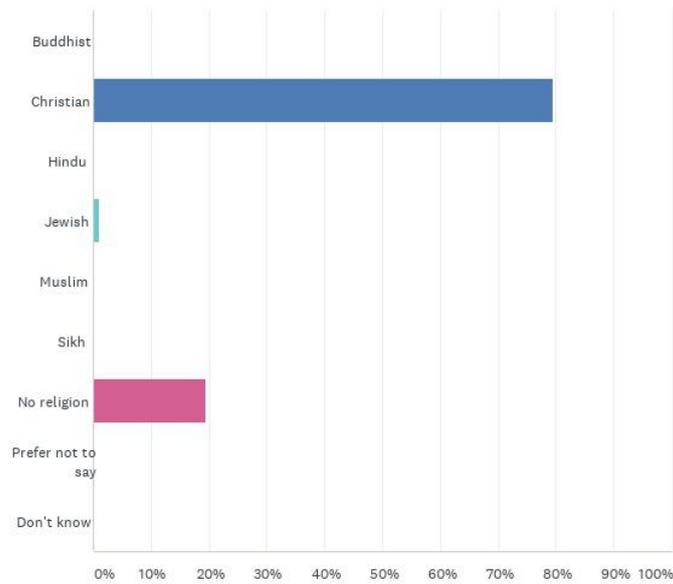
What was your relative/friend's gender?



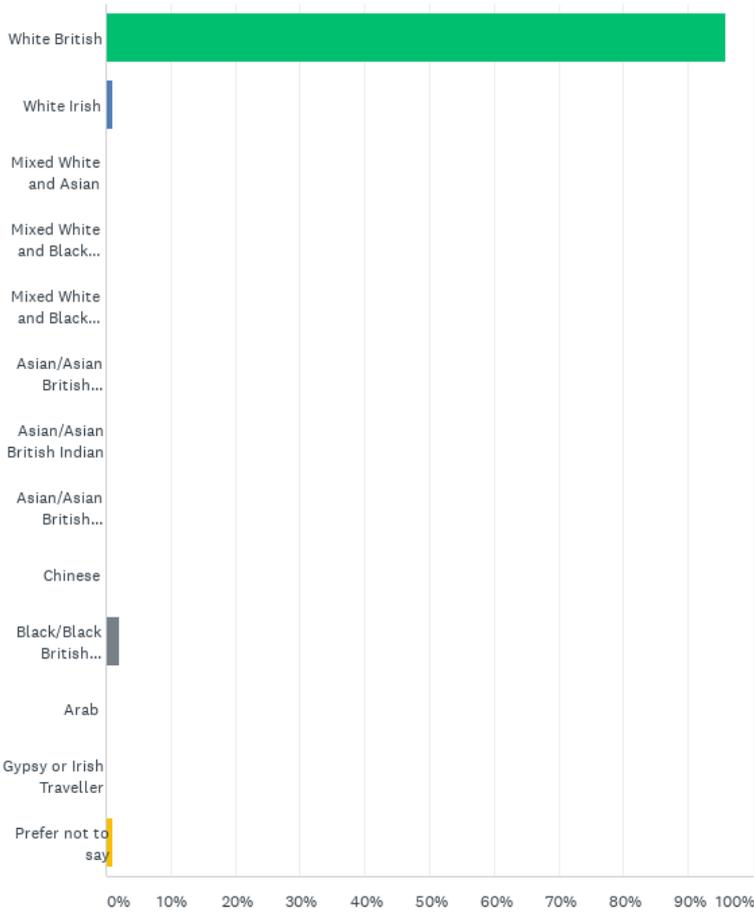
What was your relative/friend's age when they died?



What was your relative/friend's religion?



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



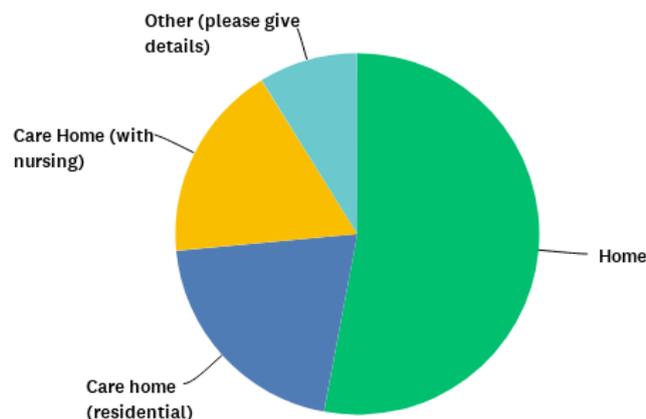
What we found - Community

There were 347 recorded deaths outside a hospital or hospice setting during the period 1st January-31st March 2020. There is no record of how many surveys were distributed to families of those that had died during this time. This is partly due to the impact of the Covid 19 pandemic and GP practices prioritising preparations for that, especially during the month of March.

34 people provided feedback about their experience of end of life care for a loved one, received from their GP or other community-based services. It is important to note that this is a small sample size and while it reflects people's individual experiences it would be difficult to pull out key trends across the system from this sample size.

Of the 34 people who responded, over half (53%) told us that their relative had died at home, 38% said their relative had died in a care home and 9% stated that they had died somewhere else. Other places that people had died were either hospital or a hospice.

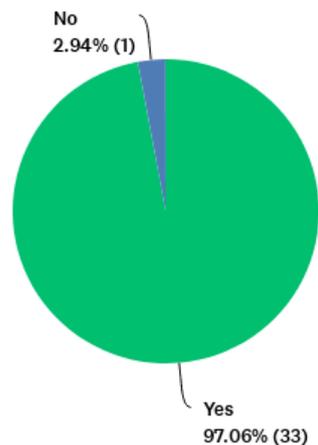
Please tell us where your relative or friend was cared for in the last days of life?



The vast majority of people (97%) stated that they felt their relative/friend had died in the right place, with only 1 person saying they had not died in the right place. The comments mostly focused on the friend or relative having wanted to die at home and this had been

the right place; others talked about the right care and support being received in the care home or other setting, which made it the right place for their loved one to die.

Do you feel that your relative or friend died in the right place?



About the Care

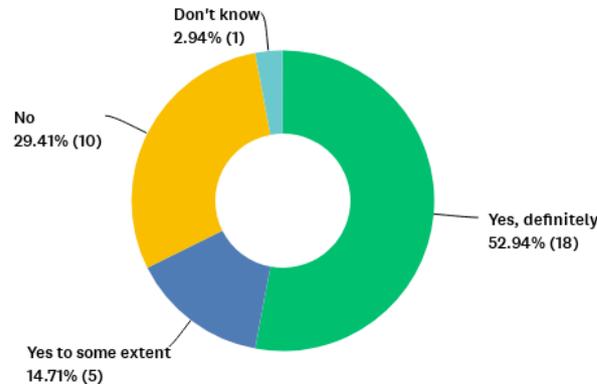
Respondents were asked if they felt their relative/friend had the opportunity to discuss their wishes about care and treatment. Just over half of the respondents (53%) said this had definitely happened and 5 people (15%) said this had happened to a certain extent. Almost a third of those who responded (29%) said this had not happened and 1 person said they did not know.

Out of the 10 people who had answered “no” to this question, 8 gave further comments and all stated that this had been due to the person having dementia or lacking mental capacity or the ability to communicate. Those that answered “yes” to this question talked about the good support and information received from staff in different settings which had enabled them to be involved in decisions.

“The (GP) practice was very approachable and gave us all the support to discuss the care needed”.

“My mother had very advanced Alzheimer's. She could not discuss anything. I had to make all of the decisions”.

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



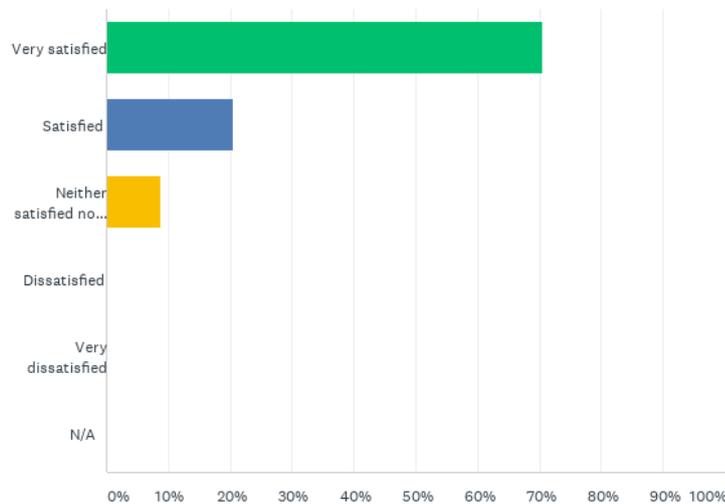
Respondents were asked about their satisfaction levels in relation to how well services had worked together in the last 3 months of their relative/friend's life. Overall, there were high levels of satisfaction, with 31 people (91%) stating that they were very satisfied or satisfied and the remaining 3 people stating that they were neither satisfied nor dissatisfied.

“All the agencies involved coordinated well. The “fast track” system really worked”.

“There was constant communication between all three mentioned parties and I found it easy to talk to either the GP, the nurses or the homecare staff about my husband's situation”.

“We didn't really know who took the lead and so many different services, lung nurse specialist, GP, community nurses, St Gemma's, needed more joined up services”.

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



Respondents were asked to rate their satisfaction levels with the care provided in the following areas:

- 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

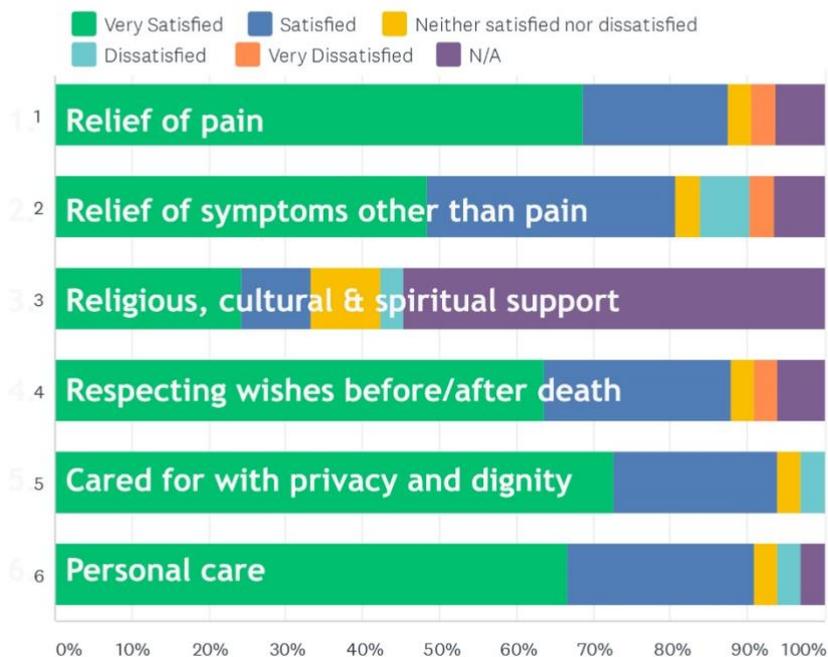
Overall, the satisfaction levels were high across most areas. The highest reported levels of satisfaction were in the areas of being cared for with privacy and dignity, where 94% of people stated they were satisfied or very satisfied and personal care, where 91% of respondents stated that they were satisfied or very satisfied. The numbers of people selecting very satisfied or satisfied for relief of pain (88%), relief of other symptoms (80%) and respecting wishes before death (88%) were slightly lower. The lowest level of satisfaction was with religious, cultural and spiritual support, where 33% rated the care as satisfactory or very satisfactory. However, it is worth noting that 55% of people also said that this was not applicable to them, 9% said they were neither

satisfied or dissatisfied and only 1 respondent stated that they were dissatisfied.

There were very low levels of dissatisfaction across all areas with 3 people expressing dissatisfaction for relief of symptoms other than pain. Only 1 person stated they were dissatisfied in each of the other areas.

2 respondents also selected the not applicable option for relief of pain, relief of other symptoms and 1 selected this option for personal care.

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.)



About the information provided

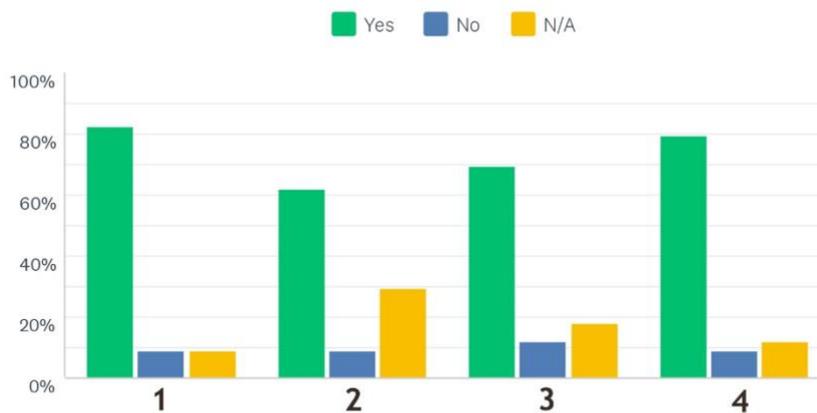
We asked people to tell us if they were given information about:

- The plan of care
- How to contact a funeral director
- How to register a death
- Support available for them

Out of the 34 respondents, 28 (82%) said they were given information about the plan of care, 3 (9%) said they were not and 3 (9%) stated this

was not applicable. 21 (62%) told us that they were given information on how to contact a funeral director, 3 (9%) answered that they were not and 10 (29%) stated this was not applicable. 23 (70%) people said they were told how to register a death, 4 (12%) people said they had not been given information about this and 6 (18%) stated this was not applicable. When asked about support available for them as relatives or friends, 27 (79%) people said they had been given information about this, 3 (9%) said they had not had any information and 4 (12%) said this was not applicable.

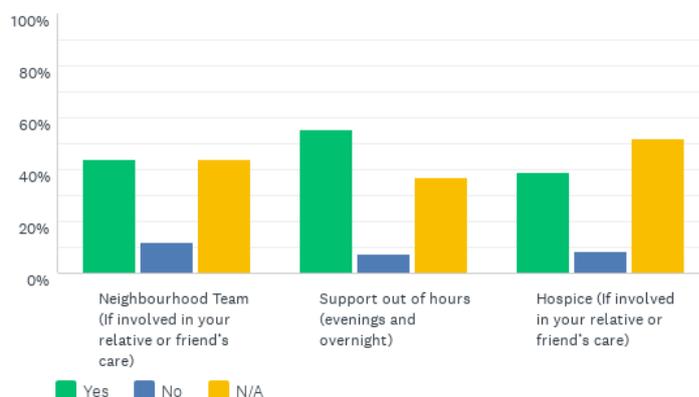
During this time were you given information about the following?



1. The plan of care for your relative or friend in the last days of their life
2. How to contact an undertaker/funeral director
3. How to register a death
4. Support available for you

People were asked if they were given contact details for other services when their relative had died at home. Out of 25 respondents, 11 (44%) had been given contact details about the neighbourhood teams, 3 (12%) had not and 11 (44%) said it was not applicable. 27 people told us about out of hours support, out of which 15 (56%) had details for out of hours support, 2 (7%) had not and 10 (37%) stated it was not applicable. 23 people told us about contact details for the hospice, with 9 (39%) saying they had been given those details while 2 (9%) said they had not and 12 (52%) said it was not applicable.

If your relative or friend died at home were you given contact details for the following services?



What worked well and what could have been better

We asked people to tell us what had worked well and what could have been better. A total of 13 people gave responses, 9 of which were positive, 3 were negative and 1 was mixed. People who talked about what could have been better told us that there was not enough care and support when it had been needed, and 1 person mentioned a lack of sufficient pain relief at the end of life. Others felt there could be clearer information about what to do out of hours and a better understanding of the practical role of relatives/carers at the end of life. Another talked about waits for equipment to be provided and later collected as something that could be better. It is important to note that these were the experiences of a very small number of people and may not be reflective of issues across the system.

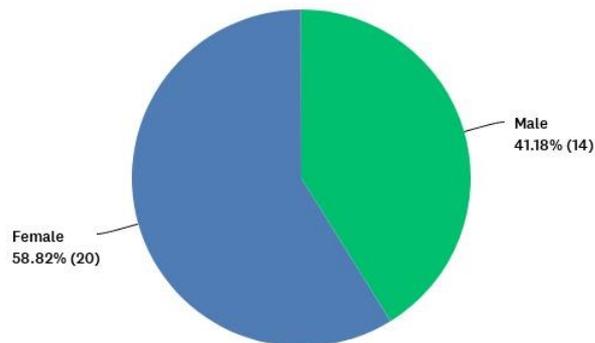
The positive comments mostly talked about the good care given at the end of life and the kindness of staff. People told us they felt their loved one had been treated with dignity and many said that they had felt well informed and supported throughout.

“I could not have asked for better care for my mother. She was treated with kindness and dignity. Family were treated with great respect and nothing was too much trouble”.

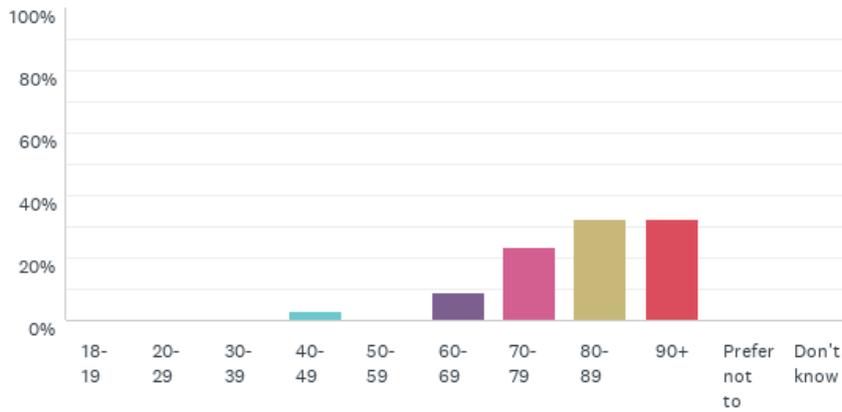
Equality Monitoring

Below is breakdown of the age, gender, ethnicity and religious group of those who had died at home or in a community setting. As can be seen, there were higher numbers of females (59%) than males (41%) and the majority of people were aged 70 upwards when they died, with the highest number in the 80 to 89 and 90+ category. For religion, Christian was selected by the greatest number of people (64%), with no religion being the second highest group (33%) and 1 person selecting Sikh. 94% of people were from a white British or white Irish background, 1 person selected Asian/Asian British Pakistani and 1 selected Gypsy or Irish Traveller.

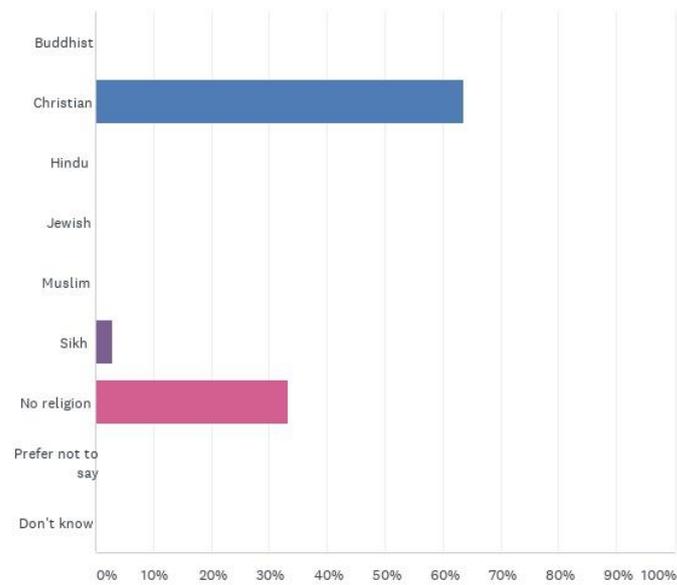
What was your relative/friend's gender?



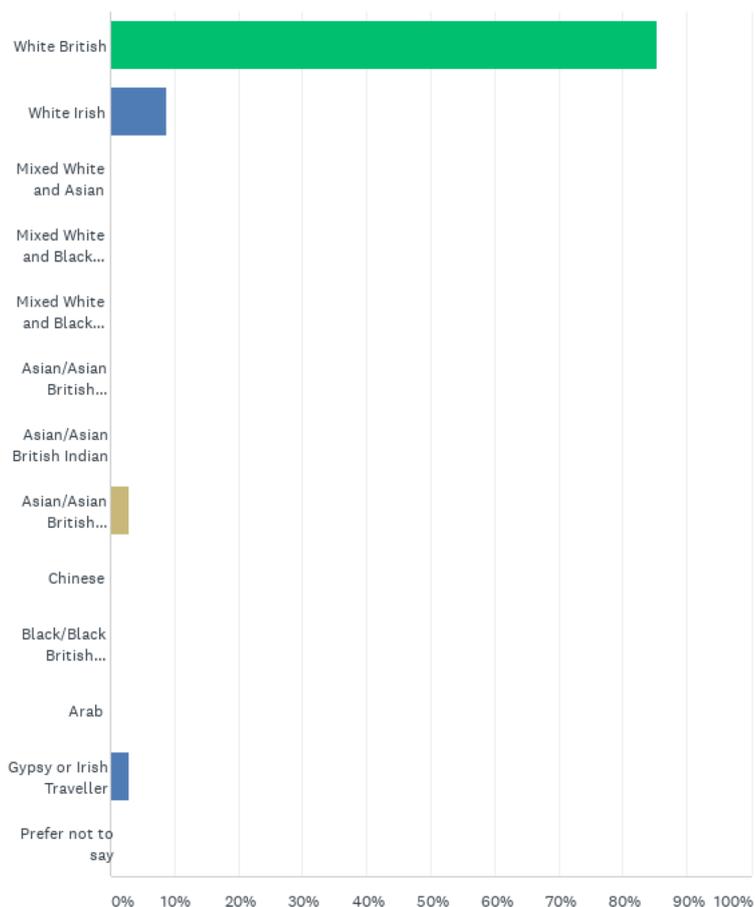
What was your relative/friend's age when he/she died?



What was your relative/friend's religion?



Please could you indicate which ethnic group in your opinion he/she belonged to:



Our Messages / Recommendations

Overall, there were high levels of satisfaction with end of life care and support across all settings. This was particularly evident in the responses for hospices, where respondents were overwhelmingly positive in the feedback provided. The other two sectors also had high levels of satisfaction and lots of positive feedback, however there were areas where some change could help ensure more people had a positive end of life experience.

Hospices

As the findings indicate high levels of satisfaction there are no recommendations for hospices other than to continue with the good level of care and support that is currently being provided.

Hospitals

The findings indicate good levels of satisfaction in many areas. Below are some recommendations to build on the good work and ensure there is a consistent approach across all services.

Key Messages/Recommendations	Response/Actions to be taken
Continue to provide end of life care training for staff to ensure there is a consistent approach across all services.	Continue to deliver on current end of life care education plan, which includes palliative care and care of the dying person, currently available virtually and as e-learning, for all nursing, medical and allied health professional staff. Monitor uptake across Clinical Service Units (CSUs)
To embed the principles of the SUPPORT campaign to ensure families of dying patients are consistently asked about their needs and given information about care available for them. For example, updates about care, car parking permits, overnight accommodation/comfort care packs, location of prayer rooms, location of toilets, drinks and a private space away from the bedside.	Relaunch the SUPPORT Campaign focusing on understanding the needs of those close to the patient and wider promotion of comfort care packs. Include these as part of the Trust-wide end of life care improvement plan.
If a dying patient wishes to be cared for in a side room and one is not available, the reasons for this should be communicated to the patient and their family.	Include information and examples of care as part of end of life care training and SUPPORT Campaign.
Processes for dealing with administrative issues following bereavement to be reviewed to ensure the individual needs of bereaved families are being met.	Continue to work with Bereavement Services to monitor and improve processes and take appropriate action if issues arise.

Community

Key Messages/Recommendations	Response/Actions to be taken
Current end of life care information provided to patients and families to be reviewed across community providers (primarily Leeds Community Healthcare Trust, Primary Care and Care Homes) to ensure consistent information is offered and available; including information about the support available out of hours. This could be delivered through a single leaflet or information point.	We will jointly review the information provided to patients and their families to ensure consistent information is provided by LCH and primary care to include information on accessing support out of hours
All providers to continue working together to support consistency of end of life care across community settings.	We will continue to build on the relationships within our primary care networks to support consistency of end of life care across the community setting

Service Provider Response

Leeds Palliative Care Network and all citywide partners within the Bereaved Carers Survey Group would like to thank Healthwatch Leeds for their support, advice and guidance in undertaking this survey and producing the report.

All providers value feedback so that we can continue to learn and improve the care we offer to our patients and their families.

We are committed to respond positively to this report and actively make changes to the areas it has highlighted this year.

The subsequent action plan will be shared with Healthwatch Leeds and made available on our website <https://leedspalliativecare.org.uk/>.

We look forward to hearing from Healthwatch how we can further develop the survey process so that next time we receive increased numbers of survey responses overall and are also able to gain insight into experiences that better reflect the full diversity of the Leeds population.

We look forward to expanding the surveys reach and will include colleagues from Leeds and York Partnership Foundation Trust next year so that we can take account of end of life care experiences in The Mount too.

We recognise that the next survey will be slightly delayed due the time required to improve the survey and also the impact of the Covid-19 pandemic on resources and capacity; but we are committed to continue with this important public engagement and feedback process.

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 BAME communities. There will be a review of the content of the survey after consultation with Healthwatch, to ensure the issues which are important to dying patients' families are being assessed.

The report will also be published on the Healthwatch Leeds website.

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.

This report has been written by Sharanjit Boughan, Community Project Worker at Healthwatch Leeds

Appendices

Appendix 1 Hospice Survey

Equality Monitoring information (optional)
 Can you please complete this section with your relative/friends 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.

8. What was your relative/friends gender?
 Male
 Female
 Prefer not to say

9. What was your relative/friends age when he/she died?
 18-19 20-29 30-39 40-49 50-59
 60-69 70-79 80-89 90+ Prefer not to say
 Don't know

10. What was your relative/friends religion?
 Buddhist Christian Hindu Jewish Muslim
 Sikh No religion Prefer not to say Don't know

11. Please could you indicate which ethnic group in your opinion he/she belonged to:
 White British White Irish Mixed White and Asian
 Mixed White and Black Caribbean Mixed White and Black African Asian/Asian British
 Bangladeshi Asian/Asian British Indian Asian/Asian British Pakistani
 Chinese Black/Black British Caribbean Arab
 Gypsy or Irish Traveller Prefer not to say

If any other ethnic background, please state here

Help us get it right
 If you have a complaint, concern, comment or compliment please let us know by speaking to a member of our team. We learn from your feedback and use the information to improve and develop our services.

Please contact:
Heather McClelland **Sue Waddington**
 Chief Nurse Head of Clinical Services
 St Gemma's Hospice Sue Ryder Wheatfields Hospice
 329 Harrogate Road Grove Road
 Leeds Leeds
 LS17 6QD – Tel: 0113 2185500 LS6 2AE – Tel: 0113 2787249

Please put this form into the freepost envelope provided and post it back to us.
 We can make this information available in Braille, large print, audio or other languages on request.

If you have misplaced your envelope, please send your completed questionnaire to:
 Healthwatch Leeds, Gipton Fire Station, Gipton Approach, Leeds LS9 6NL

Thank you for taking part in this survey.






End of Life Care Survey 2019-2020
 This survey should take around 5 minutes to complete

On behalf of the team at the hospice, 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 the autumn on the Leeds Palliative Care Network website and the Healthwatch Leeds website.

Please return this survey in the FREEPOST envelope provided (no stamp is needed). There is also an option to complete the survey online at:
<https://www.surveymonkey.co.uk/r/Hospice201920>
 You can also scan the QR code on the right.

If you need help filling in this form contact Healthwatch Leeds on 0113 898 0035

Please complete the survey by the end of April 2020



1. Please tell us where your relative or friend was cared for in the last days and hours of life?
 St Gemmas Hospice
 Sue Ryder Wheatfields Hospice

2. Do you feel that your relative or friend died in the right place? (Please tick one only)
 Yes No Don't know

Please use the box below if you would like to tell us more.

3. 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 per row)

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	N/A
Relief of pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relief of symptoms other than pain (e.g. nausea, restlessness)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious, cultural & spiritual support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respecting wishes before and after death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being cared for with privacy and dignity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care e.g. help with washing/ going to the toilet/ change of position	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If there was anything else that you would like to add, please tell us more in the box below.

4. During this time: (please answer all that apply)

	Yes	No	N/A
Were the staff professional?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did the staff make time for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel you could ask questions/raise concerns?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were you given information about how to register a death?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were you given information about how to contact a funeral director?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were you given information about accessing support for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. We would also like to know what we did well and where we can improve. Please use the box below.

Appendix 2 Hospital Survey

Equality Monitoring information (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.

8. What was your relative/friend's gender?

- Male
 Female
 Prefer not to say

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

- 18-19 20-29 30-39 40-49 50-59
 60-69 70-79 80-89 90+ Prefer not to say
 Don't know

10. What was your relative/friend's religion?

- Buddhist Christian Hindu Jewish Muslim
 Sikh No religion Prefer not to say Don't know

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

- White British White Irish Mixed White and Asian
 Mixed White and Black Caribbean Mixed White and Black African Asian/Asian British
 Bangladeshi Asian/Asian British Indian Asian/Asian British Pakistani
 Chinese Black/Black British Caribbean Arab
 Gypsy or Irish Traveller Prefer not to say

If any other ethnic background, please state here

If you have a complaint or concern, please contact:

Complaints Patient Experience Team, St James' Hospital, Trust Headquarters, Beckett Street, Leeds LS9 7TF

Contact the Patient Advice Liaison Service (PALS) Team

Tel (0113) 206 6261 – Available 9.00am – 4.30pm Monday to Friday
Tel (0113) 206 7168 – for queries outside of normal working hours, please leave a voicemail.

Email: patientexperience.leedsth@nhs.net

Please put this form into the freepost envelope provided and post it back to us. We can make this information available in Braille, large print, audio or other languages on request.

If you have misplaced your envelope, please send your completed questionnaire to: Healthwatch Leeds, Gipton Fire Station, Gipton Approach, Leeds LS9 6NL

Thank you for taking part in this survey.



End of Life Care Survey 2019-2020

This survey should take around 5 minutes to complete

On behalf of the Leeds Teaching Hospitals NHS Trust, 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 the autumn on the Leeds Palliative Care Network website and the Healthwatch Leeds website.

Please return this survey in the FREEPOST envelope provided (no stamp is needed). There is also an option to complete the survey online at:

<https://www.surveymonkey.co.uk/r/LTHTEOL2020>

You can also scan the QR code on the right.

If you need help filling in this form contact Healthwatch Leeds on 0113 898 0035

Please complete the survey by the end of April 2020



1. Please tell us which hospital your relative or friend was cared for in their last days of life?

2. If you know the ward please state

3. Do you feel that your relative or friend died in the right place? (Please tick one only)

- Yes No Don't Know

If no please tell us more below.

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 per row)

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	N/A
Relief of pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relief of symptoms other than pain (e.g. nausea, restlessness)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious, cultural & spiritual support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respecting wishes before and after death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being cared for with privacy and dignity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care e.g. help with washing/ going to the toilet/ change of position	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. During this time were you offered a drink?

- As often as you would have liked Not as often as I liked
 No

6. Were you offered information about any of the following? (Please tick if yes)

- Where to obtain food and drink Prayer room / areas of worship
 Quiet / Family room Where toilets were located for your use
 Car parking permit (if applicable) Overnight accommodation
 Shower / Bathroom for your use Option to stay with relative/friend outside of visiting hours
 Comfort care pack (which might have included toiletries, pen/notebook) Updates on your relative or friend's condition

7. We would also like to know what we did well and where we can improve. If there is anything else you would like to add, please tell us more in the box below

Appendix 3 Community Survey

Equality Monitoring information (optional)

Can you please complete this section with your relative/friends 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.

8. What was your relative/friends gender?

- Male
- Female
- Prefer not to say

9. What was your relative/friends age when he/she died?

- 18-19
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90+
- Prefer not to say
- Don't know

10. What was your relative/friends religion?

- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Sikh
- No religion
- Prefer not to say
- Don't know

11. Please could you indicate which ethnic group in your opinion he/she belonged to:

- White British
- White Irish
- Mixed White and Asian
- Mixed White and Black Caribbean
- Mixed White and Black African
- Asian/Asian British
- Bangladeshi
- Asian/Asian British Indian
- Asian/Asian British Pakistani
- Chinese
- Black/Black British Caribbean
- Arab
- Gypsy or Irish Traveller
- Prefer not to say

If any other ethnic background, please state here

Help us get it right

If you have a complaint, concern, comment or compliment please let us know by speaking to a member of our team. We learn from your feedback and use the information to improve and develop our services.

Please contact:

Heather McClelland

Chief Nurse

St Gemma's Hospice

329 Harrogate Road

Leeds

LS17 6QD – Tel: 0113 2185500

Sue Waddington

Head of Clinical Services

Sue Ryder Wheatfields Hospice

Grove Road

Leeds

LS6 2AE – Tel: 0113 2787249

Please put this form into the freepost envelope provided and post it back to us. We can make this information available in Braille, large print, audio or other languages on request.

If you have misplaced your envelope, please send your completed questionnaire to: Healthwatch Leeds, Gipton Fire Station, Gipton Approach, Leeds LS9 6NL

Thank you for taking part in this survey.



End of Life Care Survey 2019-2020

This survey should take around 5 minutes to complete

On behalf of the team at the hospice, 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 the autumn on the Leeds Palliative Care Network website and the Healthwatch Leeds website.

Please return this survey in the FREEPOST envelope provided (no stamp is needed). There is also an option to complete the survey online at:

<https://www.surveymonkey.co.uk/r/Hospice201920>
You can also scan the QR code on the right.

If you need help filling in this form contact Healthwatch Leeds on 0113 898 0035

Please complete the survey by the end of April 2020



1. Please tell us where your relative or friend was cared for in the last days and hours of life?

- St Gemma's Hospice
- Sue Ryder Wheatfields Hospice

2. Do you feel that your relative or friend died in the right place? (Please tick one only)

- Yes
- No
- Don't know

Please use the box below if you would like to tell us more.

3. 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 per row)

	Vary satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	N/A
Relief of pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relief of symptoms other than pain (e.g. nausea, restlessness)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious, cultural & spiritual support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respecting wishes before and after death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being cared for with privacy and dignity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care e.g. help with washing/ going to the toilet/ change of position	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If there was anything else that you would like to add, please tell us more in the box below.

4. During this time: (please answer all that apply)

- Were the staff professional? Yes No N/A
- Did the staff make time for you? Yes No N/A
- Did you feel you could ask questions/raise concerns? Yes No N/A
- Were you given information about how to register a death? Yes No N/A
- Were you given information about how to contact a funeral director? Yes No N/A
- Were you given information about accessing support for you? Yes No N/A

5. We would also like to know what we did well and where we can improve. Please use the box below.