



The Strategic Collaborative  
Cheshire for Palliative and  
End of Life Care

# **Dying Matters Week 2021**

## **Palliative and End of Life Care Survey**

### **Final Report**

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## Introduction

The Strategic Collaborative Cheshire (SCC) is a group 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.

One of the SCC's current priorities is to increase the number and range of opportunities for patients, carers and staff to participate, provide feedback and share their experiences about receiving or providing palliative and end of life care, which is how the idea for this survey came about. The SCC views this survey as a starting point for work to gain a better understanding of people's experiences and to make sure that this learning is used to make services for people in their last years and months of life even better.

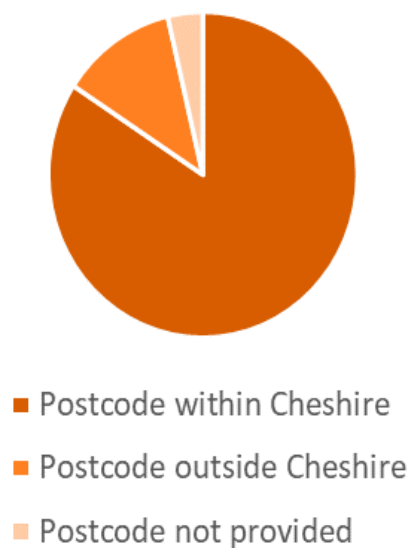
Having identified Dying Matters Week in May 2021 as the ideal time to run the survey, it was distributed through the organisations that make up the Strategic Collaborative Cheshire including the three Cheshire Hospices, NHS providers, local authorities, EOLP and other partners. Social media was identified as an effective, low cost way to reach a relatively wide audience, and partners committed to using social and other media to promote the survey and encourage as many people as possible to take part.

In addition, the survey was completed by members of the Healthwatch Citizen's Focus Panels in Cheshire. Healthwatch Cheshire is an independent voice for the people of Cheshire East and Cheshire West and Chester helping to shape and improve local health and social care services. Citizen's Focus Panels provide feedback on a range of different health and social care issues each month and Healthwatch agreed to use one of these regular surveys to engage their members in this piece of work.

**A total of 272 response were received. 40 responses were from Healthwatch members. The remaining 232 were from the wider public.**

## Where did the responses come from?

- Whilst the focus of marketing activities was on Cheshire, the nature of an online survey is that anyone may choose to respond and we did receive a number of responses from outside this area.
- People were asked to provide the first part of their postcode in order to identify the area in which they lived.
- As expected, the majority (84%) of responses were from Cheshire residents. A further breakdown is shown in Table A in the appendices.
- We did not seek any further demographic information e.g. age or gender.



## Who replied to the survey?

In the introduction to the survey, we emphasised that anyone could respond, whether they had experience of using services or not. However, as the survey was promoted by partners who have an interest in palliative and end of life care, there was a risk that the survey would only reach people who either work in these areas or who already have an interest in them. To identify whether this was the case, respondents were asked where their knowledge of palliative and end of life care came from and then each respondent has been allocated to one of four categories:

Category	Who does this include?
<b>Personal Experience</b>	People who stated that they were currently receiving palliative or end of life care, had a family member who was receiving/had received care or had a friend who was receiving/had received care.
<b>Professional Experience</b>	People working/having worked in palliative and end of life care services, or in other health and social care services.
<b>Personal &amp; Professional Experience</b>	People who reported experiences in both of the categories above, e.g. they may be currently working in healthcare and have had a family member who had received care.
<b>No Direct Experience</b>	People who did not have experience of services in either a personal or a professional capacity.



- Personal experience (36%)
- Professional experience (27%)
- Personal and Professional experience (14%)
- No experience (23%)

- 43% of Healthwatch respondents were from the “no direct experience” category, compared to 19% of respondents from the wider public
- One respondent stated that they were receiving palliative or end of life care.
- A further breakdown of this data is shown in Tables B and C in the appendices.

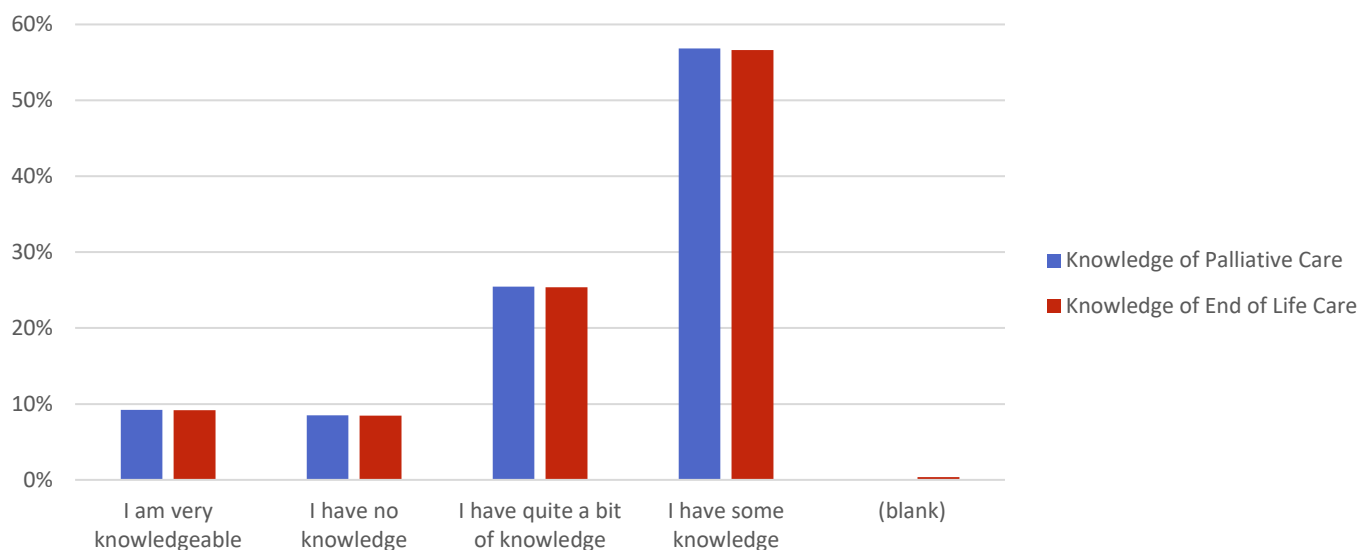
## How much do people say they know about palliative and end of life care?

When people were asked about their level of knowledge of palliative and end of life care, the majority stated that they had some or more knowledge of these subjects.

**90% of people were aware of and have some or more knowledge of palliative care**

**87% of people were aware of and have some or more knowledge of end of life care**

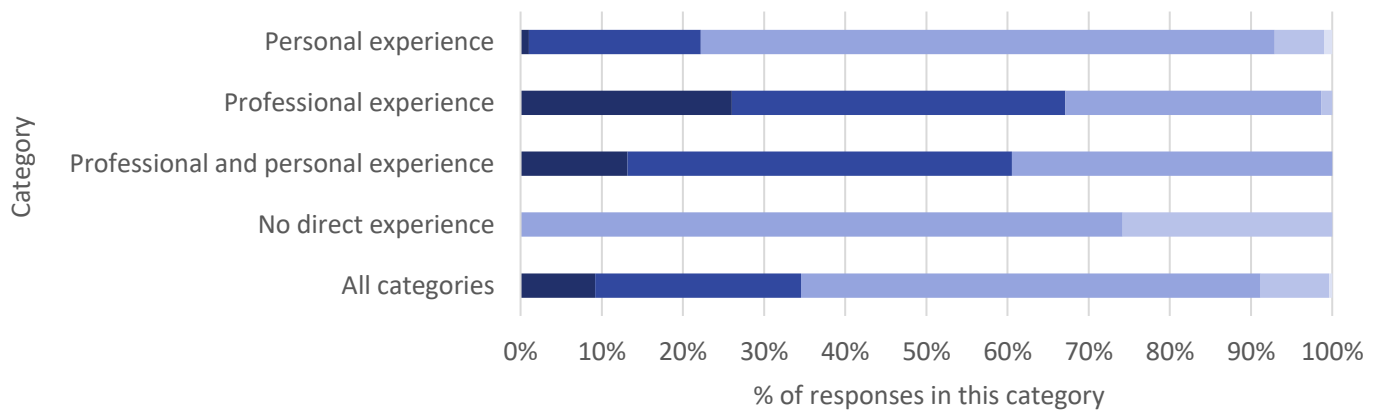
How would you describe your knowledge of ...	Palliative Care	End of Life Care
I am very knowledgeable	9%	7%
I have quite a bit of knowledge	26%	28%
I have some knowledge	55%	52%
I have no knowledge	10%	13%



- Levels of reported knowledge for both palliative and end of life care were broadly similar for Healthwatch members and the wider public. Details are shown in Table D and E in the appendices.

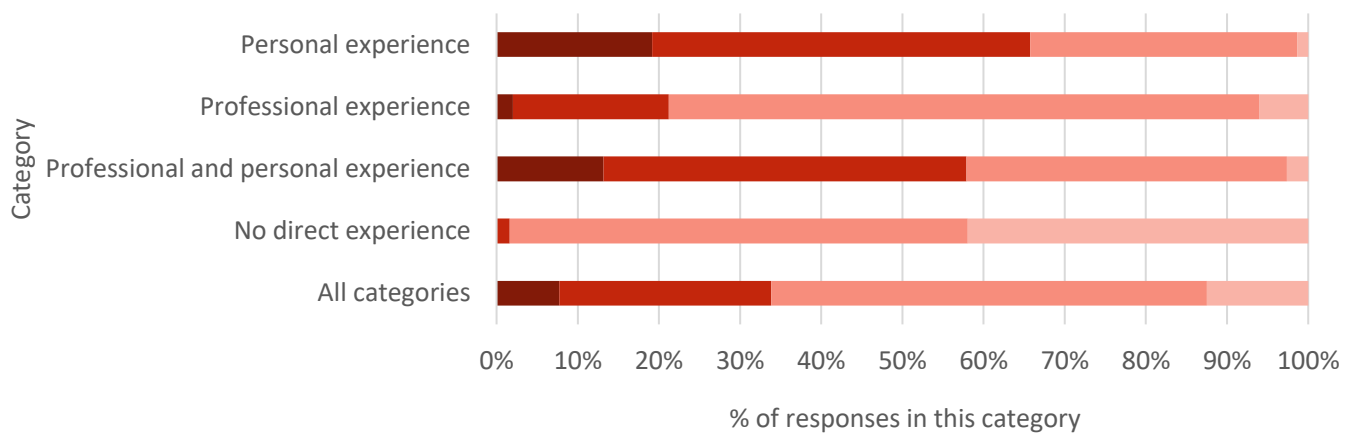
People with professional experience reported higher levels of knowledge about both palliative and end of life care than people who had either personal experience or had no experience of these services. Further information is shown in tables F and G in the appendices.

### Knowledge of palliative care



■ I am very knowledgeable ■ I have quite a bit of knowledge ■ I have some knowledge ■ I have no knowledge ■ Blank

### Knowledge of end of life care



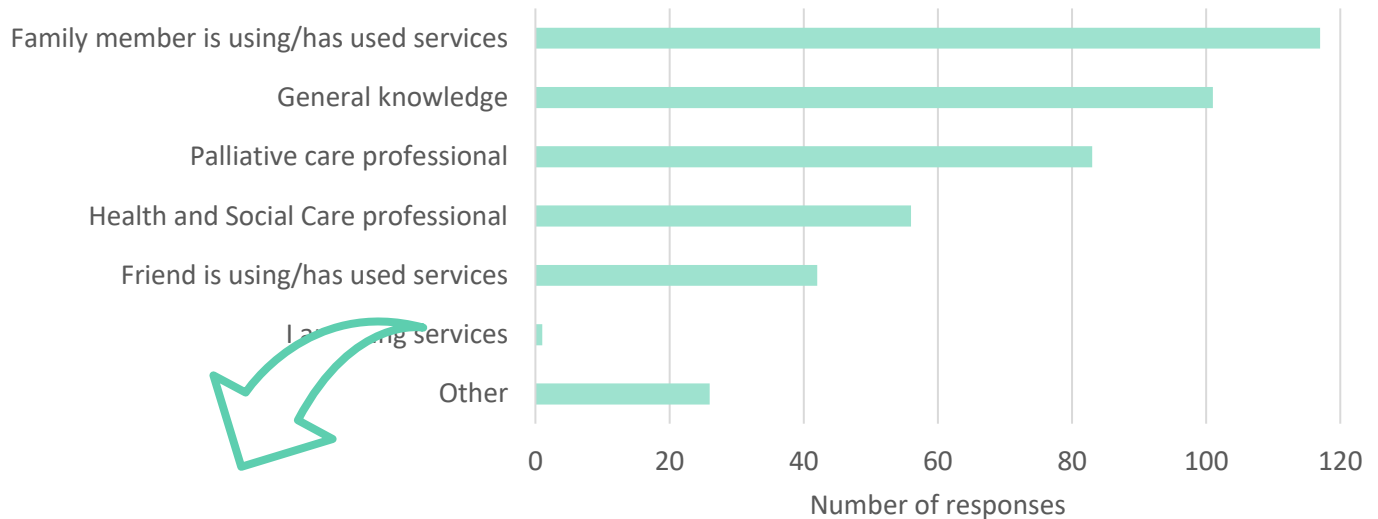
■ I am very knowledgeable ■ I have quite a bit of knowledge ■ I have some knowledge ■ I have no knowledge

## Sources of information and knowledge

When asked where people’s knowledge came from, the option of a family member receiving (or having received) palliative and end of life care scored highest, followed by “general knowledge”.

The chart below shows the number of responses to each of the options given. As respondents could tick more than one option, there are more responses than people completing the survey. Further information is shown in Table B in the appendices.

Where People’s Knowledge Comes From



23 people stated that their knowledge came from “other” sources. These can be broken down by theme:

Working in healthcare setting in a role that did not involve providing care e.g. finance job	8
Personal experience e.g. death of a family member	4
Having family or friends working in palliative or end of life care	4
Indirect personal experience e.g. talking to friends whose loved ones received palliative care.	3
Voluntary experience e.g. in a hospice	3
Media	1



## Perceptions

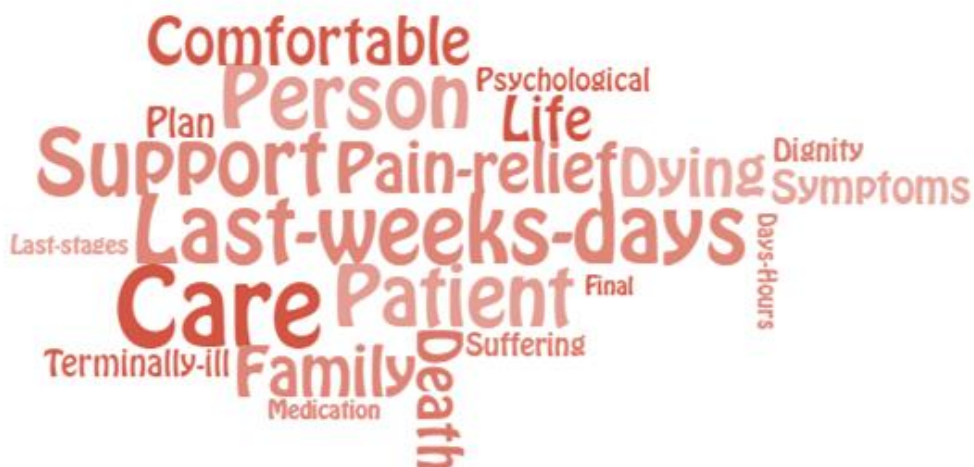
We also asked what people **understood by** the terms “palliative care” and “end of life care”.

The images below show the words or phrases that were used most often in people’s responses and indicate the themes within people’s responses. The size of the text reflects the frequency with which a word or phrase was used, with larger text indicating more occurrences. Many of the themes appear within both images, suggesting that the two terms were closely linked, or even interchangeable to some survey respondents.

### Palliative Care



### End of Life Care

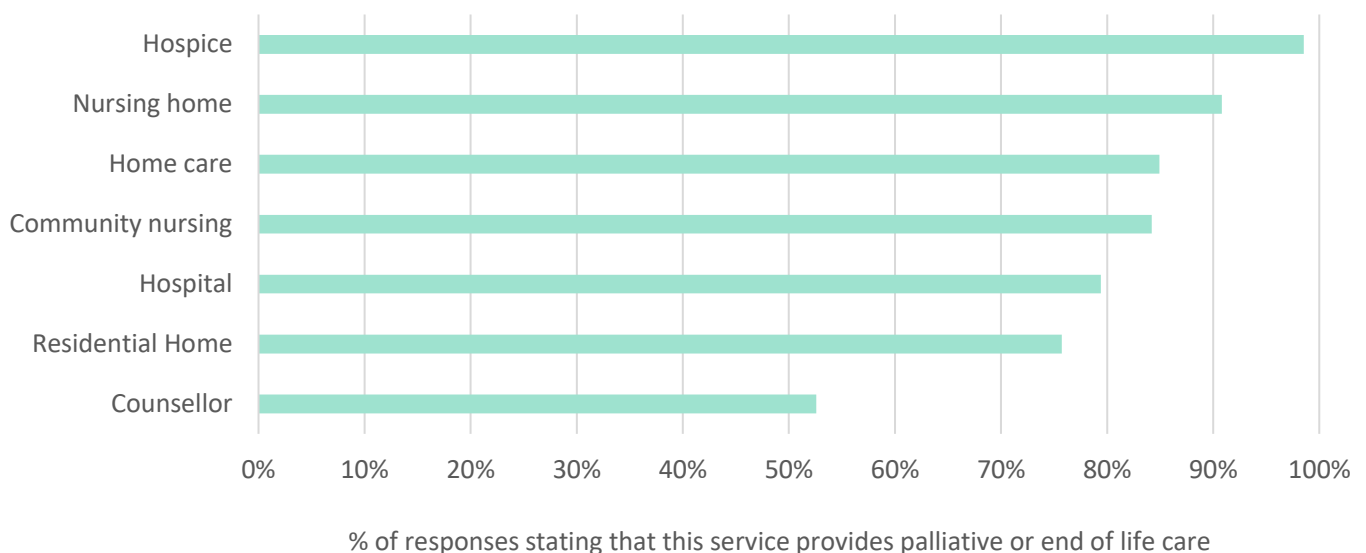


## Which services do people think provide palliative and end of life care?

Respondents were asked whether they thought the services listed below provide palliative and end of life care. The chart below shows which services were identified by respondents as providing this care.

All of the services listed provide palliative and end of life care, however the responses suggest that some providers are more strongly associated with, or recognised for, this type of support than others.

**99% of respondents recognised that Hospices provide palliative and end of life care**  
**53% recognised that counsellors may be involved in supporting people receiving palliative or end of life care**

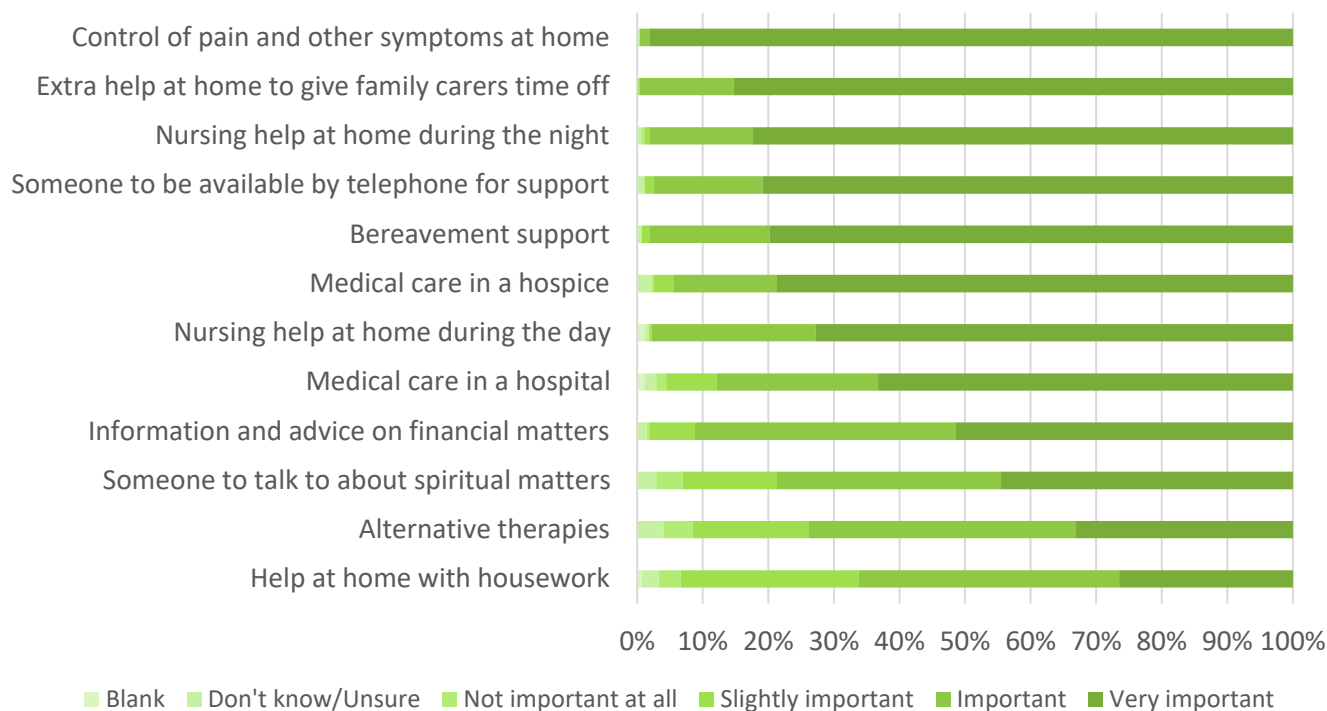


- Respondents from the wider public were more likely to identify residential homes and community nursing as being providers of palliative and end of life care than respondents who were members of Healthwatch. Further detail is shown in Table H in the appendices.
- Professionals were more likely to identify services as being providers of care than people with either personal or no experience of palliative and end of life care. A breakdown is shown in Table I in the appendices.
- When prompted, 12% of respondents suggested “other” providers, and listed a range of individuals and organisations who may provide additional care and support. Family members were cited most frequently, followed by charitable organisations who have a remit around palliative and end of life care including Marie Curie and Macmillan. Table J in the appendices shows more detail.

## How important are different aspects of palliative and end of life care?

We asked people how important they thought a range of different aspects of care were. These included practical and emotional support, support to carers and as well as support with physical health.

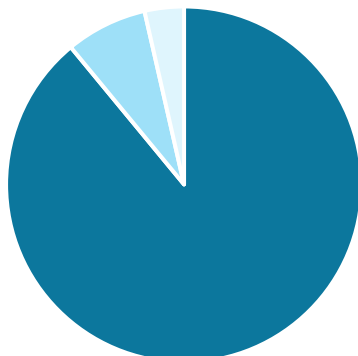
**100% of respondents said that control of symptoms at home and support to give carers a break were very important or important aspects of care.**



- Across all four categories of respondents, control of symptoms and respite care were identified as being important or very important.
- Taking these two responses as a combined %, help with housework scored the lowest with 66% of respondents considering this aspect of care to be important or very important.
- A breakdown by each respondent category is shown in Charts K – N in the appendices.
- A breakdown by each aspect of care is shown in Chart O in the appendices.

## Do we talk enough about death and dying?

89% of respondents said that we don't discuss death and dying enough



- We don't discuss these things enough
- We have about the right amount of discussions
- Don't know/Unsure

- Healthwatch respondents were more likely (12%) than the wider public (6%) to say that we have about the right amount of discussion.
- Of the different categories of respondent, people with both professional and personal experience were most likely to say that we don't discuss death and dying enough (95%). People with no direct experience were least likely to say this (84%).
- Further detail is shown in tables P -Q in the appendices.

We also asked what words or phrases people associated with death and dying and the themes from their responses are collated below. The size of the text reflects the frequency with which a word or phrase was used, with larger text indicating more occurrences.



## How do our responses compare to similar surveys?

The responses to our survey mirror findings from other pieces of work although the format of questions and responses does not allow for direct comparison:

50% of respondents to our survey had personal experience of bereavement	Almost all (97%) of UK adults have suffered a bereavement in in their life, and 40% have experienced the death of more than one person close to them (1)
98% of respondents to our survey thought that access to information and advice on financial matters was important or very important	10% were prevented from talking about their own death because they didn't want others to worry about having to sort out their financial affairs (1)
100 % of respondents stated control of symptoms at home was important or very important	Fairly uniform opinions are found about the elements comprising quality of care at the end of life, with relief from pain and other symptoms at the forefront (2)
89% of respondents said we don't discuss death and dying enough	<p>91% of people in Britain have thought about their own mortality (1)</p> <p>89% people feel comfortable talking about their death but 73% said that we don't talk enough about that death (3)</p> <p>25 % of us don't talk about death as we don't want people to worry (1).</p> <p>When asked what stops us talking about death, people responded that it was not socially acceptable, that it might distress other people, and that others just wouldn't be interested (3)</p>

### Sources

- (1) Making peace with death: National attitudes to death, dying and bereavement, YouGov/Co-op Funeralcare (2018)
- (2) Dying matters: let's talk about it, BMJ (2010)
- (3) Attitudes towards death and dying in contemporary society in Wales. [Marie Curie \(2019\)](#)

## Recommendations

This survey is a starting point for the partners in the Strategic Collaborative Cheshire work to gain a better understanding of people's experiences and to make sure that this learning is used to improve services for people who are in their last years and months of life.

In response to the survey findings, the Strategic Collaborative Cheshire partners will:

- Send a copy of this report to all those who responded and provided contact details
- Publish the report online at [www.eolp.org.uk](http://www.eolp.org.uk)
- Develop an ongoing programme of engagement with the different groups identified through this survey including people with personal experience, professionals and people with no direct experience of these services to date
- Increase engagement with people receiving palliative and end of life care, who were under-represented in this survey
- Build on partnerships with Healthwatch to raise the profile of palliative and end of life care and increase public understanding of the types of support available

## Appendices

### Where did the responses come from?

**Table A: Respondents' home area based on postcode**

Location	Number of responses	% of responses
Cheshire East*	147	54%
Cheshire West & Chester*	82	30%
Postcode outside Cheshire	33	12%
Postcode not provided	10	4%
Total	272	

\*All Healthwatch responses were from either Cheshire East or Cheshire West and Chester.

### Who replied to the survey?

**Table B: Experience of Palliative and End of Life Care broken down by Wider Public/Healthwatch members**

Responses	Wider Public	Healthwatch	Total
I am receiving palliative or end of life care*	0%	0%	0%
A member of my family is receiving, or has received, palliative or end of life care	29%	19%	27%
A friend is receiving, or has received, palliative or end of life care	10%	8%	10%
My work involves, or used to involve, providing palliative or end of life care	20%	11%	19%
My work involves, or used to involve, providing other health or social care	14%	11%	13%
General Knowledge	22%	38%	24%
Other	5%	13%	6%

\*One respondent recorded that they were receiving palliative or end of life care.

**Table C: Category of Respondent broken down by Wider Public/ Healthwatch members**

Category of Respondent	Wider Public	Healthwatch	Total
Personal experience	39%	23%	36%
Professional experience	28%	20%	27%
Personal and Professional experience	14%	15%	14%
No experience	19%	43%	23%

Data shown includes all responses (unless stated otherwise). Data is broken down further in the appendices.

## How much do people say they know about palliative and end of life care?

**Table D: Knowledge of Palliative Care by Wider Public/Healthwatch members**

Response	Wider Public	Healthwatch	Total
I am very knowledgeable	10%	5%	9%
I have quite a bit of knowledge	25%	28%	25%
I have some knowledge	57%	55%	57%
I have no knowledge	8%	13%	8%

**Table E: Knowledge of End of Life Care by Wider Public/Healthwatch members**

Response	Wider Public	Healthwatch	Total
I am very knowledgeable	9%	3%	8%
I have quite a bit of knowledge	27%	23%	26%
I have some knowledge	53%	58%	54%
I have no knowledge	12%	18%	13%

**Table F: Knowledge of Palliative Care by respondent category**

Response	Professional	Professional and personal experience	Personal experience	No direct experience	Total
I am very knowledgeable	26%	13%	1%	0%	9%
I have quite a bit of knowledge	41%	47%	21%	0%	25%
I have some knowledge	32%	39%	71%	74%	57%
I have no knowledge	1%	0%	6%	26%	8%
Blank	0%	0%	1%	0%	0%

**Table G: Knowledge of End of Life Care broken down respondent category**

Response	Professional	Professional and personal experience	Personal experience	No direct experience	Total
I am very knowledgeable	19%	13%	2%	0%	8%
I have quite a bit of knowledge	47%	45%	19%	2%	26%
I have some knowledge	33%	39%	73%	56%	54%
I have no knowledge	1%	3%	6%	42%	13%



## Which services do people think provide palliative and end of life care?

**Table H: Knowledge of Palliative and End of Life Care Providers by Healthwatch/Wider Public**

Service Provider	Wider Public	Healthwatch	Total
Hospital	80%	75%	79%
Hospice	99%	98%	99%
Residential Home	78%	60%	76%
Nursing home	91%	93%	91%
Home care	86%	80%	85%
Community nursing	87%	70%	84%
Counsellor	53%	48%	53%

**Table I: Knowledge of Palliative and End of Life Care Providers by respondent category**

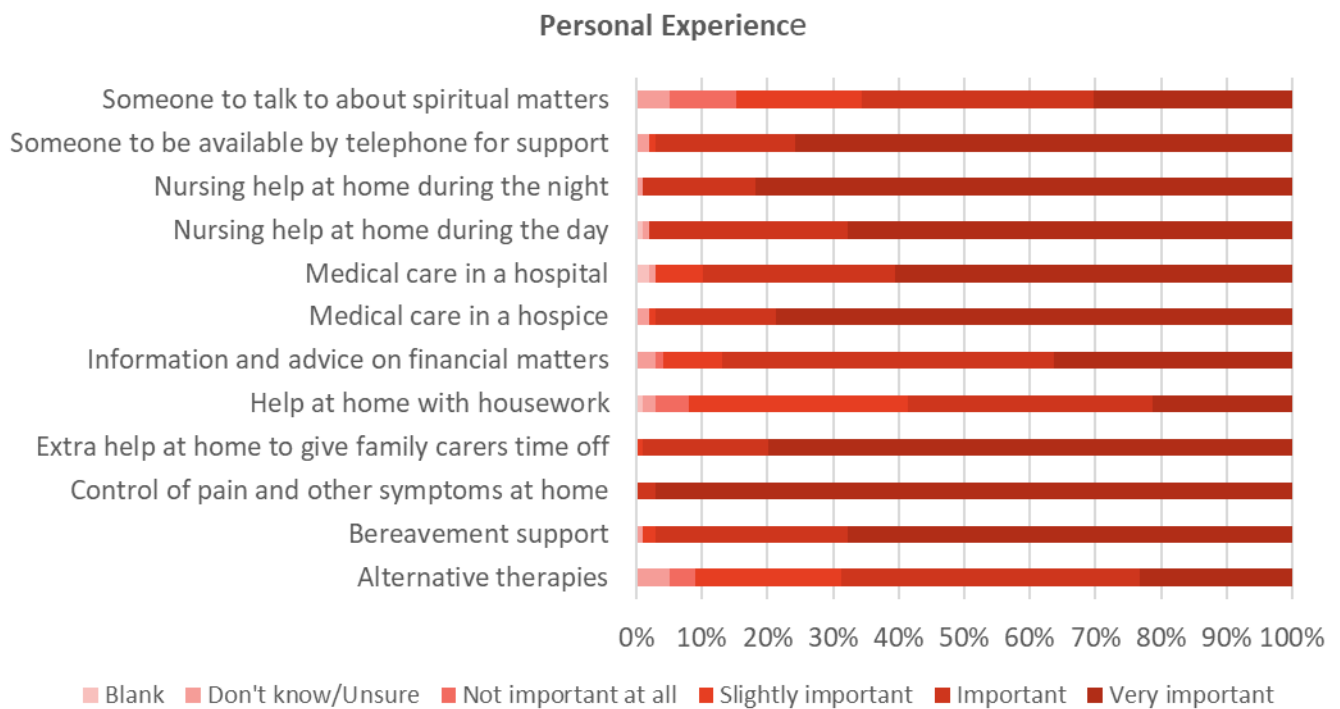
Service Provider	Professional	Professional and personal experience	Personal experience	No direct experience	Total
Hospital	96%	74%	82%	68%	79%
Hospice	100%	99%	100%	95%	99%
Residential Home	92%	67%	87%	65%	76%
Nursing home	100%	85%	92%	89%	91%
Home care	100%	77%	89%	77%	85%
Community nursing	96%	77%	92%	77%	84%
Counsellor	78%	39%	63%	37%	53%

**Table J: “Other” Sources of Support identified by theme**

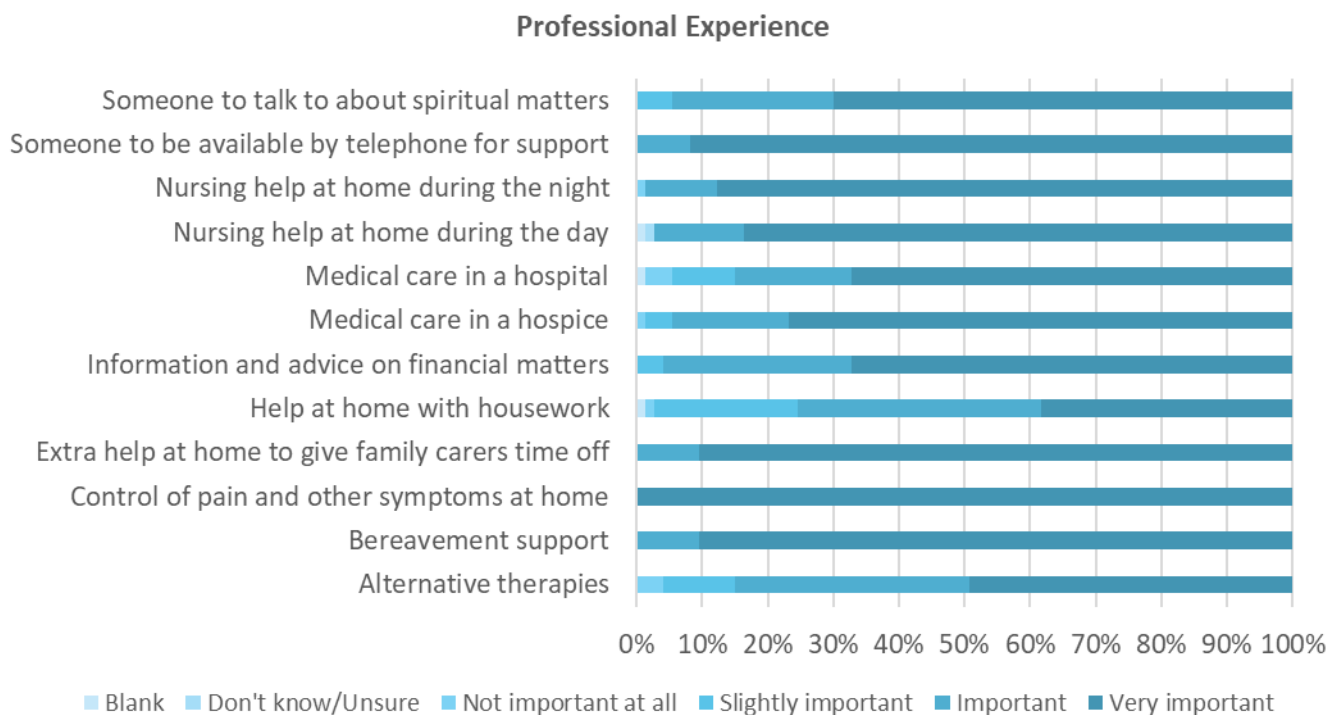
<b>Source of Support</b>	<b>Identified by X respondents</b>
Family	12
Charitable organisations (e.g. Marie Curie, Macmillan)	6
Spiritual Care	4
Physiotherapists, Occupational Therapists, Dieticians, Speech and Language Therapists	4
Friends	4
GP	3
Macmillan Nurses	3
Community members	2
Complementary Therapies	2
Ambulance Services	1
Pharmacists	1
Hospice at Home	1
Community Cancer Rehab Team	1
Carers/Personal Assistants	1

## How important are different aspects of palliative and end of life care?

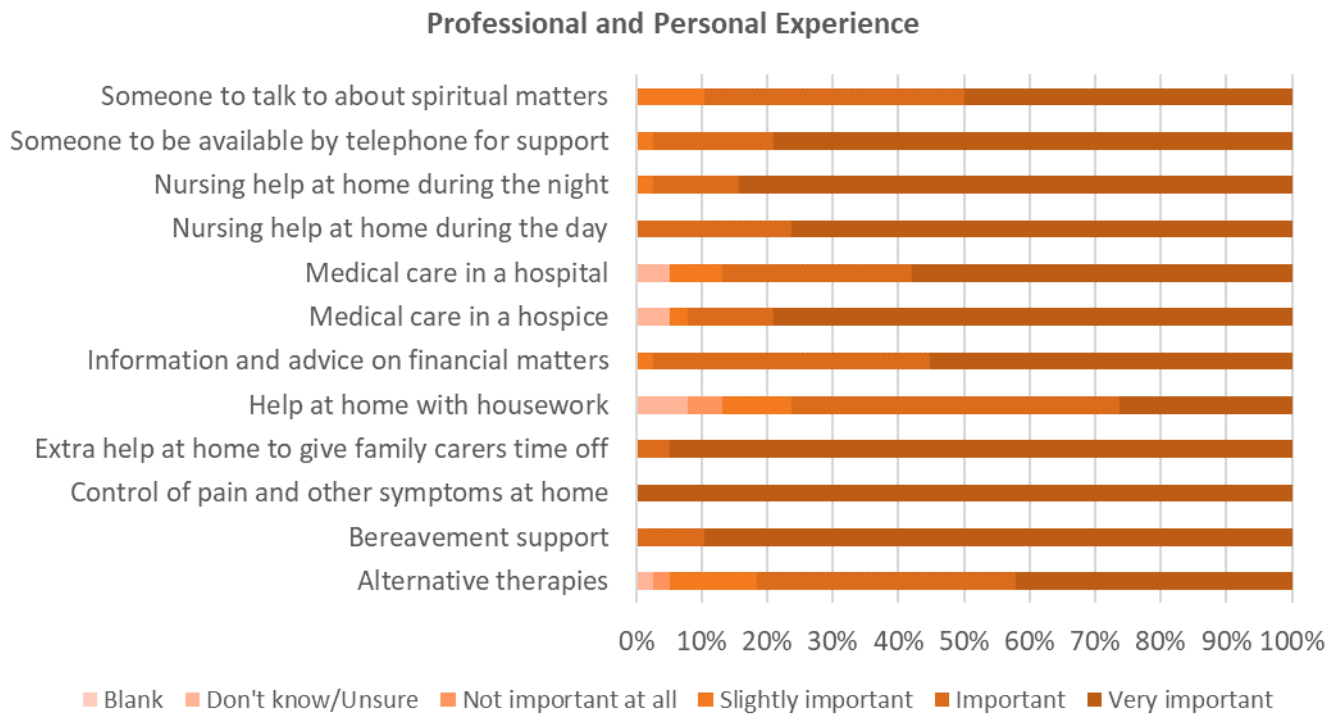
**Chart K: Importance of different aspects of care – Personal Experience**



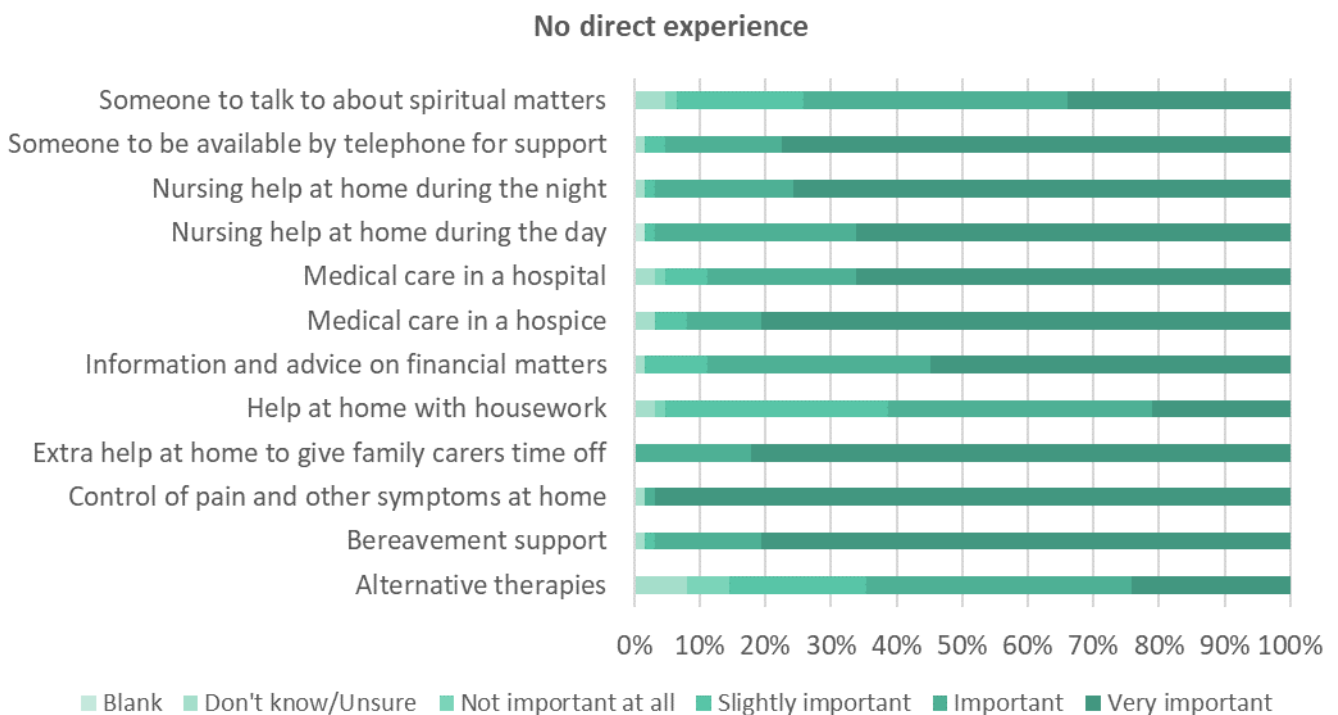
**Chart L: Importance of different aspects of care – Professional Experience**



**Chart M: Importance of different aspects of care – Professional and Personal Experience**



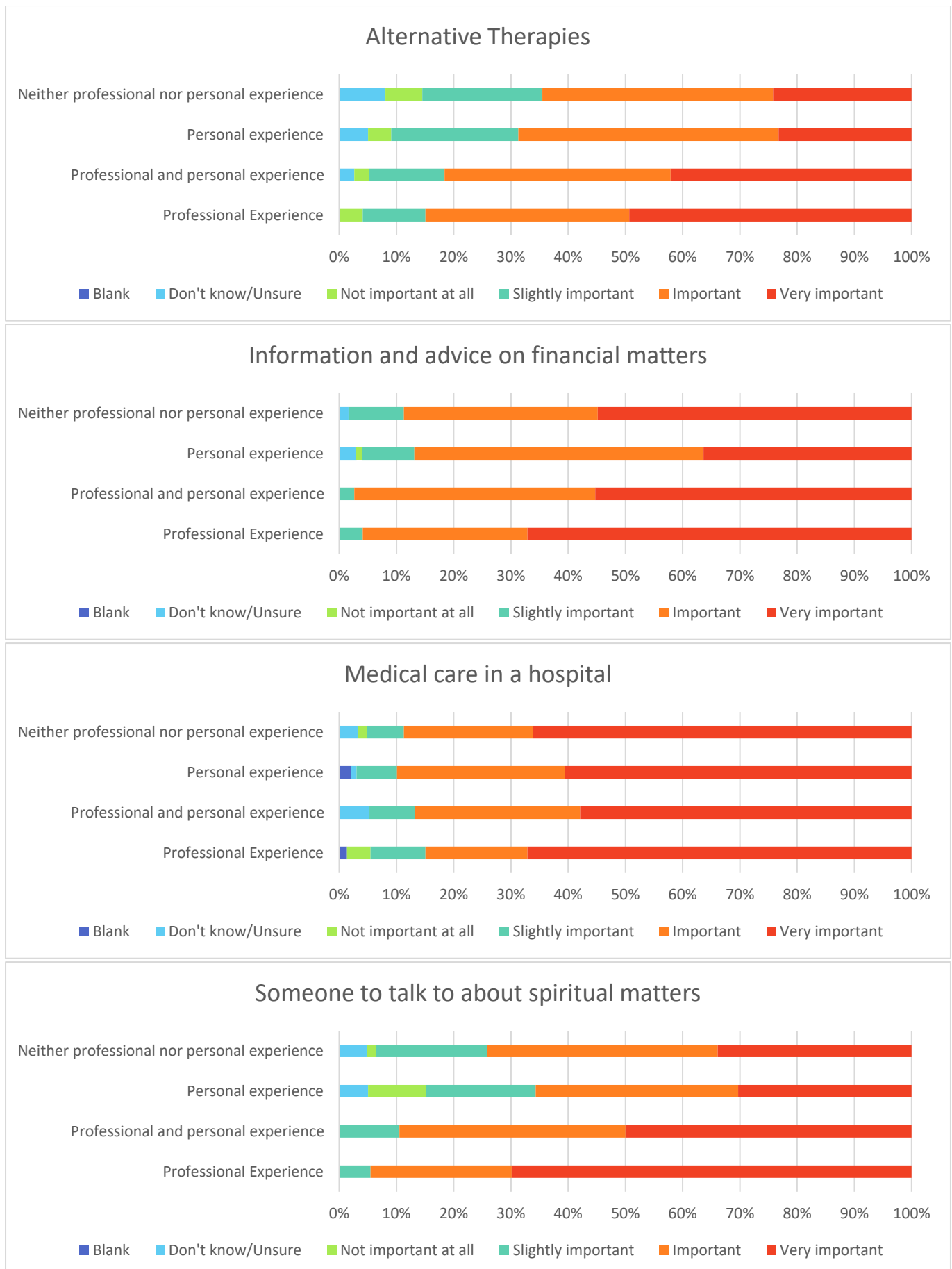
**Chart N: Importance of different aspects of care – No direct Experience**



Data shown includes all responses (unless stated otherwise). Data is broken down further in the appendices.

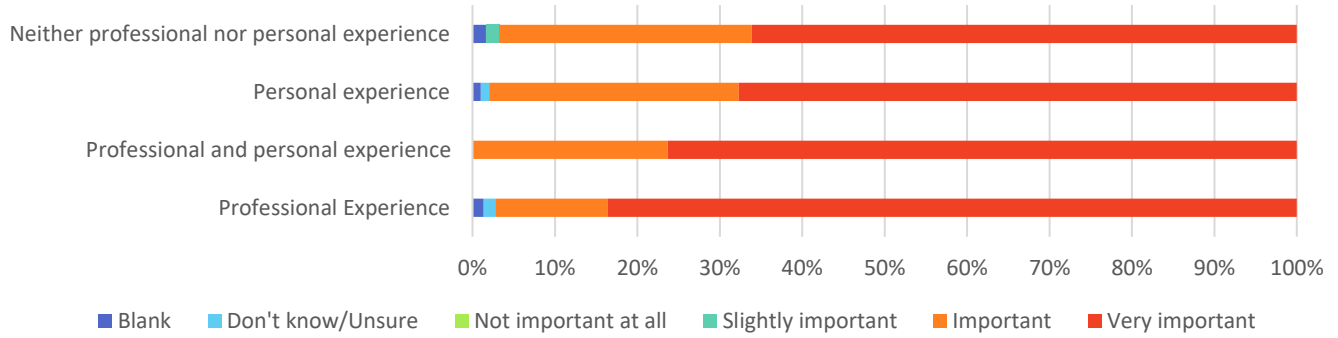
## How important are different aspects of palliative and end of life care?

Chart O – Importance of aspects of care by respondent category

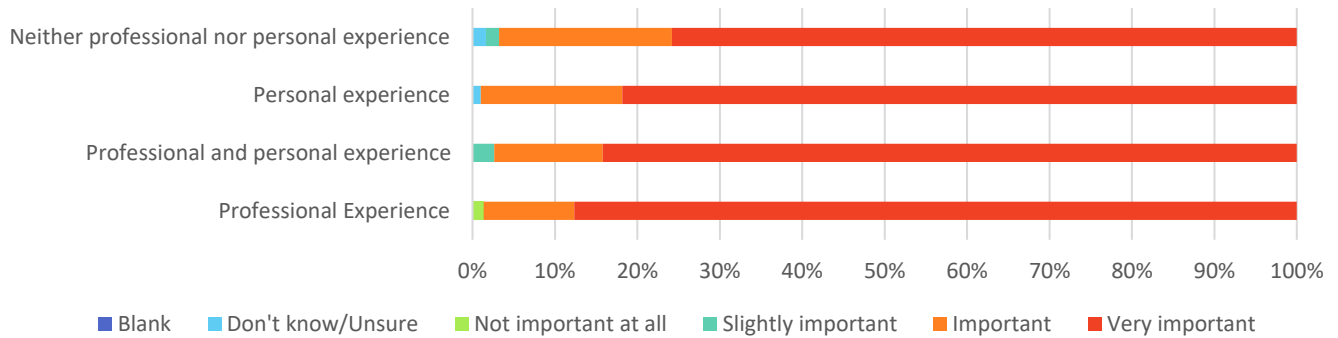


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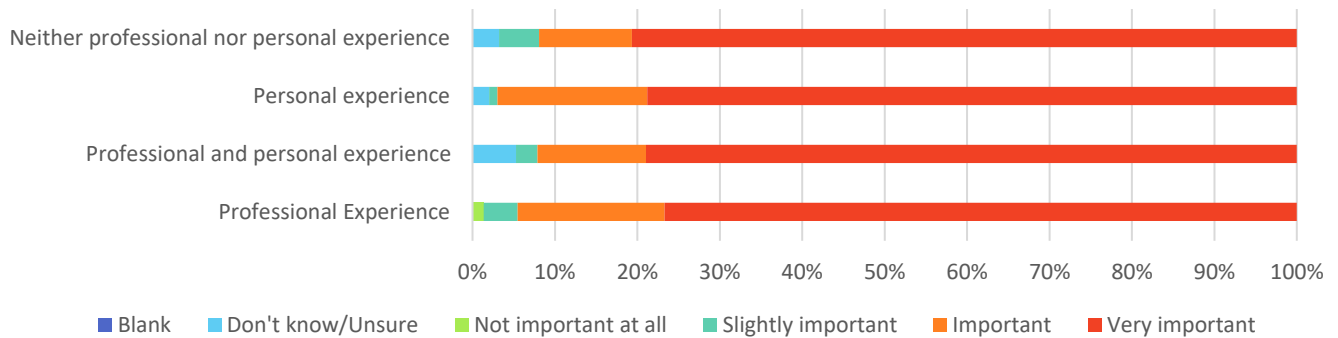
### Nursing help at home during the day



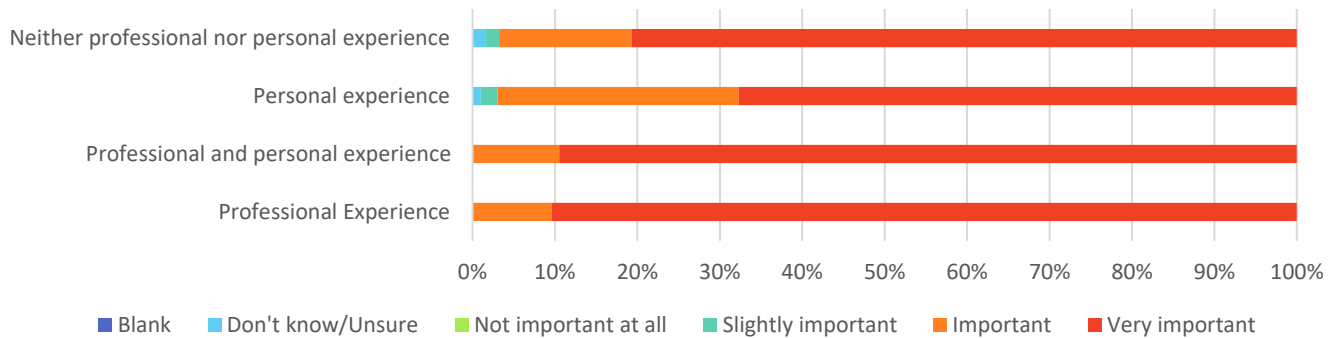
### Nursing help at home during the night



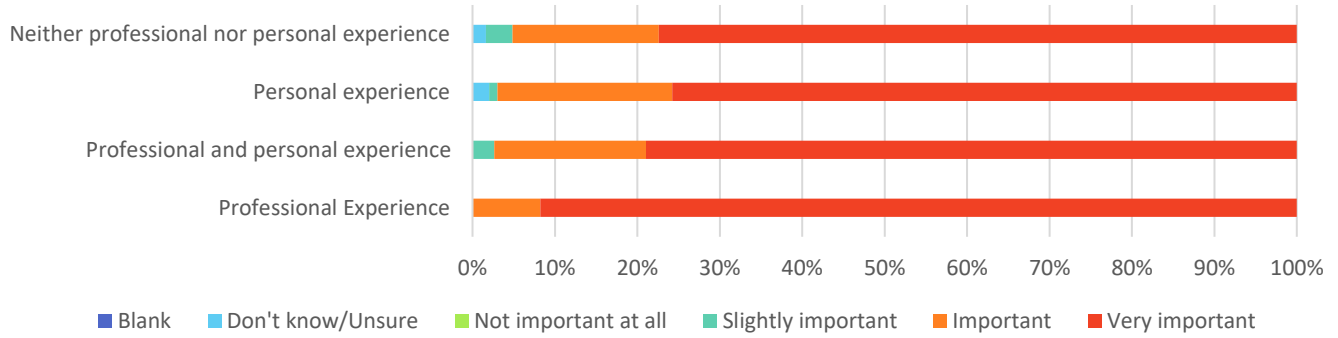
### Medical care in a hospice



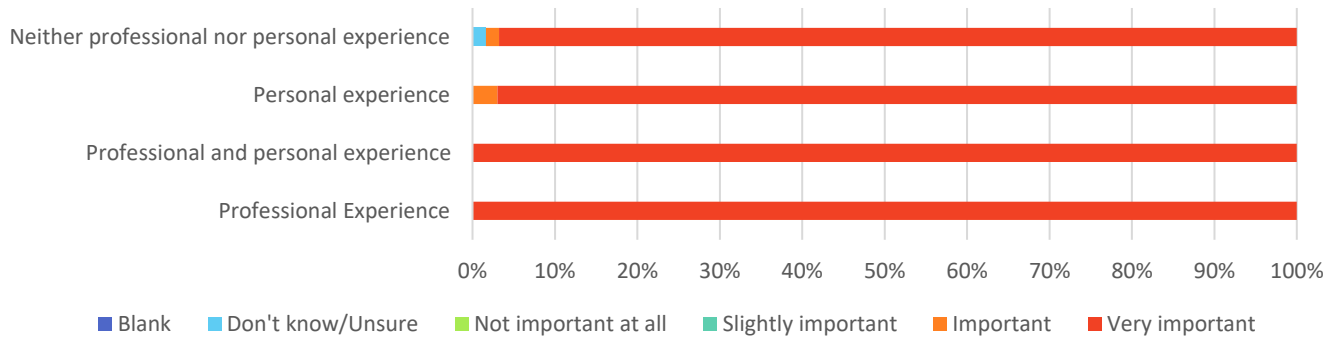
### Bereavement Support



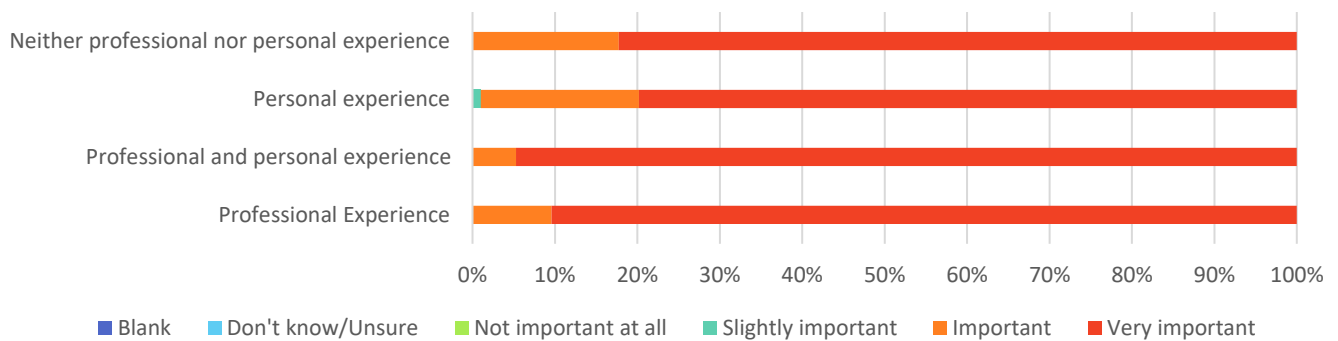
### Someone to be available by telephone for support



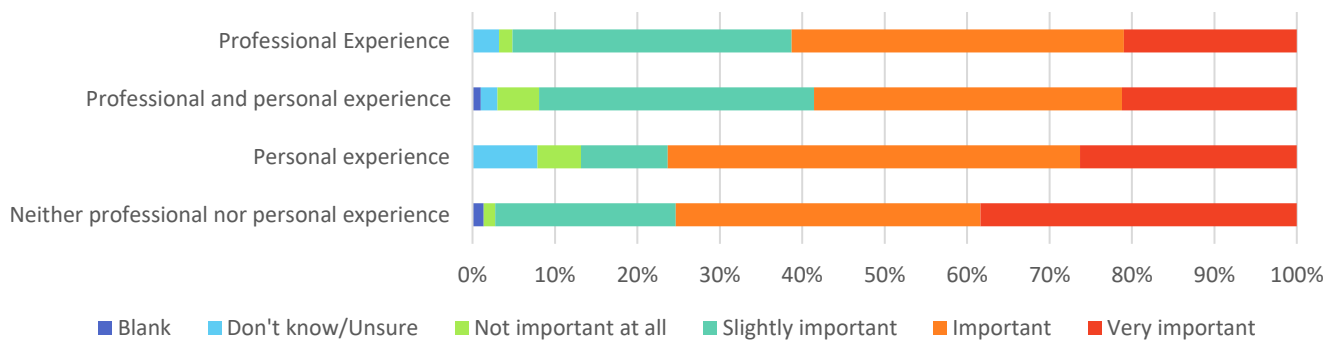
### Control of pain and other symptoms at home



### Extra help at home to give family carers time off



### Help at Home with Housework



## Do we talk enough about death and dying?

**Table P: Discussion about death and dying by Wider public/Healthwatch Members**

Row Labels	Wider Public	Healthwatch Members	Grand Total
We don't discuss these things enough	92%	80%	89%
We have about the right amount of discussions	6%	12%	7%
We discuss these things too much*	0%	0%	0%
Don't know/Unsure	2%	8%	4%
<b>Grand Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

\*1 person responding to the wider public survey stated that we discuss these issues too much.

**Table Q: Discussion about death and dying by respondent category**

	Personal experience	Professional Experience	Both Professional and Personal Experience	No direct experience
We don't discuss these things enough	89%	90%	95%	84%
We have about the right amount of discussions	6%	8%	5%	10%
We discuss these things too much	1%	0%	0%	0%
Don't know/Unsure	4%	1%	0%	6%
	100%	100%	100%	100%