# “We don’t talk about death enough”

## LGBTQ+ People’s Perspectives on Palliative and End of Life Care

Supported by
Superdrug

# Contents

# Foreword by Paul Knox

## Chair of Marie Curie's LGBTQ+ Staff Network

*"I'm gay."* Two words that may seem simple on the surface. But for me, each time I say them comes with a now well-rehearsed thought process. How is this person going to react? Where do they stand on LGBTQ+ issues? Am I in danger of harm? Am I in a safe place? For most LGBTQ+ people, these questions flash through our minds in the blink of an eye. We often have to come out whenever we enter a new space or meet new people, which is an exhausting experience to live over and over again. We can never be sure of the outcome when we share part of ourselves with someone who will likely assume we are heterosexual.

As a cisgender white gay male, I'm aware of the immense privilege I have within my community. So, I can only imagine what it is like for trans people or LGBTQ+ people from BAME (Black and Minority Ethnic) backgrounds sharing their identities as they navigate life.

We always feel vulnerable when we ask ourselves these questions. But imagine asking them when you are at your most vulnerable: the end of your life. Being at the end of our lives is an experience in which I'm sure we all want to feel safe, protected and cared for. We deserve for all our needs to be met and our priorities recognised, and to have the best possible experience as we close our final chapter of life. Healthcare providers have a huge role to play in facilitating this safe space for us all, so it's more important than ever that they have the information and tools to make this happen.

The pandemic has shown us the very real problem we have in the UK when it comes to health inequity, which is why it's important we do something to make a difference. I count myself lucky to work at the core of the UK's leading charitable provider of end of life care and use my own experiences as a member of the LGBTQ+ community to drive forward positive change for those who need our support.

Marie Curie's partnership with Superdrug aims to address the shortcomings our society faces in equitable access to care and this important piece of research will help inform not only the work we do at Marie Curie, but in turn the many health and social care providers across the UK. Only by fully understanding the needs of diverse communities, will we make the biggest difference to the final months, weeks, days, and hours of people's lives.

# Executive Summary

Marie Curie aims to improve end of life experiences for everyone, in a way that reflects what matters to them. Unfortunately, we know some people in our society are less likely to receive high quality care and support towards the end of life.

Research indicates that experiences of discrimination for LGBTQ+ people are common in many settings, including health care. This can present barriers to supporting someone who is part of the LGBTQ+ community in a way that is right for them towards the end of life.[1-5]

Marie Curie funded the research project "Hiding who I am"[6] in 2016 which highlighted how LGBTQ+ people face particular challenges in accessing the person-centred palliative care and support that they need. Much has changed since the publication of this seminal report but more work is needed to address the challenges faced by LGBTQ+ people.

This report provides fresh insight and recommendations to improve palliative and end of life care for LGB people. The low number of participants reporting a transgender, queer, or other identity means that further research is needed to explore their specific perspectives and experiences. It has been produced in partnership with Superdrug with whom we have a longstanding relationship, built upon a mutual desire to improve the health and wellbeing of everyone in our society.

> **"Research indicates that experiences of discrimination for LGBTQ+ people are common in many settings, including health care.**

Our findings, based on 2,261 respondents, indicate that as a society we don't talk enough about death and dying. Among our sample, differences were identified in responses from heterosexual people and different groups within the LGB community regarding priorities and needs for the end of life. The important role of friends in supporting LGB people towards the end of their life was highlighted as well as the importance of meeting cultural needs. Our key findings are summarised below:

- **Lesbian, gay and bisexual (LGB) people were more likely than heterosexual people to say being surrounded by friends would be a top-three priority at the end of their lives.** Just under half of gay men said this would be a top-three priority in their final year of life (46%) compared to less than one in four heterosexual people (23%).
- **LGB people were less likely than heterosexual people to prioritise being surrounded by family at the end of life.** Just over half (56%) of LGB people said family would be a top-three priority, compared to four out of five (81%) heterosexual people. Similar results were found for priorities in the final year of life.
- **LGB people were less likely than heterosexual people to prioritise being free of pain and other symptoms during the end of life.** On average, about two out of five (38%) LGB people said this would be a top-three priority, compared to three out of five (60%) of heterosexual people. Similar results were found for priorities in the final year of life.
- **Gay men were more than three times more likely than heterosexual people to say having their cultural needs met** would be in their top three priorities when rating needs for end of life care. **Bisexual people were also twice as likely to prioritise cultural needs than heterosexual people.**

These findings highlight changes that could be made to improve the care and support received by LGB people and those close to them towards the end of life. Based on these results we put forward the following recommendations:

- Health and social care professionals should recognise that LGB people may have **specific needs and desires** about the people they want around them for support, and this may or may not include family members.
- **Assumptions about a preference for support from family or friends should not be made**, and instead professionals should have open conversations about who their LGB patients want around them for support at the end of life.
- **The inclusion of "friends"** in materials for patients and those close to them should be considered to recognise the important role that friends can play in supporting people towards the end of life.
- **Cultural needs** may be particularly important for LGB people, highlighting a need for training for professionals to recognise and support cultural needs during caring activities and end of life planning.

# Introduction

The "Hiding who I am" report, published in 2016, highlighted the significant barriers to palliative care that lesbian, gay, bisexual and transgender (LGBT) people can experience. These barriers included fear of discrimination, fear of not being accepted or respected, concerns about a lack of support for people close to them and assumptions about their identify that left them hesitant to truly be themselves. Concerns such as these meant that almost three-quarters (74%) of the LGBTQ+ people who contributed to the "Hiding Who I am" report were not confident that health and social care services could provide sensitive end of life care for their needs.[6]

Many LGBTQ+ people have experienced multiple societal barriers to living life fully and safely. Negative past experiences in settings including health care can result in delayed presentation to health care services when someone becomes ill or may mean they are less likely to disclose personal information such as their sexuality to health care providers, which can limit opportunities for person-centred care.

LGBTQ+ people also experience disproportionately worse health outcomes and a higher incidence of life limiting illness compared to cisgender heterosexual persons due to increased stress risk behaviour such as smoking and/or alcohol use and being more likely to live in poverty.[7]

Common barriers reported by LGBTQ+ persons who receive end of life care include discrimination, heteronormative language and a failure by institutions to create LGBTQ+ friendly environments while providing care.[8]

A recent literature review of research into the experiences of LGBTQ+ people in relation to palliative care confirmed that there remains a need for research that focuses on the lived experience of LGBTQ+ people, particularly older LGBTQ+ adults. The review also highlighted how heteronormative cultures that assume or reject a person's sexuality and gender preferences added to the challenges faced by LGBTQ+ people towards the end of their lives. The review also noted a tendency among the research papers reviewed to treat LGBTQ+ individuals as a homogenous group, without acknowledging distinct subgroups.

Clearly there is a need to understand more about the attitudes, preferences and needs of LGBTQ+ people with regards to palliative care, death and dying to help us deliver care that meets the needs of everyone. This project aims to add to the existing evidence by exploring the preferences and attitudes to death, dying and palliative care among a sample of people who identity as LGB.

## What were our aims?

This project aimed to explore preferences and attitudes to death, dying and palliative care among a sample of Superdrug Health and Beauty Card members. We aimed to explore differences in responses from heterosexual people and people from different sectors of the LGBTQ+ community to develop recommendations for health care providers and other organisations with the potential to improve palliative and end of life care for LGBTQ+ people.

> **"This project aimed to explore preferences and attitudes to death, dying and palliative care among a sample of Superdrug Health and Beauty Card members.**

# What did we do?

We developed a survey (appendix 1) using a selection of questions from a survey developed by the Marie Curie Palliative Care Research Department at Cardiff University which were designed to explore attitudes to death and dying among the UK public[10]. This survey was sent to Superdrug's Health and Beauty Card members who completed it online. We also asked Health and Beauty Card members to tell us their gender identity, their sexual orientation, their age and where they lived in the UK.

## Who took part?

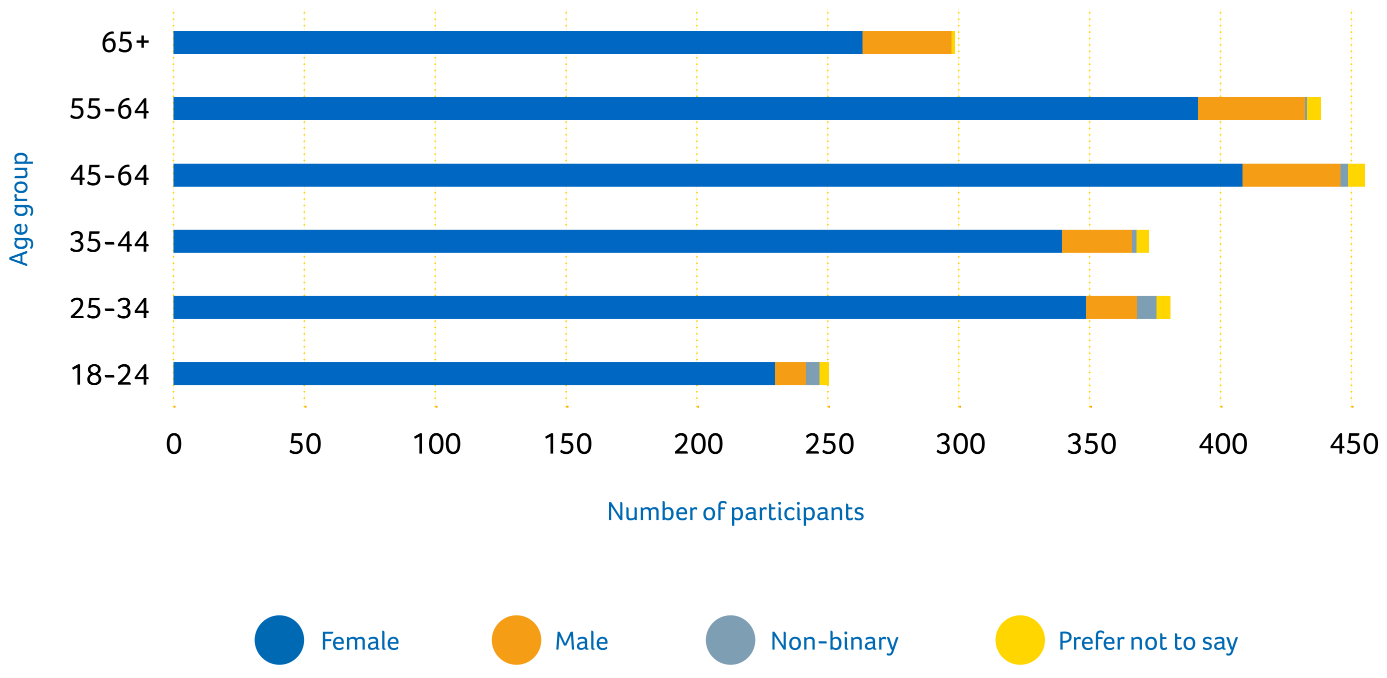
A total of 2,261 people took part in the survey, from a range of backgrounds. Demographic details can be seen in the tables and charts below.

For broad comparisons, differences between heterosexual, cisgender people and people from the LGBTQ+ community were examined. When looking at specific differences among identities, the perspectives of lesbian, gay and bisexual people (LGB) were considered. The low number of participants reporting a transgender, queer, or other identity means that further research is needed to explore their specific perspectives and experiences.

## Age and gender

The majority of participants (almost 90%) were female. Less than 1% identified as non-binary and 2.5% did not wish to disclose their gender. All age groups were well-represented, with slightly fewer individuals in the youngest and oldest age groups.

*Age and gender of participants*



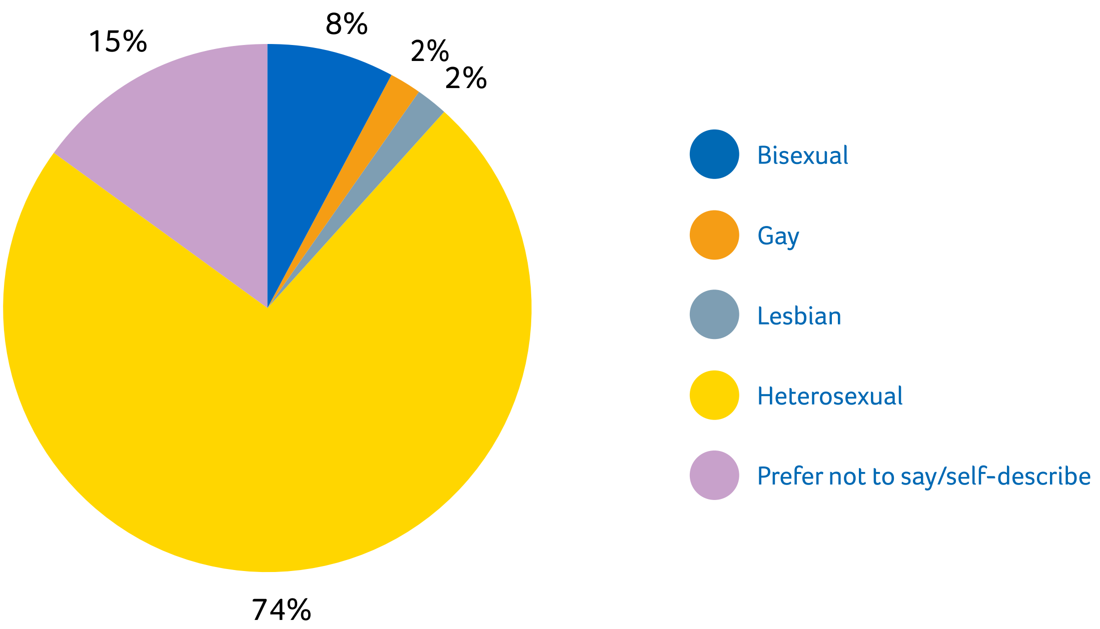
## Sexual orientation

12% of participants identified as part of the bisexual, lesbian or gay (LGB) communities. This is substantially larger than the 2-3% population estimate of LGBTQ+ people in the UK according to the Office of National Statistics[11] (though this national estimate may not be robust[12]). The 12% of respondents who did identify as LGB allowed for a variety of statistical analyses to be conducted to examine their experiences and answers compared to heterosexual individuals.

## LGBTQ+ community

People who participated came from bisexual, lesbian, gay, transgender, agender and non-binary and heterosexual backgrounds. When analyses were done comparing all LGBTQ+ people to heterosexual and cisgender people, the LGBTQ+ acronym is used. For analyses that look at differences between specific identities, only those from a lesbian, gay or bisexual background were able to be considered due to low number of transgender and non-binary people that completed the survey. For these analyses, the shorter acronym LGB will be used.

*Sexual orientation of participants*

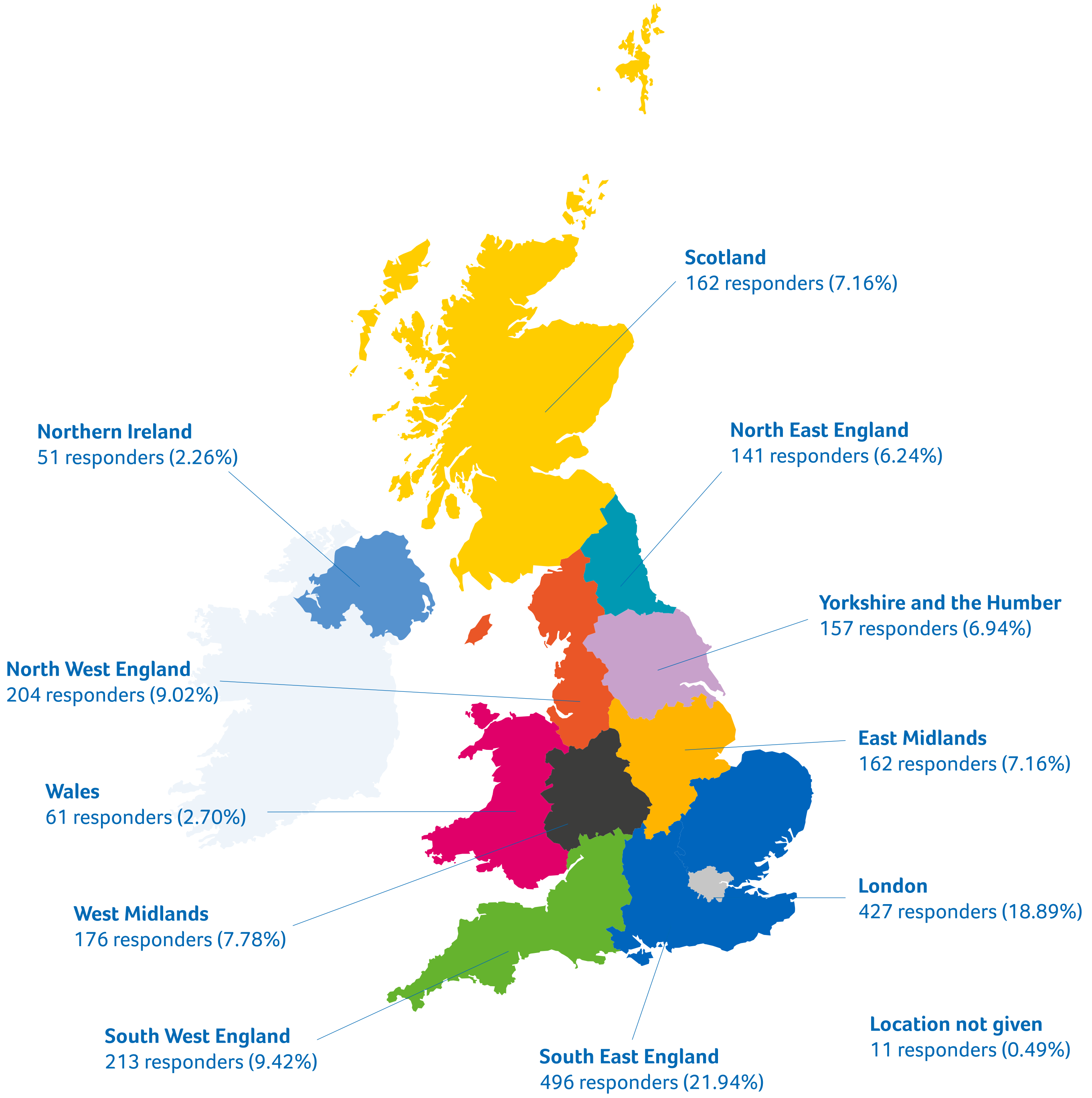


## Region of the UK

Participants were from all parts of the UK. The largest portion came from London and the Southeast, but all regions were represented (see below breakdown).

## Ethnicity

Most participants (80%) identified as white. Within participants from minority ethnic groups (19%), the largest groups were those from black (30%), Indian (24%), Pakistani (13%) or multiple backgrounds (13%).



# Findings: Talking about death and dying

Most people agreed that as a society we don't talk enough about death and dying. These views were expressed regardless of sexual orientation.

> "We don't talk about death enough. People should be happy and comfortable before dying and everyone should be prepared in advance to lesson burdens."
>
> Female who preferred not to disclose her sexual orientation, aged 25-34

## How to increase discussions about death and dying

Among those who felt that we don't talk enough about death and dying as a society, the top three ways we could address this were:

- talking about the matter openly when someone you know dies
- talking about own preferences for end of life with loved ones
- learning about death and dying at school.

Only 2% of respondents indicated that death should not be discussed due to its "sad and uncomfortable" nature, which shows the vast majority of people are open to discussion around death and dying.

## Evaluations of services around death and dying

Participants were asked to evaluate various aspects of end of life care by sharing how strongly they agreed or disagreed with various statements such as "there are adequate health and social care services available for people who are approaching end of life" and "in general, people who are dying are treated with dignity and respect by health and social care professionals."

There were no differences between LGB individuals and heterosexual individuals in their overall evaluation of end of life services. On average, end of life services were rated at the centre of the scale near the "neutral" opinion option. This may reflect a general level of unfamiliarity with end of life services leading to the absence of firm positive or negative opinions in general.

> "Deaths in my family have made some surviving members severely depressed...
> I feel that they weren't appropriately supported before and after the death which makes present discussions more difficult."
>
> Person aged 18-24 who preferred not to say their gender identity or sexual orientation

## Importance of planning for death and dying

> "I feel it is important to discuss this before it's needed so that family know your wishes in advance and do not need to question or worry about that."
>
> Bisexual female, aged 35-44

People were asked how important they thought it was to plan in advance for serious illness and dying. Most participants, both LGB and heterosexual, chose the strongest option, "very important", and less than 1% said it was "not at all important", indicating that planning ahead is a priority for people when they consider serious illness.

## Benefit of planning for death and dying

> "...Having plans in place can ease the stress on the person who is sick, and the confusion afterwards when things need to be planned, and gets rid of a majority of the 'well what do we think they would of wanted' questions."
>
> Female aged 25-34 who preferred to self-describe her sexual orientation

People were asked what the most important benefit would be from planning their end of life care. Overall patterns were the same for both LGB people and heterosexual people, with both groups being most likely to choose "reducing stress around planning and making decisions about my care."

> "I like to be open and honest and truthful with my immediate family as it's a fact of life (as sad as it is). If I express my future wishes with my husband (NoK) [Next of Kin] then it takes a little stress out of any future decisions he would have to make for me as he'd know my wishes."
>
> Bisexual female aged 25-34

Though the overall pattern was the same, when each answer was looked at individually it was seen that LGB people were more likely than heterosexual, cisgender people to see "creating openness among friends" as the greatest benefit of end of life planning.

# Findings: Feelings about death and dying

## Comfort level discussing and planning for death and dying

People were asked how comfortable they felt discussing various aspects of death and dying, both in general and with specific people in their lives. For example, their comfort level with "funeral arrangements" or discussing "death and dying with family."

LGB and heterosexual people showed a similar level of comfort discussing death and dying with friends, family and medical professionals.

More than half of responders said they were either comfortable or very comfortable with each type of discussion, with both medical professionals and family members.

> "I come from an open family where death has been discussed openly in a variety of ways. Therefore I don't think there is anything that prevents me from talking about it with any circle of people."
>
> Bisexual female aged 25-34

> "I'm a very open and honest person and have had interest in Green death and modern funeral practices for a while and like to talk about it."
>
> Non-binary aged 18-24 who preferred not to disclose their sexual orientation

However, between 8% and 18% said 'not at all comfortable' to each option. While many people were comfortable discussing their end of life, a sizeable majority were not. This indicates that people may need support to help them have such discussion with their loved ones at the end of life.

> "It is inevitable and no need not to talk about my own, though I wouldn't ask my mum who is very old but I would ask my sister who is comparable age to me."
>
> Gay man aged 45-54

> **"Between 8% and 18% said 'not at all comfortable' to each option. While many people were comfortable discussing their end of life, a sizeable majority were not.**

# Findings: What prevents or encourages discussion about death and dying?

People were given an open-ended space to explain anything that prevented them from talking about death and dying. Across respondents, a number of themes were identified that either prevented people from discussing death and dying or meant they were comfortable or more likely to talk about these issues. These themes were described by people from all groups, with no major differences between respondents from each sector of the LGB community or heterosexual and cisgender respondents.

The following things prevented people talking about death and dying:

### Feeling like death and dying are taboo subjects or that they would make others feel uncomfortable

> "It's seen as taboo to be open about death. It makes a lot of people feel uncomfortable."
>
> Female aged 25-34 who preferred not to disclose her sexual orientation

### Worry about upsetting others, including finding it more difficult if they had younger children and hesitant with people who are in early stages of grief

> "[I feel] concern about the reaction of friends and family, worry that I may upset them."
>
> Bisexual woman aged 45-54

### Fear or anxiety around death and dying

> "Absolutely terrified to approach the subject."
>
> Gay man, aged 45-54

> "My fear of dying, although this is something that I'm working through in order to be more comfortable discussing these topics."
>
> Non-binary agender aged 25-34 who preferred not to say their sexual orientation

### Uncertainty about their own wishes around death and dying

> "Not entirely sure what my wishes would be"
>
> Bisexual woman, aged 25-34

On the other hand, other factors were found to be helpful in encouraging people to talk about death and dying, including:

### Viewing death as a natural and inevitable part of life and wanting to be prepared for it

> "We all have to die one day, it's not something anyone can pass so I would rather talk about it and express what I want to happen."
>
> Bisexual woman aged 35-44

### Having previous experiences of bereavement which made death and dying seem less mysterious

> "I've had enough friends and family die that it is something I feel I can talk about openly..."
>
> Bisexual man aged 25-34

### Professional knowledge of death, dying and bereavement support and services

> "The women in my family are nurses and carers so we have always been open about death."
>
> Gay man aged 18-24

> "I work as a paramedic and am aware of what is available, how to access and support/care for people who are end of life."
>
> Gay woman/lesbian aged 45-54

### Wanting to make their own wishes for the end of life known and lessen any burden on friends and family

> "I want to be certain that my wishes are known."
>
> Female aged 45-54 who preferred not to disclose her sexual orientation

> "I have been honest with my kids and the rest of my family, being disabled you have to face these issues and lessen the burden on my family."
>
> Bisexual woman aged 45-54

# Findings: Knowledge about death and dying and support available

People were asked to share how strongly they agreed or disagreed with statements about how much knowledge they had around end of life care. They were asked whether they knew where to find information on end of life planning, who among their loved ones they could talk to about end of life, what palliative care is and how it can support them, and finally where to find support if they were bereaved.

There were no differences between LGB individuals and heterosexual individuals in their level of knowledge about end of life. Overall, people were not confident in their knowledge levels and tended toward the middle, 'neutral' option.

> "The reality of it and the lack of education I have."
>
> Heterosexual female aged 18-24
> (an open-ended response to the question: Is there anything that prevents you from talking about death and dying?)

People felt most confident on who among their loved ones they would speak to about planning their end of life, and least confident on where to get information to plan their end of life. This indicates that, while people were able to identify who they could talk to about their end of life wishes, they may not have access to all the information needed to have meaningful conversations about these wishes.

> **"People felt most confident on who among their loved ones they would speak to about planning their end of life, and least confident on where to get information to plan their end of life.**

# Findings: Preferences about death and dying

Participants were asked to share their caring needs and personal priorities for the end of their lives. This was the area where the LGB and the heterosexual communities diverged the most, with significant differences arising in each area. The specific differences are discussed below.

## Needs at end of life

Having a trained carer nearby to help them or their family and having access to professionals for last minute concerns about family or legal affairs, were both consistently in the top three needs for end of life amongst all groups.

One need varied by sexual orientation

- Heterosexual people listed having access to emergency care as a top-three need. This was not one of the most common top three needs listed by LGB individuals.
- LGB people consistently listed privacy as one of their top three needs. This was not one of the most common top three needs listed by heterosexual individuals.

When comparing the needs for each aspect of end of life care, more differences were found in the responses from different LGB groups.

- For bisexual people, gay men and lesbians, access to emergency care was less likely to be a top-three need.
- For bisexual people and gay men, having a trained carer nearby was less likely to be a top-three need.
- For bisexual people and gay men, having cultural needs met was more likely to be a top-three need.

## Personal priorities for the final year and final days of life

When comparing the top three priorities by group, being surrounded by family was most frequently chosen as a top-three priority for the final year and final days of life for people of each sexual orientation.

The following differences were noted in personal priorities for the final year and final days of life:

| | Personal priority 1 | Personal priority 2 | Personal priority 3 |
|---|---|---|---|
| **Final year of life** | | | |
| Heterosexual people | being surrounded by family | free of pain and other symptoms | Being at home |
| Bisexual people | being surrounded by family | chose making decisions about their care | being free of pain and other symptoms |
| Gay men | being surrounded by family | being surrounded by friends | Being surrounded and personal belongings/pets |
| Lesbians | being surrounded by family | being surrounded by friends | Being at home |
| **Final days of life** | | | |
| Heterosexual people | being surrounded by family | Being at home | free of pain and other symptoms |
| Bisexual people | being surrounded by family | being free of pain and other symptoms | being in a calm and peaceful atmosphere |
| Gay men | being surrounded by family | being surrounded by friends | Being surrounded and personal belongings/pets |
| Lesbians | being surrounded by family | being free of pain and other symptoms | being in a calm and peaceful atmosphere |

## Key differences between groups for the final year of life and final days of life

- For bisexual people, gay men and lesbians, being surrounded by family was less likely to be a top-three priority during their final year and days of life.
- For gay men and lesbians, being surrounded by friends was more likely to be a top-three priority during the final year and days of life.
- For gay men, being surrounded by their personal things/pets was more likely to be a top three priority during final year and days.
- Bisexual people were less likely to say being at home was a top-three priority for the final year of life.
- Bisexual people and gay men were less likely to say being free of pain and other symptoms was a top-three priority in the final year and days of life.
- Bisexual people and lesbians were less likely to rate appointing someone to make care decisions for them as a top-three priority in the final year of life.
- Lesbians were also less likely to rate appointing someone to make care decisions for them as a top-three priority in the final days of life.

> **"When comparing the top three priorities by group, being surrounded by family was most frequently chosen as a top-three priority for the final year and final days of life.**

# Conclusions

This work has highlighted important learning for health and social care professionals and organisations around the importance of involving those who are important to a person with a life limiting illness, and an awareness that this may not be the person's biological family. This should be reflected in the information that is provided to people approaching the end of their lives and those close to them. Furthermore, people from LGB groups identified having their cultural needs met as one of their top three priorities for the end of life.

Previous research describes LGB people's fear of experiencing discriminatory attitudes, heteronormative cultures and the negative impact of assumptions about someone's identity on the experiences of LGBTQ+ people. Our recommendations support the findings of research that suggest that the characteristics of positive experiences with healthcare staff for LGB people included asking about their partner and acknowledging the nature and importance of the relationship, clear signposting towards support in line with their preferences for disclosure, and communicating a clear and visible message of acceptance and support[4,5].

There may be different person-centred priorities and clinical considerations specific to gender identity[13], as well as additional social, financial and bereavement support needs as a result of the wider societal implications[13,14] which warrant further investigation.

As a society, we have much work left to do to enable people to feel comfortable and supported in having conversations about their wishes and the wishes of their loved ones towards the end of life and also in providing care that meets the needs of individuals. We are pleased that this work can contribute to Marie Curie's existing diversity training. Sharing the knowledge gained through this work and implementing findings from previous research to educate health and social care providers about the needs of different groups has the potential to positively impact the end of life experiences for many.

> **"As a society, we have much work left to do to enable people to feel comfortable and supported in having conversations about their wishes and the wishes of their loved ones towards the end of life.**

# Recommendations

In order to continue to improve the care and support received by everyone, we put forward the following recommendations based on the findings of this report:

- Health and social care professionals should recognise that people from the LGB community may have specific needs and desires about the people they want around them for support, and this may or may not include their family members.
- Assumptions about a preference for support from family or friends should be avoided, and instead professionals should have open conversations about who their LGB patients want around them for support at the end of life.
- The inclusion of "friends" in materials for patients and those close to them should be considered to recognise the important role that friends can play in supporting people towards the end of life.
- Cultural needs may be particularly important for LGB people, highlighting a need for training for professionals to recognise and support cultural needs during caring activities and end of life planning.

# Next Steps

Learning from this work will be incorporated into Marie Curie's existing diversity training so our staff are equipped to care for LGB people. This work represents another step in our ambition to reduce inequity in palliative care access by highlighting aspects of care and support that are important to different groups.

Evidence that considers lived experiences of LGBTQ+ individuals and acknowledges the different needs of subgroups and their intersection with social determinants of health is still limited and more work is needed to understand the issues and perspectives of these groups[10].

Marie Curie is committed to tackling inequity in palliative care access to ensure that everyone gets the end of life care that is right for them.

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# Appendix 1 – Survey questions

## Demographics

How would you describe your gender identity? (If you would rather not share your answer, please select the "Prefer not to say" option)

1. Male
2. Female
3. Non-binary
4. Prefer not to say
5. Other ___________ please describe [OPEN]

What is your sexual orientation?

1. Bi
2. Gay man
3. Gay woman/lesbian
4. Heterosexual /straight
5. prefer not to say
6. prefer to self-describe

Please state your age

drop down box increasing by 1 year

I live in...

1. Northeast England
2. Northwest England
3. Yorkshire & Humberside
4. East Midlands
5. West Midlands
6. East of England
7. London
8. Southeast England
9. Southwest England
10. Wales
11. Scotland
12. Northern Ireland

Which of the following best describes your ethnicity? (If you would rather not share your answer, please select the "Prefer not to say" option)

1. White
2. British
3. English
4. Irish
5. Northern Irish
6. Scottish
7. Welsh
8. Any other white
9. Mixed / Multiple ethnic groups
10. White and Black Caribbean
11. White and Black African
12. White and Asian
13. Any other Mixed / Multiple ethnic background
14. Asian / Asian British
15. Indian
16. Pakistani
17. Bangladeshi
18. Chinese
19. Any other Asian background
20. Black / African / Caribbean / Black British
21. African
22. Caribbean
23. Any other Black/African/Caribbean background
24. Other ethnic group
25. Arab
26. Any other ethnic group
27. Prefer not to say

If you have moved to the UK from another country, how long have you been in the UK?

1. Less than 5 years
2. 5 to 10 years
3. 10-15 years
4. More than 15 years
5. Not applicable

## Your views about death and dying

As a society, how much do we talk about death and dying?

1. Too much
2. About the right amount
3. Not enough
4. Don't know

You said that we don't talk enough about death and dying as a society. How do you think this can be increased? Please select all that apply

1. Learn about at School
2. Talk openly when someone dies
3. Have media discuss is more
4. Spoken about in family more
5. Talk about EOL preferences with family
6. Don't talk about death, it is sad and uncomfortable

To what extent do you agree or disagree with the following statements about End of Life Care?

Options: STRONGLY AGREE - AGREE - NEUTRAL -SOMEWHAT DISAGREE - STRONGLY DISAGREE

1. There are adequate health and social care services available for people who are approaching end of life.
2. The religious/spiritual needs of people who are thought to be in the last 6 months of their life are supported adequately by End of Life Care services.
3. The cultural needs of people who are thought to be in the last 6 months of their life are supported adequately by End of Life Care services.
4. People who are important to the person approaching the end of life are well supported by End of Life Care services
5. Everyone who is thought to be approaching end of life can access End of Life Care facilities.
6. People who are approaching end of life are able to take part in the decision-making process of their health care.
7. In general, people who are dying are treated with dignity and respect by health and social care professionals.

How important do you think it is to express your future health care preferences in advance of serious illness and dying?

1. Very important
2. Quite important
3. Not that important
4. Not at all important
5. Don't know
6. Other, please specify here [OPEN]

What do you think is the most important benefit of expressing future health care preferences in advance of dying? Please tick one option.

1. Creating openness among family members
2. Creating openness among friends
3. Lessening the burden to family members
4. Reducing stress around planning and making decisions about my care
5. Preventing me from having the treatment I don't want Other, please specify here [OPEN]

## Your feelings about death and dying

How comfortable would you feel about discussing the following topics?

NOT ALL COMFORTABLE, SOMEWHAT COMFORTABLE, COMFORTABLE.VERY COMFORTABLE

1. Death and dying in general with your family
2. Death and dying in general with your friends
3. My End of Life wishes around treatment and care with family
4. My End of Life wishes around treatment and care with friends
5. My End of Life wishes around treatment and care with doctors and nurses
6. Selecting someone who can decide for my treatment decision when I am unable to do it.
7. My End of Life wishes around death (where I want to die, what will happen to my body/organ etc.).
8. My funeral arrangements.
9. Arrangement of my financial affairs.
10. Arrangement for my virtual possessions in the social media accounts (Facebook, Instagram etc.).

Is there anything that prevents you from talking about death and dying?

1. Yes
2. No

Please explain why you said this

## Your knowledge about death and dying

Please show to what extent you agree or disagree with the following statements about the availability of information or services regarding End of Life Care.

STRONGLY DISAGREE, DISAGREE, NEUTRAL, AGREE, STRONGLY AGREE

1. I know where to find information on how to plan in advance for my care at the end of life.
2. If I'd like to make my End of Life Care plans, I know who among my friends or family I could discuss it with.
3. I know what palliative care is and how it can support me and those important to me
4. If someone close to me were to die, I would know where to find support that would meet my needs

## Your preferences about death and dying

Please select the 3 most important needs you would like to be managed during your final days of life.

1. Having access to emergency care
2. Having access to professionals for last minute concerns about my family or legal affairs
3. Having a trained carer nearby to help me and my family
4. Having privacy
5. Having my religious needs met.
6. Having my cultural needs met.
7. Having my spiritual needs met.
8. Don't know.

Please select the 3 most important personal priorities you think you might want to apply during your final days of life.

1. Being surrounded by my family
2. Being surrounded by my friends.
3. Being surrounded by my personal things/pet.
4. Being surrounded by other people around who are going through the same thing, to talk to and provide support.
5. Being in my familiar surroundings.
6. Being at my home.
7. Being in a calm and peaceful atmosphere.
8. Free of pain and other symptoms.
9. Being able to maintain my dignity and self-respect.
10. Feeling safe.
11. Being involved in decisions about my care.
12. If I were not able to decide, being able to involve my family or person I trust to make decisions about my care.
13. Don't know.

Please select the 3 most important personal priorities you think you might want to apply during your last year of life.

1. Being surrounded by my family
2. Being surrounded by my friends
1. Being surrounded by my personal things/pet
2. Being surrounded by other people around who are going through the same thing, to talk to and provide support
3. Being in my familiar surroundings
4. Being at my home
5. Being in a calm and peaceful atmosphere
6. Free of pain and other symptoms
7. Being able to maintain my dignity and self-respect
8. Feeling safe
9. Being involved in decisions about my care
10. If I were not able to decide, being able to involve my family or person I trust to make decisions about my care.
11. Don't know

Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit our website **mariecurie.org.uk**

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