

Thinking and Talking about Palliative and End of Life Care

October 2018

This report is based on conversations or responses freely given by members of the public. Where possible quotations are used to illustrate individual or collectively important experiences.

Engagement officers collect responses verbatim and we also present these in our final report as an appendix. This is important in showing the accuracy of our analysis, and so that further work can be done by anyone wishing to do so.

A full explanation of the guiding principles and framework for how we do engagement and analysis can be found online on our website www.healthwatchbolton.co.uk.

Please note that this report relates to findings observed and contributed by members of the public in relation to the specific project as set out in the methodology section of the report.

Our report is not a representative portrayal of the experiences of all service users and staff, only an analysis of what was contributed by members of the public, service users, patients and staff within the project context as described.

- The theme of Palliative Care and End of Life Care was voted the 3rd most important priority by our members and the public in 2018.
- Bolton's Palliative Care and End of Life Strategy was launched in December 2016, with an aim of consolidating the guidance currently available. In order to address the needs of the local population, the new strategy also aimed to provide clear guidance and direction on good quality end of life care.
- This project will enable both those with experience of palliative and end of life care as well as the general public to share their experiences, thoughts, knowledge, desires, and inform best practice for all providers.
- The project also provides for an opportunity to discuss the sensitive topic of end of life with members of the public and create a debate.

The meaning of 'palliative care'

A significant proportion said they knew the term 'palliative care', though a greater proportion either; directly associated the term 'palliative care' with end of life care, were unsure, or thought the term related to caring.

Talking about palliative care

Though there was some gate keeping behaviour from groups who we worked with around this topic (some thought it insensitive) most people we spoke to were open to talking about palliative care.

Information on palliative care and end of life care

The most popular places to go for information are healthcare professionals or a published information source, primarily the internet.

Ideal end of life support

Home and hospice care were the preferred choices for end of life. Comfort and choice were key concepts for people. Though many people who wished to die at home were concerned about the potential impact on family.

Priorities for end of life care

People wanted end of life care to be well run, provide sensitive treatment, prioritise choice, and include family and friends.

**The first two topics were cross analysed by demographic information. There were slight differences between gendered, ethnic, and age related responses, but overall there was a similar pattern to the overall data for these questions.*

BMC Palliative Care:

- *Public awareness and attitudes toward palliative care in Northern Ireland (2013)*

In this study people were also found to have a generally non-specific understanding of palliative care. The home or hospice was also preferable for end of life care. – see page 3, 6, of the report.

National Council for Palliative Care (NCFPC):

- *A 2030 Vision (2012)*
- *20-20 Vision (2005)*

These two short reports make a wealth of suggestions on how the conversation about palliative and end of life care could be taken forward.

World Health Organization (WHO):

- *Global Atlas of Palliative Care (2014)*
- *Palliative Care (The solid facts) (2004)*

The WHO have produced two reports which detail the global situation on palliative care. They have also produced a useful and clear definition of the term.

**all publications are available online*

Methodology

Who we talked to

- End of life care is something that affects us all and at all ages; the living, the dying, and the bereaved. We engage those with experience of palliative and end of life care and those without.
- The general public with and without experience of palliative and end of life care.
- We aimed to reach around 100 individuals with this engagement.

How we carried out the research

- A survey was available online and on paper and promoted through our website and social media channels, membership list, and primarily through our presence at various community events. We used a snowball sampling method, asking gatekeepers such as the voluntary and statutory sector to publicise the survey and encourage people to participate.
- We collected qualitative, comment based, data about awareness, experiences, personal choice, ideas for best practice and information needs, and individual sensitivities around communication.
- We collected quantitative data on the knowledge and preferences around this subject.
- We collected demographic data from survey participants and, where possible from those participating in guided discussions.

The questions

We focussed on five key questions with the intention of gauging people's awareness of, openness about, and priorities, around palliative and end of life care.

1. What do you know about the term palliative care?
2. If you needed to or have needed to get information about this topic where would you/did you go?
3. Would you feel comfortable talking to those closest to you about end of life?
4. What would you like an end of life experience to be like for yourself or someone close to you?
5. If you were in charge of end of life services what 3 things would you prioritise and why?

We spoke to **178** people in this study. A full list of groups attended can be found at the end of the report.

Gender	Respondents
Female	138
Male	32
n/a	8
TOTAL	178

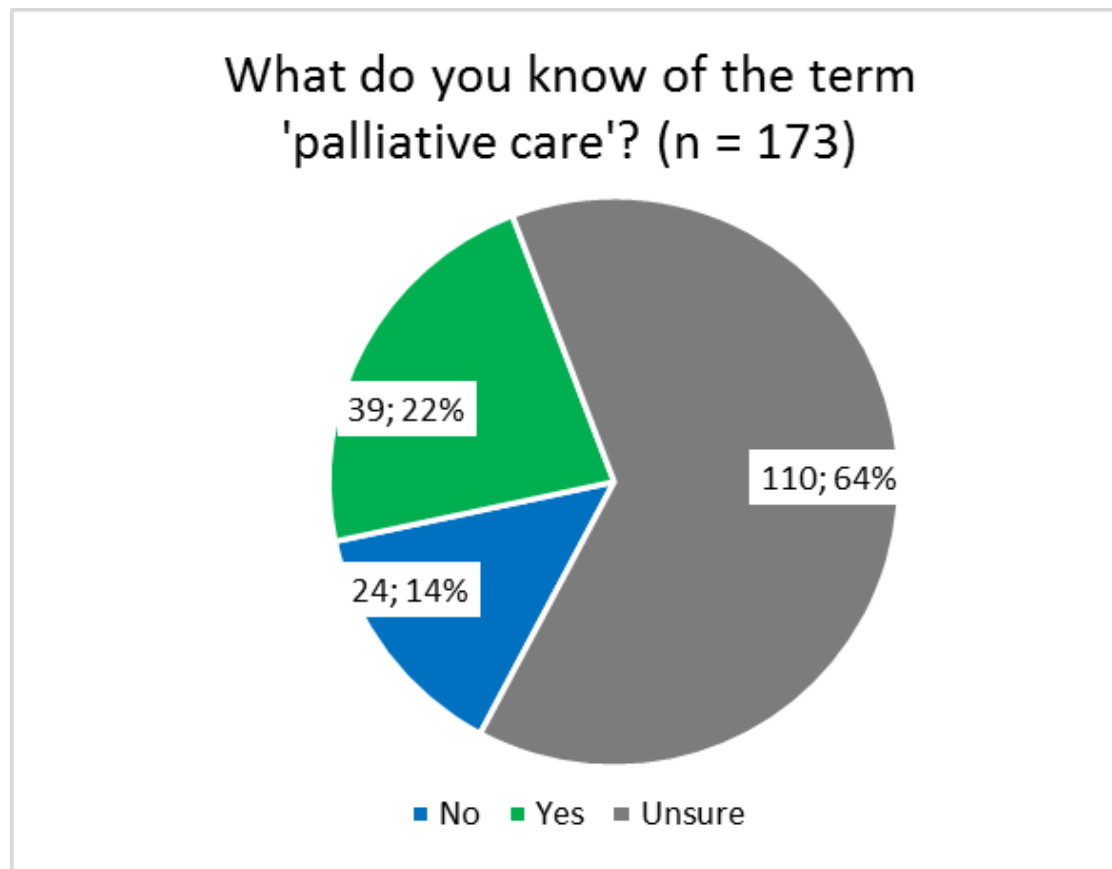
Age	Respondents
16 and under	7
17-25	9
26-35	25
36-45	18
46-55	39
56-65	29
66-75	27
76-85	14
86-95	3
n/a	7
TOTAL	178

Ethnicity	Respondents
African	6
Asian	2
Indian	2
White + Black African	2
White + British	137
White + Irish	2
Other (ethnicity)	9
Other (gave a nationality)	11
n/a	7
TOTAL	178

Analysis – understanding the term ‘palliative care’?

Generally we found that people were not completely confident in recognising the full meaning of palliative care, though most were willing to guess. Palliative care was often associated with end of life, or serious illness.

When we looked at the answers by demographics such as gender, ethnicity, and age, we did not see a large difference to the general findings. The sample size for males and BAME was small, which meant a few responses could shape the overall picture.



**we had 5 responses that were n/a*

“Palliative care is holistic care given to someone with a long-term condition that is not necessarily life-limiting.”

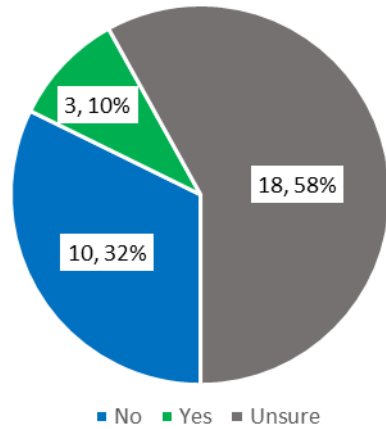
“It’s the care people receive when they are near end of life.”

Roughly a fifth of people said they knew what palliative care meant.

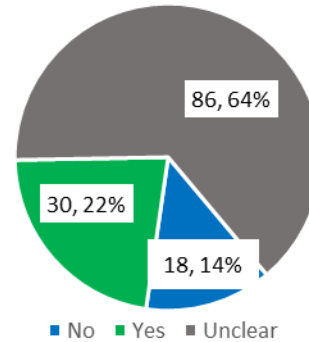
Over half were willing to offer a response, but within this most believed this referred to or involved end of life care (96 people, 55% of the total responses).

Palliative Care – Analysis – Do people recognise the term ‘palliative care’?

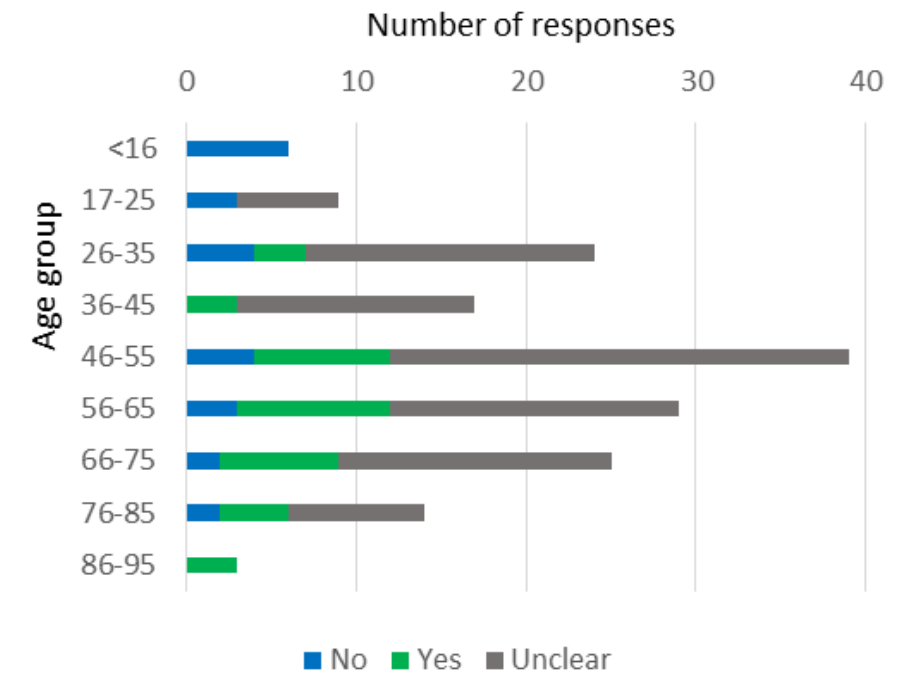
What do you know of the term 'palliative care'? - Male (n = 31)



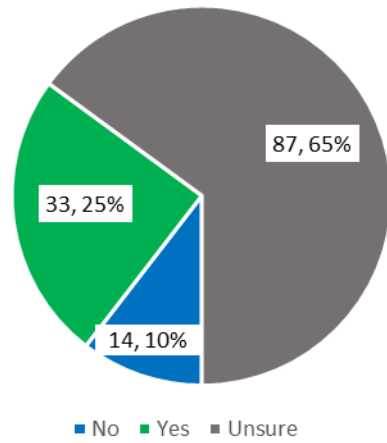
What do you know of the term 'palliative care'? - White + British (n=134)



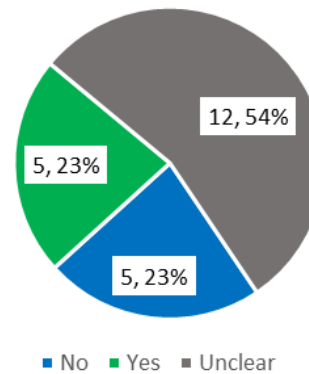
What do you know of the term 'palliative care'? - Age (n = 166)



What do you know of the term 'palliative care'? - Female (n = 134)



What do you know of the term 'palliative care'? - BAME (n = 22)



Analysis – talking about end of life care

Overall the study showed people were willing to talk about the difficult subject of end of life care.

The comments we received showed the many challenges individuals and families have faced which have given them first hand experience of end of life care.

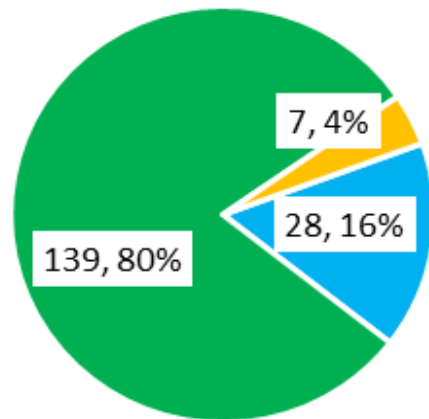
There were some notable reasons why people would not wish to talk about this topic, they could be cultural, down to worry this would cause arguments or upset, people not being able to engage their nearest and dearest in the conversation, people feeling they were too young to talk about it, or people felt that the time for talking about this would come naturally.

“I would probably find it upsetting. I haven't discussed this topic with anyone.”

‘No people will think you are challenging nature or Allah.’

‘Couldn't discuss with husband as he was in denial.
Couldn't discuss with brother as he had dementia.’

Would you talk about EOL with those close to you?(n = 174)



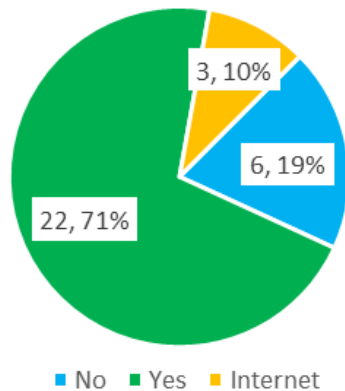
■ No ■ Yes ■ Internet

“Yes we've done so. What prompted the conversation? Getting older - making sure those we leave behind know exactly what to do and also with regard to funerals making sure everyone's final wishes are respected.”

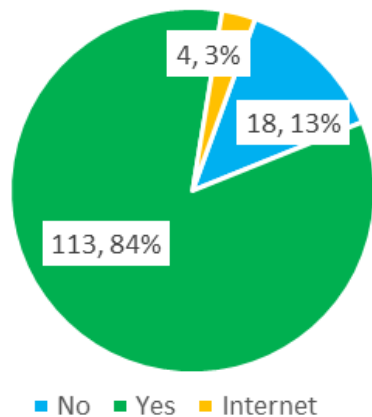
‘Yes. My brother and his partner died from AIDS in the 90s. We learned to talk about dying and death in those terrible years. We talked about stopping treatment and not resuscitating. Where they would like to die, who they would like with them, funerals and burials, what made the days left living good and we learned the power of talking about these things in achieving a happy life and good death.’

Palliative Care – Analysis – Are people comfortable talking to those closest to them about End of Life care?

Would you talk about EOL with those close to you? - Male (n = 31)



Would you talk about EOL with those close to you? - Female (n = 135)



“My Dad was diagnosed with terminal cancer, had many conversations about what he wanted for end of life care, his funeral and will, which we needed to rewrite as my mum had dementia, was very difficult for both of us but must have been unbearable for him.”

‘I also believe in advance directive. I have touched on the subject with my sons’, but they blank it out.’

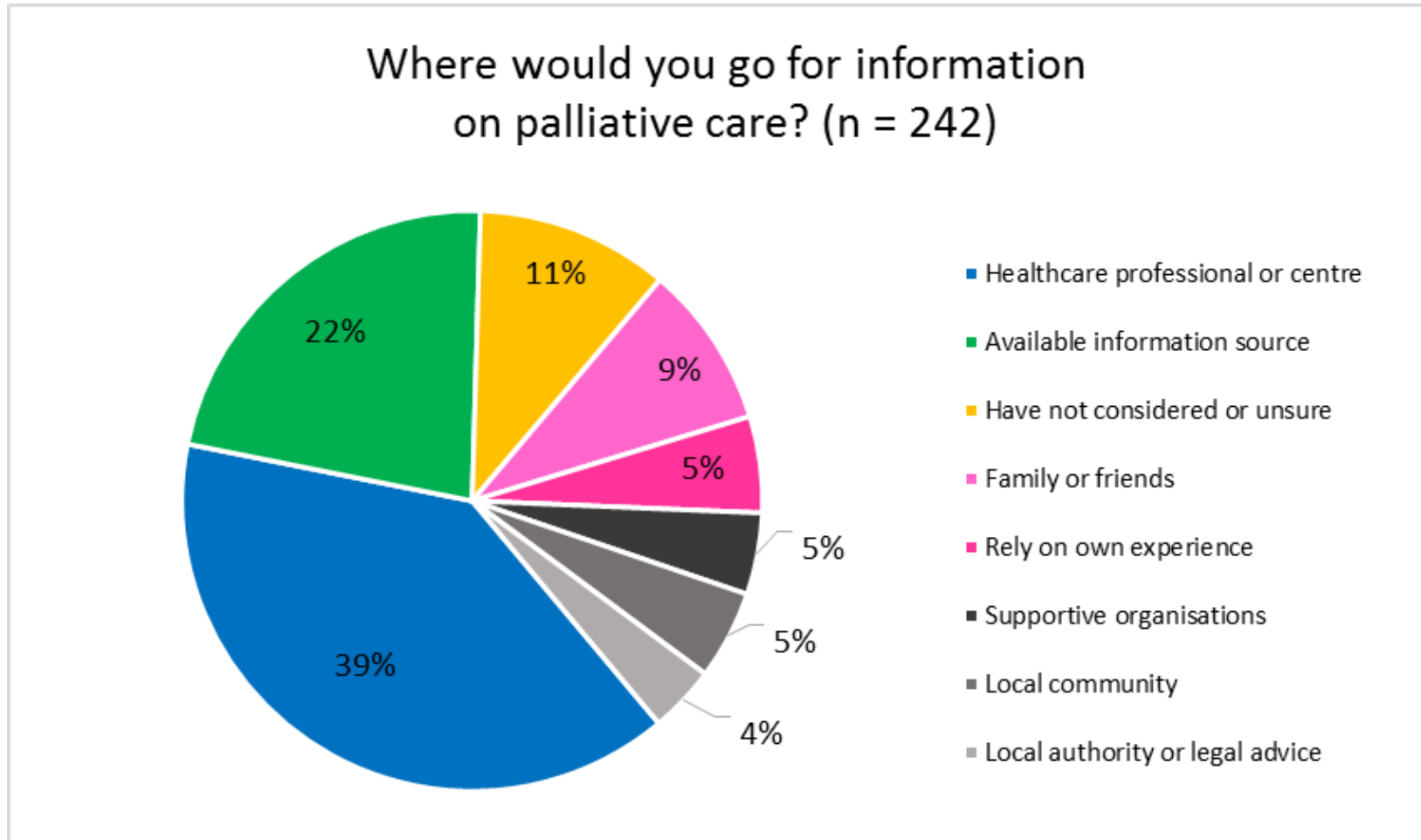
“Yes - this is something that is very important, we need a culture change around talking about end of life instead of brushing it under the carpet. Promote general acceptance of living and dying, more dignity in dying well.”

Analysis – finding information on end of life care

When asked about where people would look for information about end of life care, most people mentioned the health professionals or healthcare system. Either they would seek advice here or would be given advice by those attending to the patient.

Where people said they would seek information from published sources, the internet was highly dominant making up almost all the comments.

Some people mentioned that having sessions at groups they attended had helped them to understand more, and, less popular, but possibly relevant for planners wishing to improve public knowledge, were mortgage advisors, solicitors, charities, and religious groups.



Information Source	Responses
Healthcare professional or centre	95
Available information source	54
Have not considered or unsure	26
Family or friends	22
Rely on own experience	13
Supportive organisations	11
Local community	12
Local authority or legal advice	9

*No category = 15

Healthcare professionals or health related spaces were most likely to be the source of information. Note that 'available information source' was almost completely related to the internet.

“We spoke to Macmillan nurses and staff from Christie’s. we didn’t have any extra emotional room to go hunting for extra information.’

‘My doctor, nurse practitioner or my younger son who is a nurse. I am not aware of anyone/anywhere else I could turn to.’

“Probably Google it or just go on the NHS website.”

“I’d ask at a group like this (Senior Solutions) people here can find things out. We had a speaker the other week about wills it was really useful. I learnt loads and sorted my will out now.”

“Healthcare professional/doctor. I expect they have the knowledge or know someone with knowledge to ensure I find what I’m looking for.”

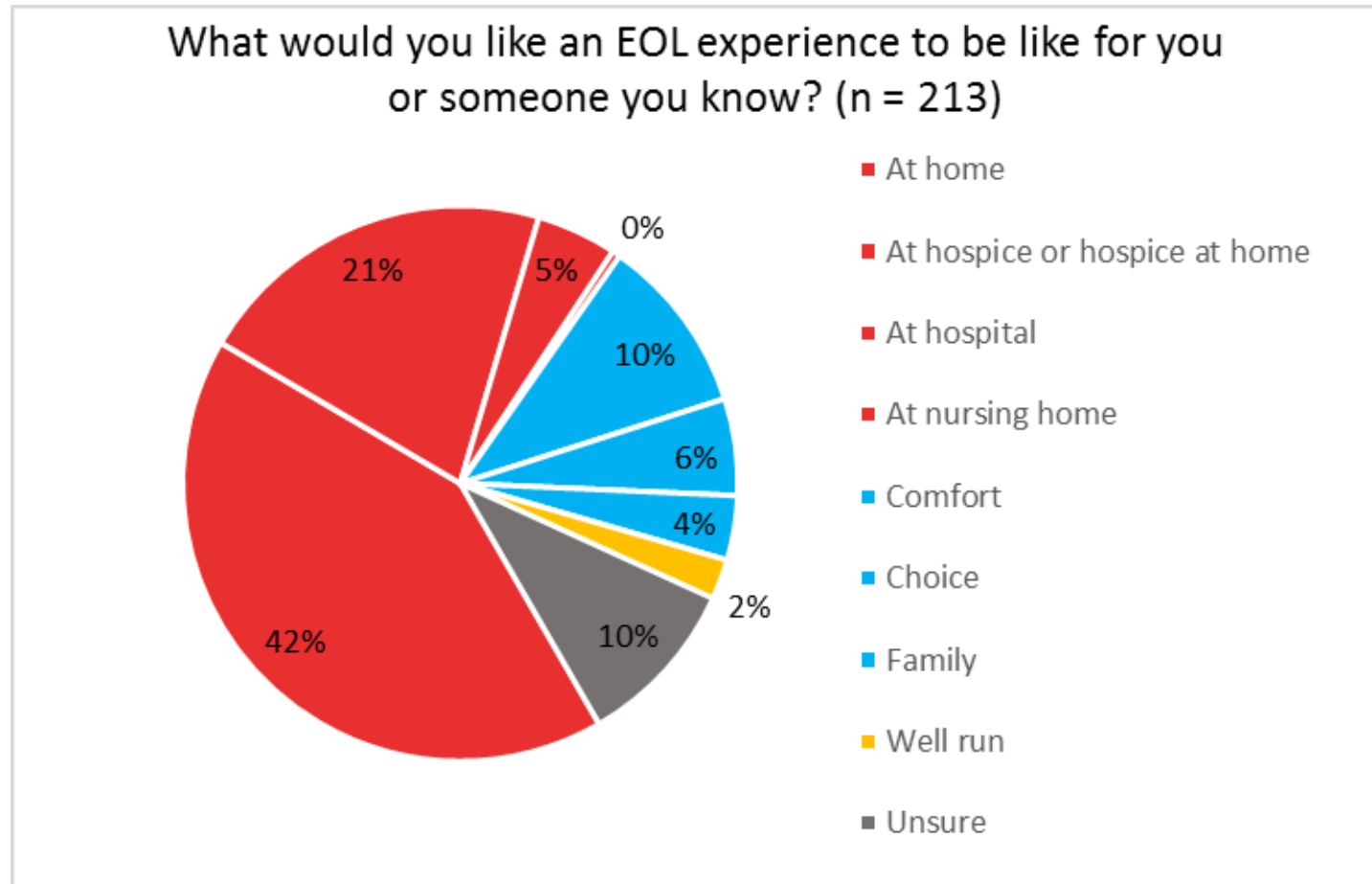
Analysis – thoughts on end of life care

People in this preferred the idea of remaining at home, or being supported by a hospice when nearing end of life.

Though most people preferred home many gave the caveat that this was only if there were not adverse impacts on their family.

There was a consensus around having family, dignity, a caring environment, peace and effective pain management.

It was important that any care given would be well run, which meant effective communication, family involvement and attentiveness to individual needs at a sensitive time.



Important place or issue	Responses
At home	89
At hospice or hospice at home	45
At hospital	10
At nursing home	1
Comfort	22
Choice	12
Family	8
Well run	5
Unsure	21

See page 3 in *BMC Palliative Care: Public awareness and attitudes toward palliative care in Northern Ireland (2013)*, which appears to show a similar ranking of preference for locations.

Palliative Care – Analysis – What do people think End of Life care should be?

“At home, surrounded with friends and family, in a place that is familiar and comfortable, with support to manage my pain and daily living activities.”

“I've not thought about it. I'll cross that bridge as it comes.”

“Home - is my first thoughts, but I know that this can be very difficult for the family that have to care for the patient. Hospice - great care, support for the family members as well as patient, all the necessary drugs, equipment is there and the staff are wonderful.”

“I would like to be at home but understand that hospice care is excellent and would be an acceptable alternative.”

‘I would like to die at home and my family to be supported to care for me, I want to be pain free and comfortable, if my family feel it's too much then my next choice would be the hospice. I would not like to be admitted to hospital.’

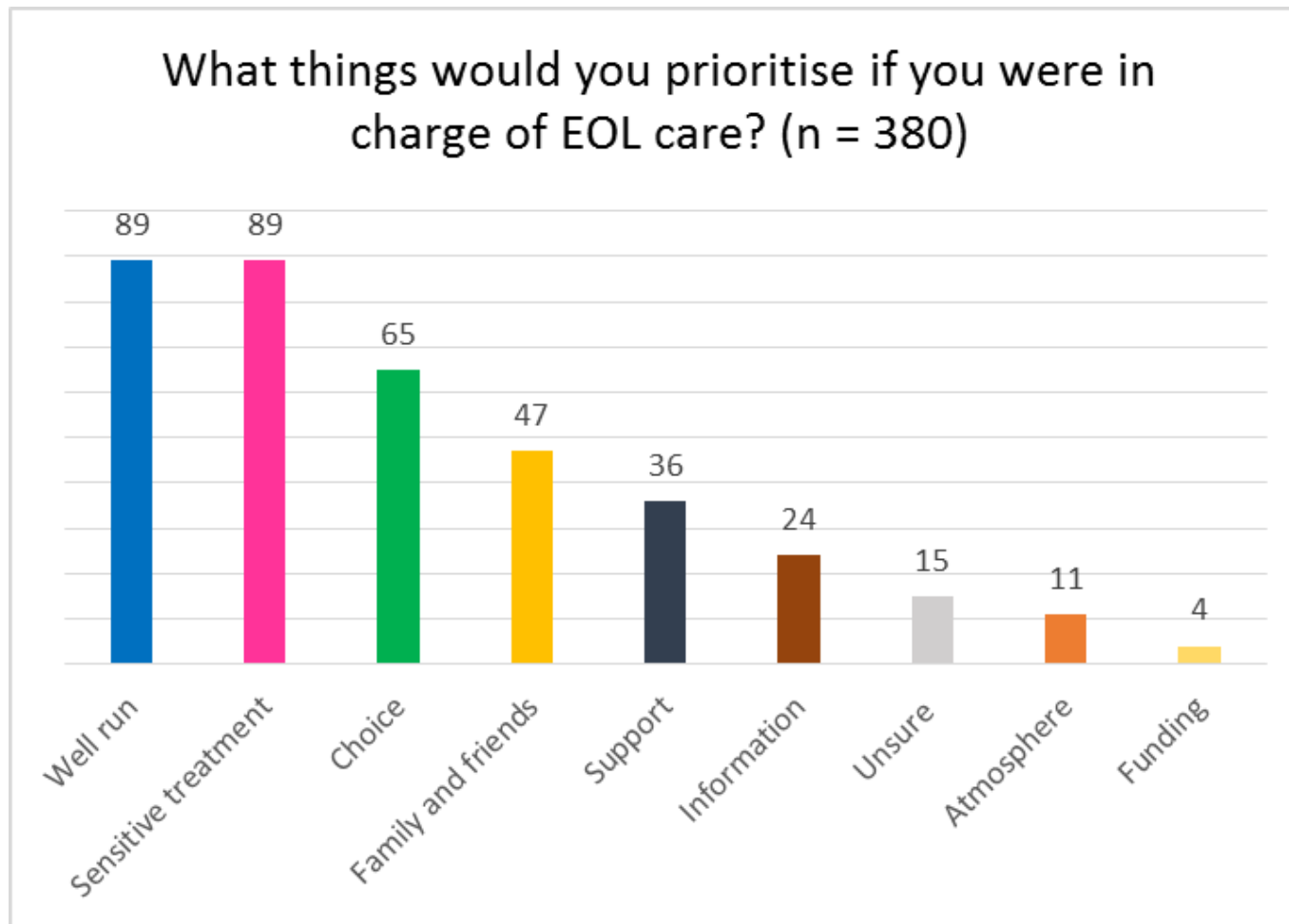
“Not hospital - but can't always choose. Would be fine with hospice. Have visited several people in hospices and really calm, caring, homely atmosphere. Kinder to the family too.”

Analysis – priorities for end of life care

Good, well coordinated services – especially for people who choose to die at home - were important to people.

There was overlap with responses to the previous question, with organisation, sensitivity, choice, and family involvement being important for many.

Based on the responses to this part of the study, people might benefit from some key examples being shown to illustrate the range of options and what to expect from end of life care.



Important place or issue	Responses
Well run	89
Sensitive treatment	89
Choice	65
Family and friends	47
Support	36
Information	24
Unsure	15
Atmosphere	11
Funding	4

People expected services to be well run, which would mean personalised treatment and good communication.

Palliative Care – Analysis – What would people prioritise in End of Life care?

“Quick painless death, comfort for families, affordable meals for families on hospice/hospital stay overs.”

“To include the person, person centred. Help the family understand. Accessibility for all under the accessibility standard and equality act.”

“To make the person as comfortable as possible, to have someone on hand to talk to and to be able to sort out all of my finances etc.”

‘Pain free without suffering . Dignity. At home.’

‘Impact on others. Supporting others. Care at home.’

‘When I die, how and with who.’

“Dignity because we all deserve that. -Experiences and living life to best of ability so it isn't always morbid. -Pain prevention.’

“Faith, family and kind wishes.”

Analysis – other comments

'I'm glad to fill this survey and that you're taking the time to help people talk of what they want on a hard topic.' 'Come visit here, people want to know more.' 'I would like to come to any Healthwatch event regarding End of Life please.'

"Pain is far too low on the agenda No patient should be in pain at the end of their life but quite a lot including myself are."

"When someone is undergoing debilitating treatment there comes a time when this is probably only prolonging life for a short time, so to recognise when to stop treatment and start palliative care is an important point in time."

"Patients should not be denied food or water under any circumstances without their families consent. Water should not be refused under any occasion."

"My dad's end of life care was particularly traumatic simply because it was over the Christmas period, it didn't need to happen like this, carers didn't turn up, district nurses took a long time to come out, took lots of phone calls from the family to sort a lot of this out, very stressful and unnecessary."

People are looking for opportunities to talk more about this subject.

Pain management was a key topic for many

A number of responses highlighted the need to avoid unnecessary suffering, there was concern this could happen

A small number of people directly reference the Liverpool Care Pathway, this has clearly concerned some people, even many years after the discussions.

End of life care co-ordination can be complex, particularly over busy periods.

Conclusions and recommendations

1. This study focused on a difficult topic for many people, either due to many feeling uneasy talking about serious illness, but also the number of respondents with direct experience of their own relatives having passed away, or had palliative care. Nevertheless people expressed interest in talking about palliative and end of life care and many would like more opportunities to do so.
2. We found a consensus around remaining in the home or being supported by a hospice should end of life care be needed. This was desirable due to people wanting choice, privacy, unlimited access for loved ones.
3. People want a well coordinated, compassionate and personalised service that respects their wishes at the end of life. Many people expressed concerns about the impact on their friends and family if they choose to die at home. More information about the practicalities of end of life care at home might clarify choices and help reduce anxieties in this respect.
4. There is a need to explain the difference between palliative and end of life care and an opportunity to clarify the various options that are available for people and the various circumstances in which they might apply. People might find some case studies helpful.
5. People may benefit from more information about advance care plans and power of attorney.

Healthwatch Bolton is aware of the work being done on end of life care pathways in Bolton. This engagement and report was principally intended to support that work by encouraging the public to talk about end of life care, by finding out what people know about end of life care and by finding out what information people would like.

1. Healthwatch Bolton has committed to running a forum/market place on palliative care, end of life and bereavement in early 2019. We would like to invite the Bolton End of Life Care Strategy group to work with us to support this event.
2. We would like the Bolton End of Life Care Strategy Group to work with us to co-produce some information resources to help people think about and discuss palliative and end of life care.
3. We would like the End of Life Care Strategy Group to give some consideration to establishing or encouraging and supporting the establishment of some public information events such as Death Cafes (see below for more details)
 - https://deathcafe.com/c/United_Kingdom/
 - <https://www.theguardian.com/lifeandstyle/2014/mar/22/death-cafe-talk-about-dying>
 - <https://deathfest.net/>

Healthwatch Bolton would like to thank all those that took part in this research or facilitated it to take place.

We are grateful to the following groups who helped us find respondents:

● Band ● Youth Council ● Videobox film club ● Senior Solutions ● Flower Estate Residents Associations ● Macmillan ● Age Well in Brightmet ● Tongue Moor Carers Group ● Dementia Carers Groups ● Jigsaw ● Golden Oldies ● 4 Neighbourhood Health Market Place events (Rumworth, Brightmet & Little Lever, Farnworth & Kearsley & Horwich & Blackrod) ● Healthwatch Bolton Forum ● Farnworth & Kearsley Food Bank

Response from the End of Life Care Strategy Group

This report was presented at the End of Life Strategy Group (EoL) on 6th November 2018. The group thanked Healthwatch for the Report and were pleased to note that many of the themes in the Report were already being discussed and developed by the group.

The EoL Strategy Group has a broad and active programme of development which includes a number of areas covered by the Report.

- In particular the Group has plans to create some specific pages on End of life care and Bereavement services within the Bolton Council 'My Life' web platform.
- The EoL Education Alliance (A sub-group of the Bolton EoLC Group) have activated a programme of education and training to support all partners to provide better information to the public around topics associated with EoL Care. The programme includes a 'Six Steps' style programme for Care Home staff as well as Harm Free Care, delivered by two Hospice staff working specifically with Bolton's Care Homes to support good EoL care in residential settings. The Education programme also includes EoL Care Awareness events for GP Practice staff and GP Practice EoLC leads.
- The Group welcomes Healthwatch Bolton's suggestions around public education events and proposes to set up a 'Dying Matters Week Planning Group to which Healthwatch will be invited. The group will coordinate a series of Public Awareness events for Dying Matters Week 2019.