Healthwatch Cheshire Citizens Focus Panel

Survey 4 - May 2021

Palliative and End of Life Care

Healthwatch Cheshire are helping to plan, shape and improve local health and care services. We're gaining feedback and starting discussions to influence decision making, using your voice to encourage those who run health and care services to act on what matters to you.

Healthwatch Cheshire's Citizens Focus Panel enables us to get feedback on topical issues from a set group of Cheshire residents on a regular basis. Our panel is made up of a wide range of people from all across Cheshire and continues to grow, we're always looking for new volunteers to join us.

This survey is being conducted in partnership with Strategic Collaborative Cheshire (SCC). SCC are leaders of organisations who provide, commission and influence palliative and end of life care in Cheshire. The group also includes people with personal experience of care.

Healthwatch Cheshire and members of the SCC have created a short, online survey to find out what people understand about palliative and end of life care and their attitudes to discussing death and dying. This is a matter that affects everybody at some point in their lives. The survey was shared with 91 of our members during May 2021 and provides a snapshot of the key findings from the 40 responses that we received.

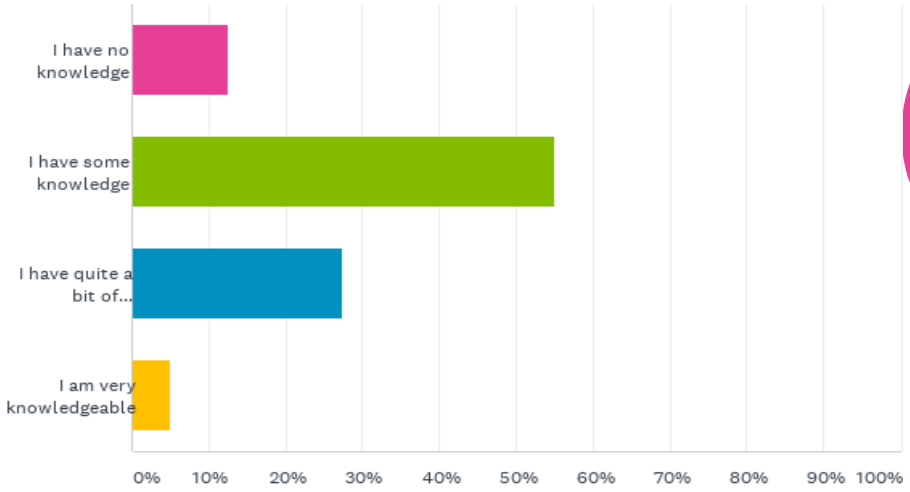
The findings of this report will be used by the SCC to inform the development of a long-term communications and engagement plan around palliative and end of life care. We'll also feed this information into those who provide and commission health and care services to improve the future experiences of people. This includes the Care Quality Commission, Cheshire Clinical Commissioning Group, Cheshire West and Chester and Cheshire East Councils and Local NHS Foundation Trusts as well as our colleagues at Healthwatch England. To view previous reports, please visit:

healthwatchcwac.org.uk/what-we-do/our-reports

healthwatchcheshireeast.org.uk/what-we-do/our-reports

The below questions are illustrated in the form of graphs and word clouds to offer an easy-to-see visual representation of people's responses.

1. How would you describe your knowledge of *palliative* care?



55% told us they had *some* knowledge on this topic

The graph above shows us that the vast majority of people who responded to our survey are aware of and have a reasonable knowledge of palliative care.

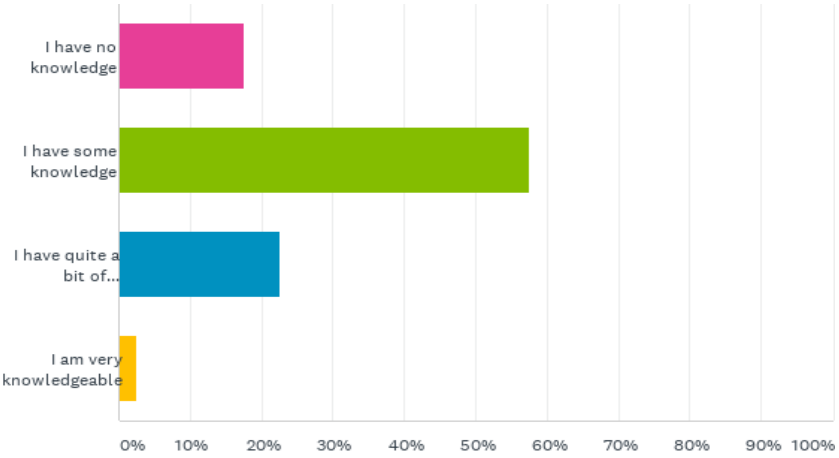
Out of the 40 responses we received, more than half (22 people), told us that they had some knowledge of palliative care. A quarter (11 people) told us that they had quite a bit of knowledge and a little over 10% (5 people) told us they had no knowledge on the topic. Only 2 people told us that they were very knowledgeable.

2. What do you understand by the term "palliative care"?

Respondents to this question overwhelmingly associated Palliative Care with finality; the end of life, terminal illness and increasing comfort in this stage of life.

The Word Cloud above shows a visual representation of the responses to this question on Palliative Care. This highlights popular words and phrases based on their frequency and relevance.

3. How would you describe your knowledge of *end-of-life* care?



58% told us they had *some* knowledge on this topic

The graph above shows us that the vast majority of people who responded to our survey are aware of, and have a reasonable knowledge of, end of life care.

Out of the 40 responses we received, more than half (23 people), told us that they had some knowledge of end of life care. Nearly a quarter (9 people) told us that they had quite a bit of knowledge, whilst 7 people told us they had no knowledge on the topic. Only 1 person told us that they were very knowledgeable.

4. What do you understand by the term "end of life care"?

The Word Cloud above shows a visual representation of the responses to this question on end of life care. This highlights popular words and phrases based on their frequency and relevance.

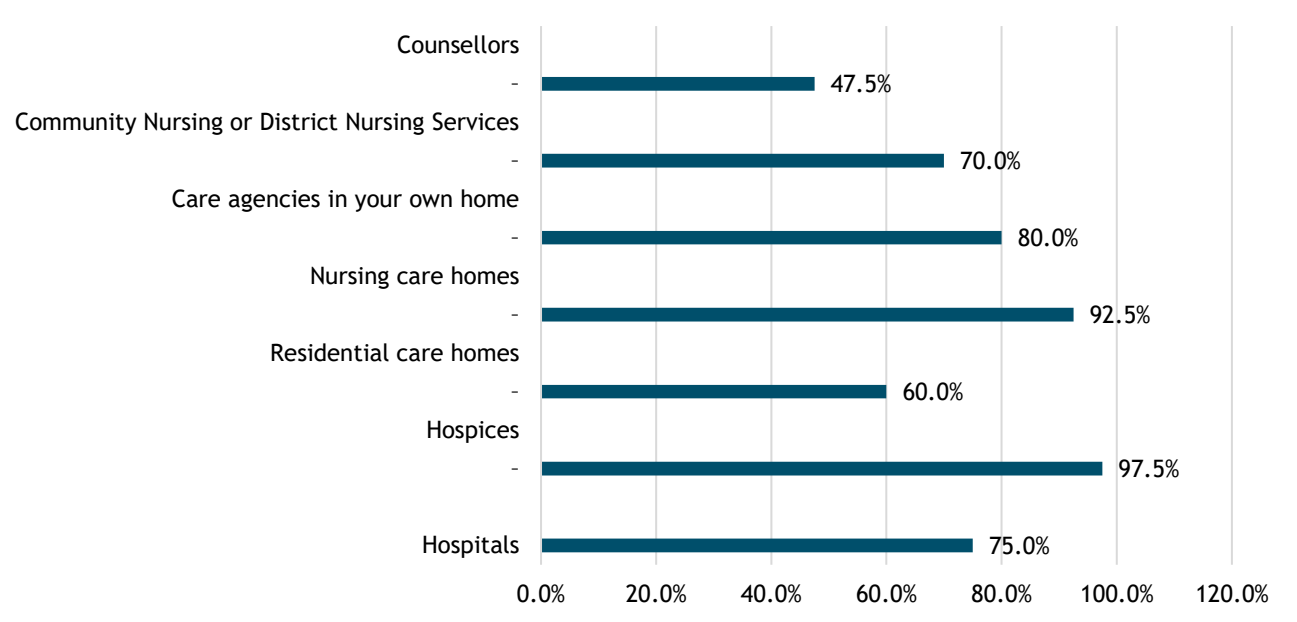
It shows us that people associate end of life care with terms such as; preparation, comfort, pain relief and care in the final stages of life. All of which appear to be positive interventions designed to settle people's affairs and live the final days of life as comfortably as possible.

5. Where does your knowledge of palliative care, or end of life care come from? Tick as many that apply.

ANSWER CHOICES	RESPONSES	
I am receiving palliative or end of life care	0.00%	0
A member of my family is receiving, or has received palliative or end of life care	30.00%	12
A friend is receiving, or has received palliative or end of life care	12.50%	5
My work involves, or used to involve providing palliative or end of life care	17.50%	7
My work involves, or used to involve providing other health or social care services	17.50%	7
General knowledge	60.00%	24
Other (please specify)	20.00%	8
Total Respondents: 40		

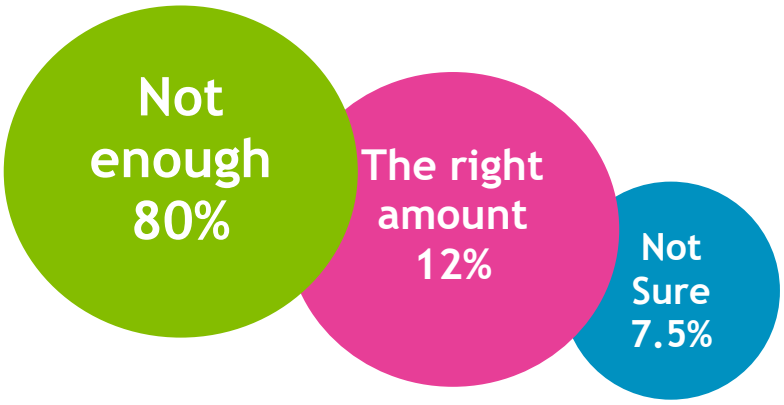
The table above shows us that the vast majority of people we asked, have gained their knowledge or experience of palliative or end of life care from general knowledge or a member of their family receiving or having received end of life care.

6. Which of the following do you think provide palliative care and/or end of life care? Tick as many that apply.



The bar chart above shows us that the vast majority of people we asked, thought that the primary providers of palliative and end of life care are Hospices and Nursing Homes. However, it's also clear from this that most people believe that this type of care takes place in a wide variety of healthcare and community settings.

7. As a community, do you think that we discuss death and dying enough?



ANSWER CHOICES	RESPONSES	
We don't discussion these things enough	80.00%	32
We have about the right amount of discussions	12.50%	5
We discuss these things too much	0.00%	0
Don't know/unsure	7.50%	3
TOTAL		40

From the answers to the question above, we can see that most people believe that we do not talk about death and dying enough in our community.

8. How important do you think each of the following are as a part of palliative care and/or end of life care?

Control of pain and other symptoms at home

Extra help at home

Medical care in a hospice

Very Important

Nursing care at home during the day

Nursing care at home at night

Medical care in a hospital

Bereavement support

Someone to be available by telephone

Information and advice on financial matters

Help at home with housework

Important

Alternative therapies

Someone to talk about spiritual matters

9. What words or phrases come to mind when you think about death and dying?

"End of life."

"Dignity."

"Family."

"Sadness."

"Piece of mind."

"A better place."

"Loss."

"Pain."

"Caring."

"Legacy."

"The unknown."

"A celebration of life."

"Grief."

"Sorrow, anxiety, Uncertainty."

"The End."

"Friends and Loved ones."

"Peace."

Summary

The vast majority of people who responded to our survey are aware of and have a reasonable knowledge of both palliative and end of life care.

A large percentage of people had gathered their understanding from general knowledge, however, most had personal experience of family or friends receiving this type of care, or providing direct or similar services through their own working life.

Interestingly, most who answered associated palliative care with finality, terminal illness and the end of life. However, people associated end of life care with positive interventions, such as; making desirable preparations for death, and living the final stages of life in comfort, free from pain.

Most respondents thought that the primary providers of palliative and end of life care are Hospices and Nursing Homes. However, it's also clear from their responses, that a sizeable number also believed that this type of care can be tailored to people's needs and takes place in a wide variety of healthcare and community settings.

Death and dying is understandably a difficult topic to discuss, but one that affects all of us at some point in our lives. Whatever views, experiences and associations people held on palliative and end of life care, it was clear that, from those that answered our survey, people believe that we don't talk about death and dying enough in our community. The findings of this report will be used by the SCC to inform the development of a long-term communications and engagement plan around palliative and end of life care.