AIIHPC

All Ireland Institute of
Hospice and Palliative Care

Report on the Department of Health's Public Consultation for the Palliative Care Policy for Adults

A Report By All Ireland Institute Of Hospice And Palliative Care For The Department Of Health

Contents

Glossary 4
Introduction 6
Executive Summary 7
Survey Methodology 8
Structure of the Report 8
Section 1: Profile of Respondents 9
- Gender 9
- Age 9
- Location 9
- How Individuals Identified Themselves 10
- Type of Organisation 11

Section 2. Analysis of Findings 12
- 2.1 Understanding and Awareness of Palliative Care 12
- 2.1.1 Question 2.1 12
- 2.1.2 Key Findings of Section 2.1 16
- 2.2 Individual's Views on Current Palliative Care Services 16
- 2.2.1 Key Findings of Section 2.2 20
- 2.3 Organisation's Views on Current Palliative Care Services 21
- 2.3.1 Key Findings of Section 2.3 25
- 2.3.2 Cross-cutting Themes Between Individuals and Organisations 25
- 2.4 Strengths of the Current Provision of Palliative Care Services 25
- 2.4.1 Dedicated and Skilled Staff 26
- 2.4.2 Multidisciplinary Team Approach to Patient Care 26
- 2.4.3 Integration of Specialist Palliative Care 27
- 2.4.4 Physical Infrastructure 28
- 2.4.5 Training and Education 28
- 2.5 Weaknesses of the Current Provision of Palliative Care Services and How to Improve Them 29
- 2.5.1 Staff Shortages and Staff Education 30
- 2.5.2 Inadequate Support for Family Carers 32
- 2.5.3 Barriers to Integration 33
- 2.5.4 Lack of Infrastructure 34
- 2.5.5 Inconsistent Multidisciplinary Team Provision 35
- 2.5.6 Lack of Public Awareness 36
- 2.5.7 Lack of Adequate Key Performance Indicators 37
- 2.5.8 Lack of Equity 38
- 2.6 Views on the Future of Palliative Care Services 39
- Individuals and Organisations 39

Section 3. Conclusion 41
References 43
Appendices 44
- Appendix 1: Public Consultation Questionnaire – Individuals 44
- Appendix 2: Public Consultation Questionnaire – Organisations 50
- Appendix 3: List of Respondent Organisations 55

List of Tables and Figures

Figure 1.1 Age profile of individual respondents 9
Figure 1.2 Individual's location 9
Figure 1.3 How individuals identified themselves 10
Figure 1.4 Type of organisation 11
Figure 1.5 Response to Question 2.1 / Statement 1 12
Figure 1.6 Response to Question 2.1 / Statement 2 12
Figure 1.7 Response to Question 2.1 / Statement 3 13
Figure 1.8 Response to Question 2.1 / Statement 4 13
Figure 1.9 Response to Question 2.1 / Statement 5 14
Figure 2.0 Response to Question 2.2 14
Figure 2.1 Response to Question 2.3 15
Figure 2.2 Response to Question 3.1 / Statement 1 17
Figure 2.3 Response to Question 3.1 / Statement 2 17
Figure 2.4 Response to Question 3.1 / Statement 3 18
Figure 2.5 Response to Question 3.1 / Statement 4 18
Figure 2.6 Response to Question 3.1 / Statement 5 19
Figure 2.7 Response to Question 3.1 / Statement 6 19
Figure 2.8 Response to Question 3.1 / Statement 7 20
Figure 2.9 Response to Question 2.1 / Statement 1 21
Figure 3.0 Response to Question 2.1 / Statement 2 21
Figure 3.1 Response to Question 2.1 / Statement 3 22
Figure 3.2 Response to Question 2.1 / Statement 4 22
Figure 3.3 Response to Question 2.1 / Statement 5 23
Figure 3.4 Response to Question 2.1 / Statement 6 23
Figure 3.5 Response to Question 2.1 / Statement 7 24
Table 3.6 Individual's priorities for the new policy 39
Table 3.7 Organisation's priorities for the new policy 40

Glossary

AIIHPC – All Ireland Institute of Hospice and Palliative Care
CSO – Central Statistics Office
IPUs – Inpatient Units
KPIs – Key Performance Indicators
NACPC – National Advisory Committee on Palliative Care
ROI – Republic of Ireland

Disclaimer: This work was commissioned by the Department of Health and carried out by All Ireland Institute of Hospice and Palliative Care (AIIHPC). It does not represent the opinions of the Department of Health or AIIHPC. This report provides a breakdown of the responses to the questions asked in the public consultation and is an indication of the views and opinions of individuals and organisations on the new Palliative Care Policy for Adults.

Introduction

The Department of Health policy on palliative care for patients and families is contained in the 2001 Report of the National Advisory Committee on Palliative Care. The policy was developed at a time when specialist palliative care was at a relatively early stage of development in Ireland. It recommended that services be structured across three levels of ascending specialism to ensure everyone who required palliative care received it at the right place and time. Notwithstanding its longevity, Ireland's national policy on palliative care continues to be highly regarded internationally.

The 2015 Quality of Death Index report by the Economist Intelligence Unit, which measures the current environment for end of life care services across 40 countries, ranked Ireland fourth in the world (Economist Intelligence Unit, 2015). The latest Cross Country Comparison of Expert Assessments of the Quality of Death and Dying in 2021 places Ireland in second place in the rankings among 81 countries (Finkelstein, et al., 2021).

However, demand for adult palliative care has greatly increased since 2001. Around 30,000 people in Ireland die each year. Central Statistics Office (CSO) mortality projections in 2018 suggested there will be about 38,000 deaths in Ireland in 2031, rising to 54,000 per year by 2050 (CSO, 2018). Due to the ageing population, and as more people with life-limiting illnesses live longer, Ireland faces the challenge of ensuring high-quality palliative care is available to increasing numbers of people with life-limiting conditions, in all settings. To ensure healthcare services can meet the palliative care needs of the population into the future, the Programme for Government 2020 committed to developing a new Adult Palliative Care Policy.

In September 2021, the Department of Health launched a public consultation to obtain the views of those who work in the field of palliative care, interested organisations and members of the public. These views are essential to shaping the development of the new policy.

Executive Summary

The Department of Health launched a public consultation on 13 September 2021 to understand the views of a wide range of stakeholders, including members of the public, with the aim of using these findings to inform the new Palliative Care Policy for Adults. The public consultation was launched by the Minister for Health, Stephen Donnelly and remained open for six weeks closing on 25 October 2021. During the six weeks, the public consultation was promoted by the Department of Health through diverse channels, including social media platforms, to ensure a broad public response was obtained. The public consultation consisted of an online survey for individuals and a separate survey for organisations. A total of 1652 responses were received; 68 responses were made on behalf of an organisation or representative body and 1584 were submitted by individuals.

The result of the public consultation shows that individual respondents believe they have a strong understanding and awareness of palliative care. Individuals feel they know where to access information and are comfortable talking about end of life care, dying, death and bereavement. They would also like to plan in advance for the type of care they receive at the end of their life and they would like to receive this care in their own home.

Regarding views on current palliative care services, there were mixed and contrasting views from individuals and organisations. There was a lack of consensus on whether people with a serious and progressive illness, and their families and carers, currently receive the necessary information to assist them with planning for end of life care and death. There was also a lack of consensus on whether people can access the appropriate type of palliative care services and whether healthcare staff recognise the palliative care needs of people with a serious and progressive illness in all care settings.

When asked about the future of palliative care services, both individuals and organisations agreed that all eight priorities (refer to tables 3.6 and 3.7) presented in the consultation were important and need to be considered when developing the new policy. Several of these priorities resonated with the changes and improvements that organisations suggested for the new Palliative Care Policy for Adults:

- Access to palliative care services should not depend on location, age, or diagnosis. Equity should be a top priority when drafting the new policy.
- Lack of appropriate funding was considered one of the main underlying issues.
- Staff were commended by organisations for their excellent skills, hard work and commitment. However, workforce planning and ensuring appropriate staffing levels with consideration of skill mix will be required in light of the changing demographics.
- Education and training for all healthcare staff to support a palliative care approach in all care settings.
- Continue to raise public awareness about palliative care, including the different types of services and how people can access them.
- Meaningful key performance indicators need to be developed and implemented in order to promote continuous learning and improvement.

Organisations provided additional narrative regarding the strengths and weaknesses of current palliative care services, and the following key themes emerged:

STRENGTHS

- Dedicated and skilled staff
- Multidisciplinary team approach to patient care
- Integration of specialist palliative care services
- Physical infrastructure
- Training and education for healthcare workers at both specialist and non-specialist palliative care levels

WEAKNESSES

- Staff shortages
- Palliative care education for non-specialist palliative care staff
- Barriers to integration
- Inconsistent multidisciplinary teams
- Lack of information technology (IT) infrastructure
- Lack of public awareness
- Lack of adequate key performance indicators
- Lack of equity

Survey Methodology

The surveys were designed by the Department of Health in conjunction with AIIHPC. The surveys sought to understand public awareness of palliative care and capture public opinion on existing services, as well as future priorities for the new policy update. The individual survey was designed to be short, accessible and mobile-friendly to enable maximum participation.

The survey was comprised of four sections: Respondent's Profile, Understanding and Awareness of Palliative Care, Views on Current Palliative Care Services and Views on the Future of Palliative Care Services. The consultation included multiple choice and Likert scale questions. The full questionnaire is available in Appendix 1. The survey for organisations or representative bodies was divided into three sections: Organisation's Profile, Views on Current Palliative Care Services, and Views on the Future of Palliative Care Services. The questions included Likert scale questions as well as three additional open-ended questions (qualitative data) for respondents to expand on the strengths and weaknesses of the current services and any changes or improvements they would recommend in the new Adult Palliative Care Policy. The answer to each open-ended question was limited to 2500 characters. The full questionnaire is available in Appendix 2.

The quantitative data was analysed using Microsoft Excel for data entry, manipulation, presentation, statistical and analysis functions. The qualitative data was analysed using content analysis, which is a method of analysing text based on systematic coding and categorisation. The information was analysed unobtrusively to determine trends, patterns in wording, their frequency and their relationship. The key themes were then extracted to form this report.

Any personal information that was provided to the Department of Health in the public consultation has been treated with the highest standards of security and confidentiality, strictly in accordance with the General Data Protection Regulation 2016/67 and the Data Protection Act 2018. A data processing agreement was signed between the Department of Health and AIIHPC in respect of the submissions received.

Structure of the Report

The following sections of this report present the findings of the analysis undertaken. In relation to the qualitative analysis, quotes are used to illustrate the viewpoints of the respondents. The quotes have been anonymised and the exact text submitted has been used as much as possible to reflect the respondent's views.

The report has been divided into sections, matching the structure of the surveys:

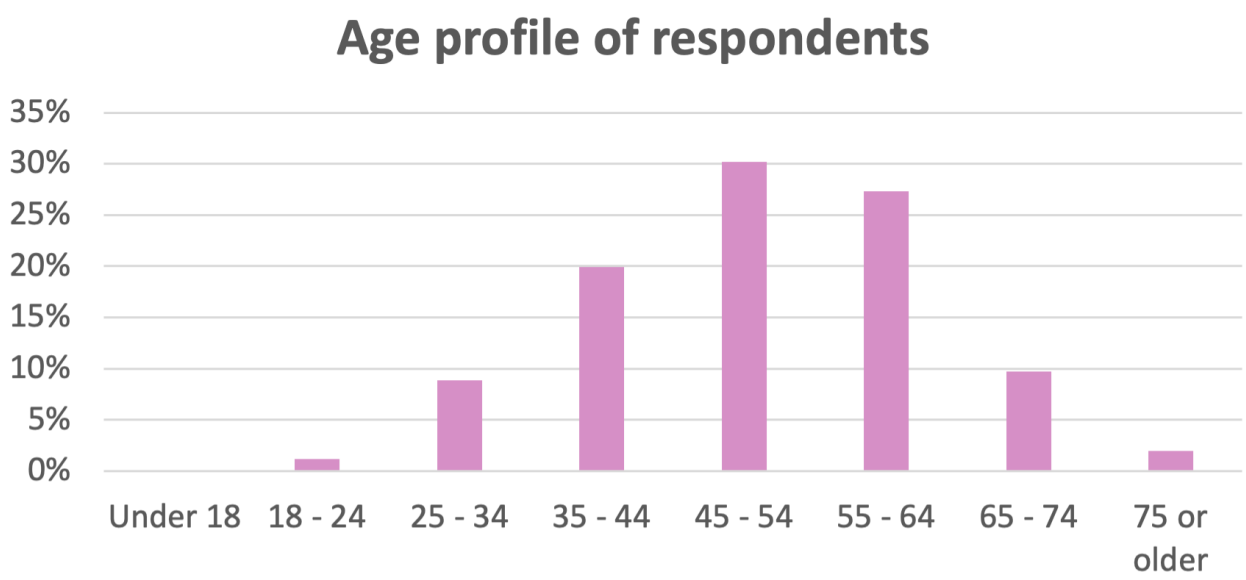
- Section 1 presents the profile of the respondents, including their demographic information and the capacity in which they responded to the survey.
- Section 2 is divided into three sub-sections:
  - ◊ Individual's understanding and awareness of palliative care.
  - ◊ Individual's and organisation's or representative bodies' views on current palliative care services.
  - ◊ Individual's and organisation's or representative bodies' views on the future of palliative care services.
- Section 3 concludes the report by summarising the key areas that are working well, those that are not working well and the top priorities for the new Adult Palliative Care Policy.

Section 1: Profile of Respondents

The first section of the survey asked respondents about their profile with the aim of understanding demographic characteristics and the capacity in which respondents answered the survey. A total of 1652 submissions were received; 68 responses were made on behalf of an organisation or representative body and 1584 were submitted by individuals.

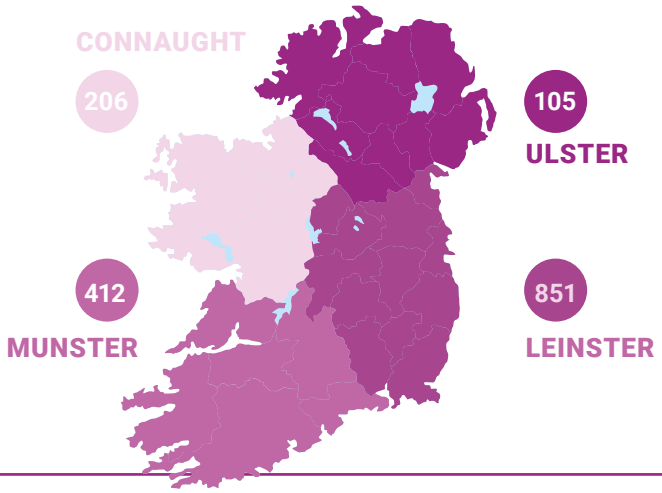
GENDER
The majority of respondents to the individual survey were female (85%). The individual survey was responded to mainly by females (85%). Males made up 13% of the responses and less than 3% preferred 'Not to say', 'Not answer' or chose 'Other'.

AGE | Figure 1.1 Age profile of individual respondents



Most of the respondents (77%) were between the ages of 35-64.
Only 10% were between the ages of 65-74 and 9% between 25-34.

LOCATION | Figure 1.2 Individual's location



Of the 1584 individual responses, ten did not answer this question and of those who did answer, the majority (54%) were located in Leinster, followed by Munster, Connaught, and Ulster.

Section 1: Profile of Respondents

HOW INDIVIDUALS IDENTIFIED THEMSELVES

Figure 1.3 How individuals identified themselves

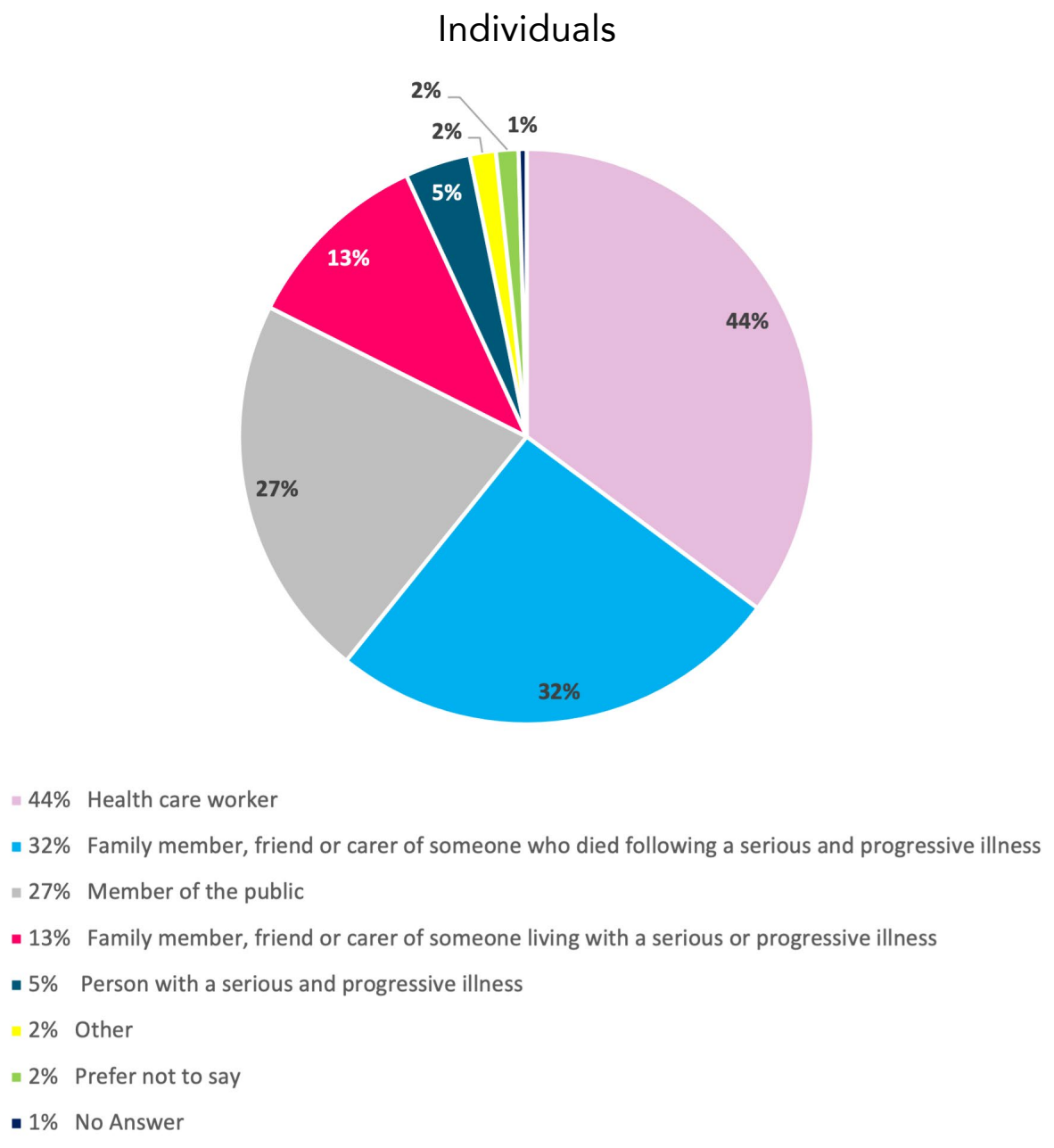


Figure 1.3 illustrates how individual respondents identified themselves. Individuals were able to select more than one answer. Of the 1584 respondents, the greatest proportion identified themselves as health care workers (44%), followed by family member, friend or carer of someone who died following a serious and progressive illness (32%) and member of the public (27%).

Section 1: Profile of Respondents

TYPE OF ORGANISATION | Figure 1.4 Type of organisation

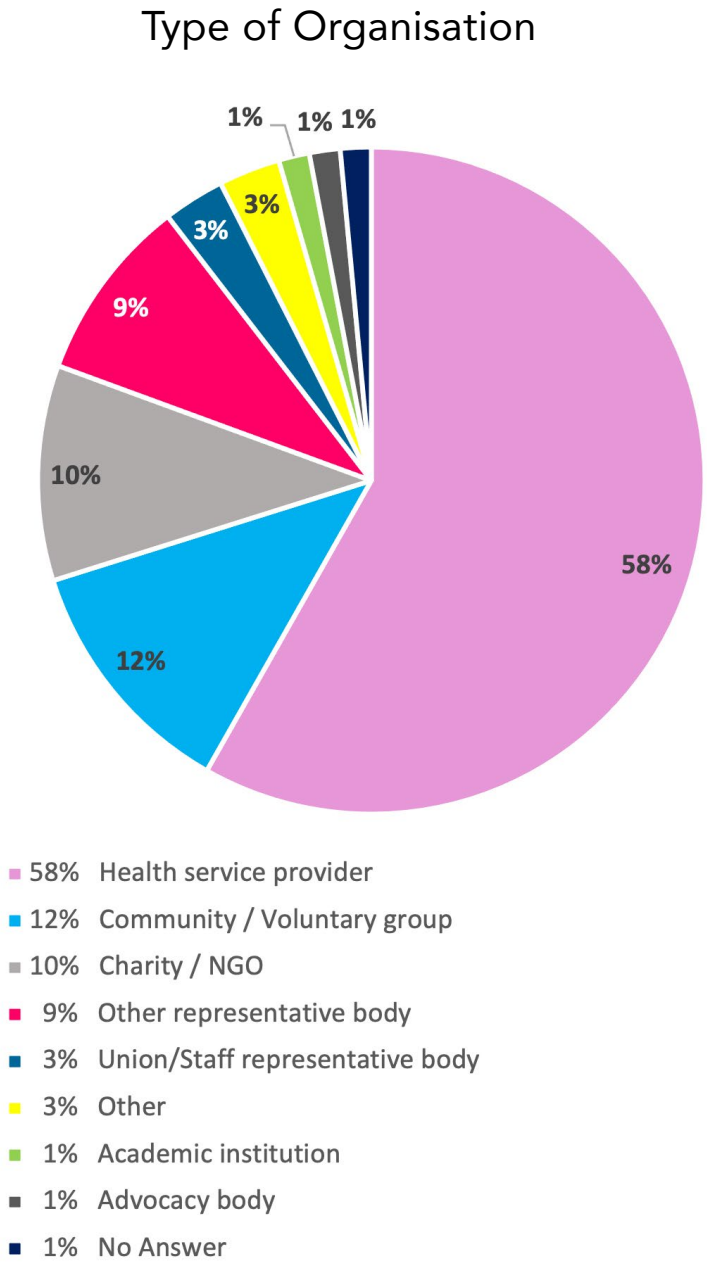


Figure 1.4 illustrates the type of organisation that responded to the survey. The greatest proportion (56%) were health service providers and 30% were a mix of community/voluntary groups, charities/NGOs and other representative bodies.

Section 2: Analysis of Findings

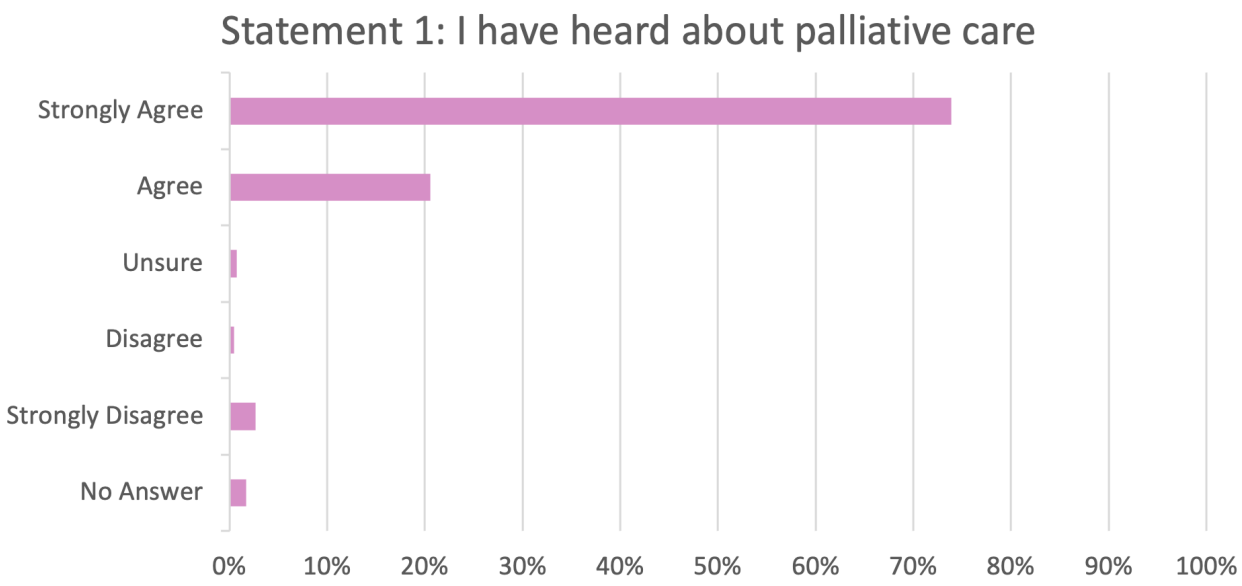
2.1 Understanding and Awareness of Palliative Care

The second section of the individual survey sought to capture the individual's understanding and awareness of palliative care through three questions

2.1.1 Question 2.1

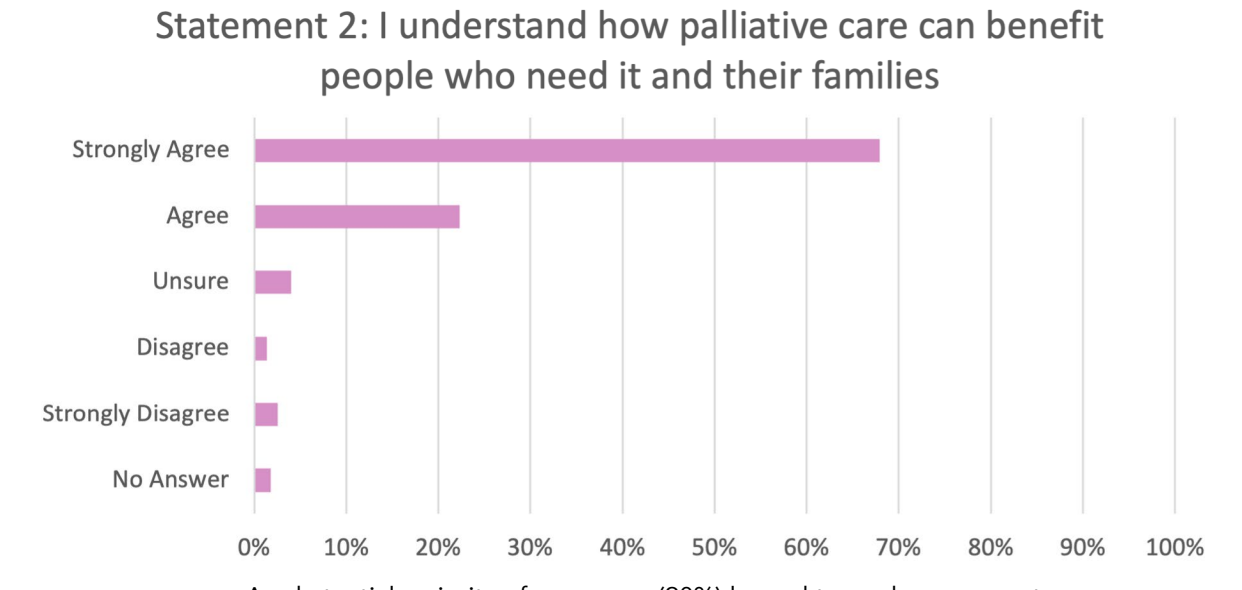
The first question (2.1) included five different statements and asked the individuals to what extent they agreed with each statement. The possible answers were 'Strongly Agree', 'Agree', 'Unsure', 'Disagree', 'Strongly Disagree' and 'No Answer'. Overall, respondents tended to either 'Strongly Agree' or 'Agree' with the statements.

Figure 1.5 Response to Question 2.1 / Statement 1



The vast majority of individuals (95%) leaned towards agreement.

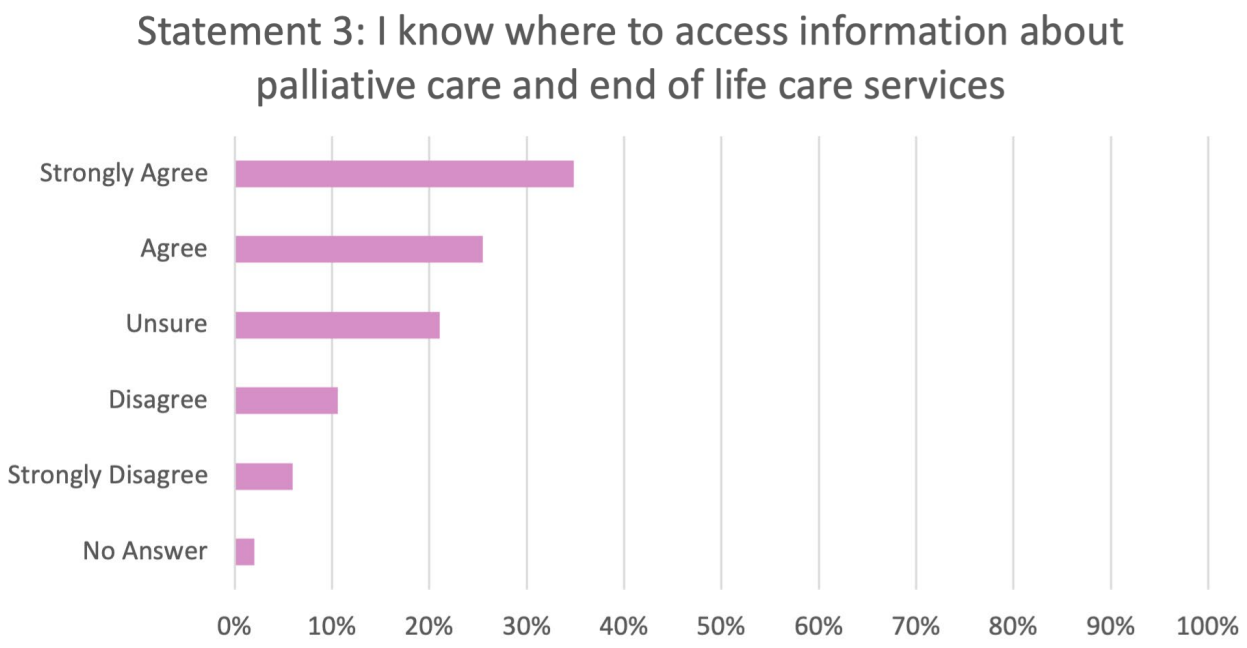
Figure 1.6 Response to Question 2.1 / Statement 2



A substantial majority of responses (90%) leaned towards agreement.

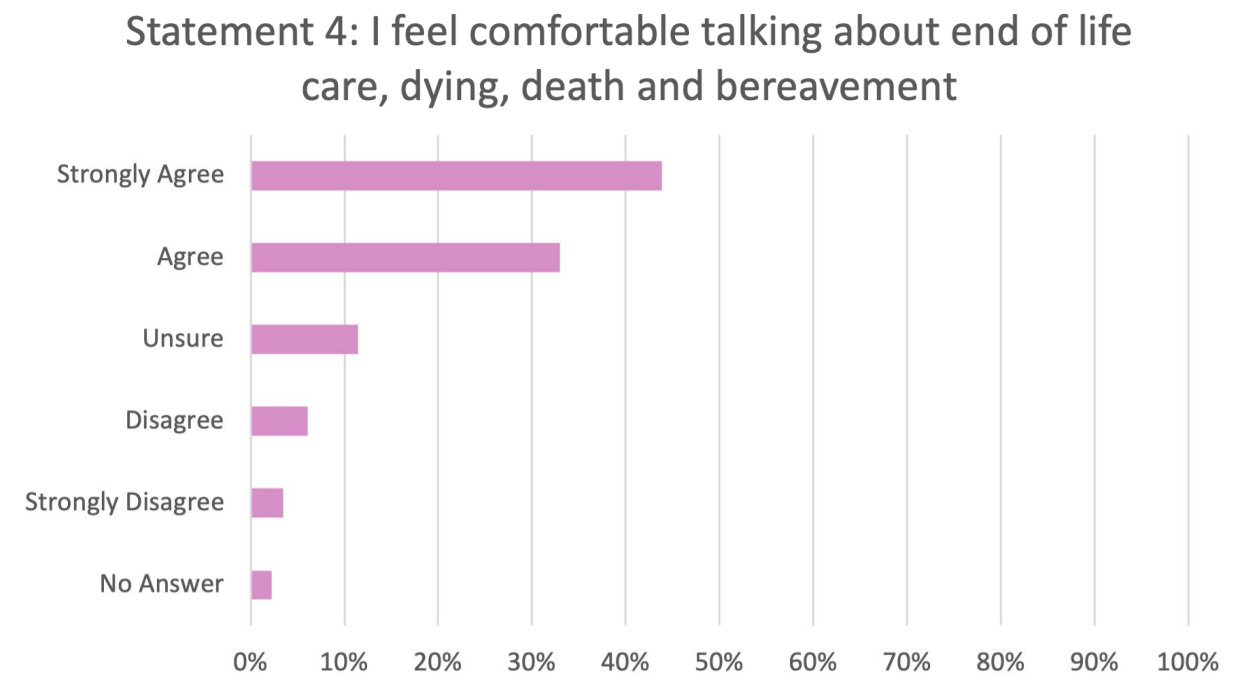
Section 2: Analysis of Findings

Figure 1.7 Response to Question 2.1 / Statement 3



A majority of the individuals (60%) leaned towards agreement, 21% were 'Unsure' and 17% leaned towards disagreement.

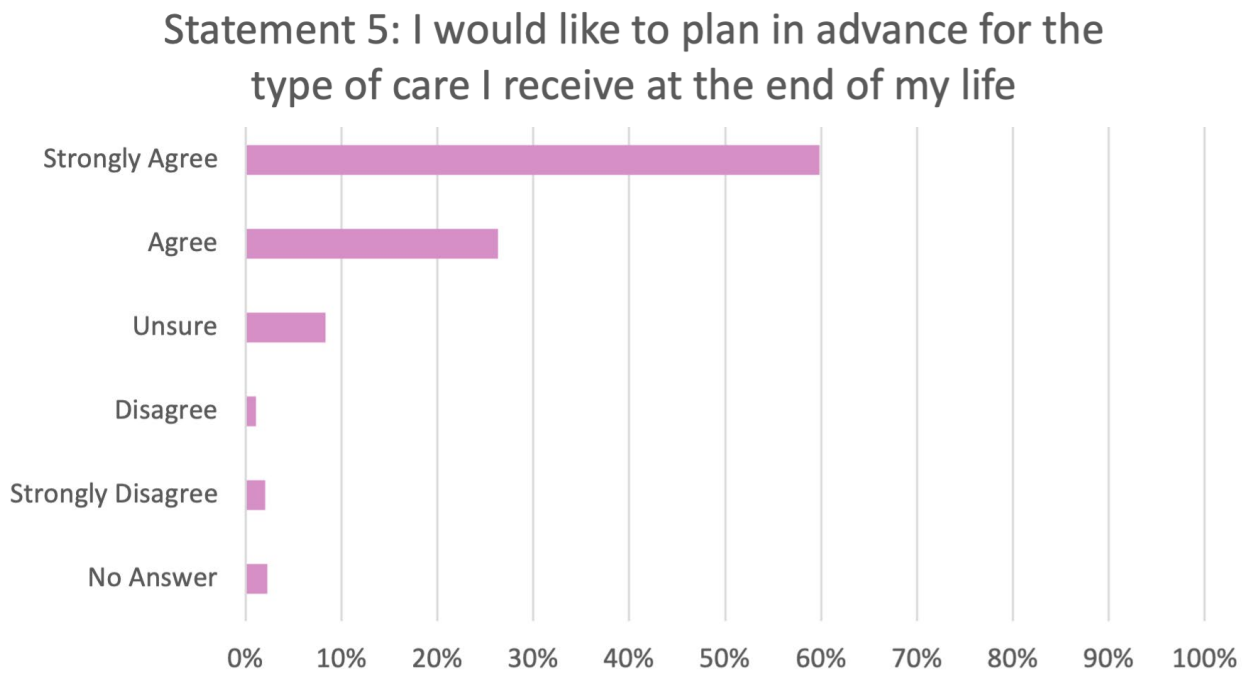
Figure 1.8 Response to Question 2.1 / Statement 4



Most individuals (77%) leaned towards agreement.

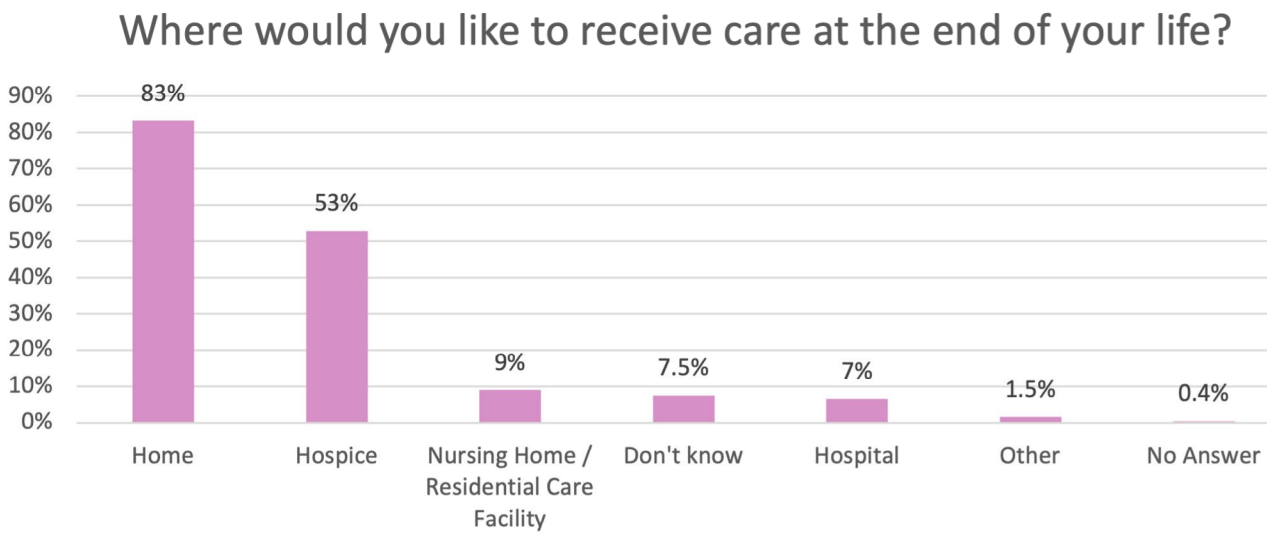
Section 2: Analysis of Findings

Figure 1.9 Response to Question 2.1 / Statement 5



A significant majority of respondents (86%) leaned towards agreement.

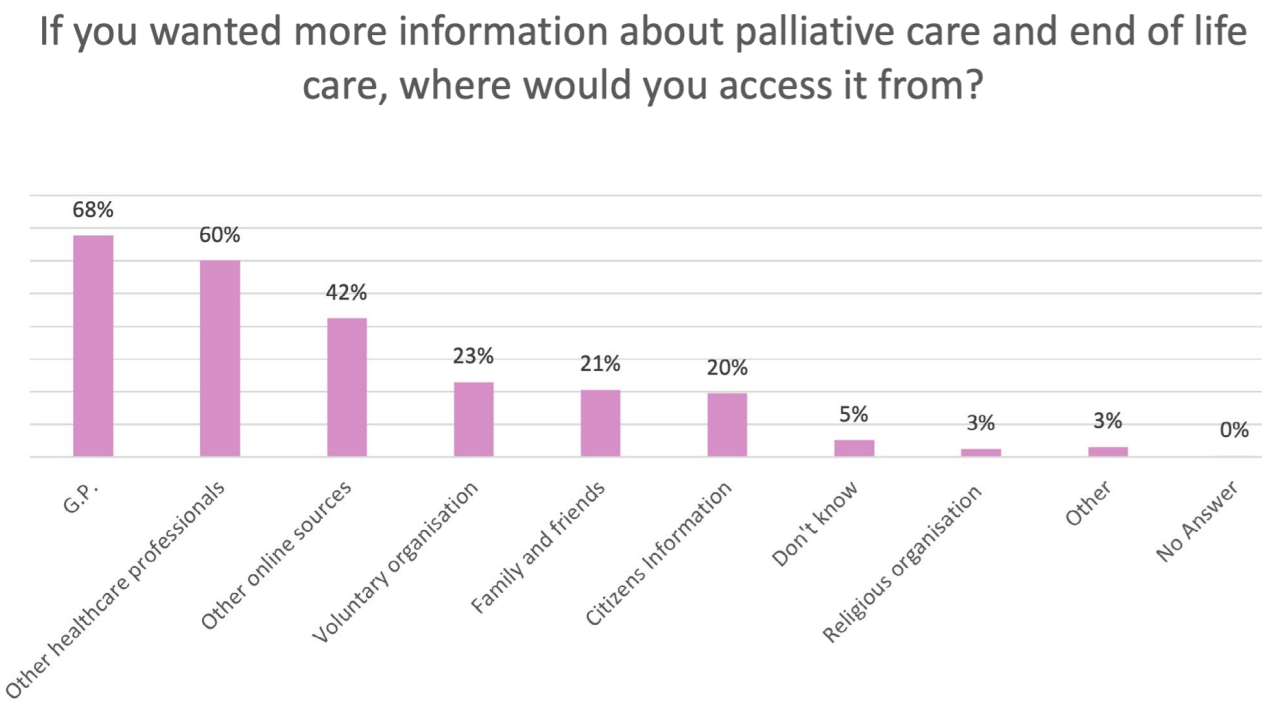
Figure 2.0 Response to Question 2.2



Respondents were able to select more than one answer. Home was the clear preference with 83%, followed by hospice with 53%.

Section 2: Analysis of Findings

Figure 2.1 Response to Question 2.3



Respondents were able to select more than one answer. Most individuals said they would seek information from their General Practitioner (68%) or other health care professionals (60%). That was followed by 42% of individuals who would look for information online. Only 5% of respondents said they 'Don't know' where to seek information about palliative care and end of life care.

2.1.2 Key Findings of Section 2.1

From the graphs depicted in the section above, we can note that most individuals consider themselves to possess a strong understanding and awareness of palliative care. On average, 92% of respondents either 'Agreed' or 'Strongly Agreed' when asked about their awareness and understanding of palliative care. This is consistent with the fact that the majority of people who responded to the public consultation were healthcare workers or family members/carers for a person with a serious and progressive illness.

In relation to knowing where to access further information about palliative and end of life care, there is a consensus that most people know where to look. Figures 1.7 and 2.1 both illustrate this understanding and show that the General Practitioner as well as other health care professionals are a key source of information for the public, followed closely by online sources. However, it is interesting to note that when this question was asked in the form of a generic statement (Figure 1.7 – I know where to access information about palliative and end of life care services) there were 21% of individuals who stated they were 'Unsure' about where to access information and 15% who disagreed with the statement entirely. In contrast, when the question was asked with a set of possible answers to choose from (see Figure 2.1), only 5% of individuals stated they 'Don't Know' where to access information.

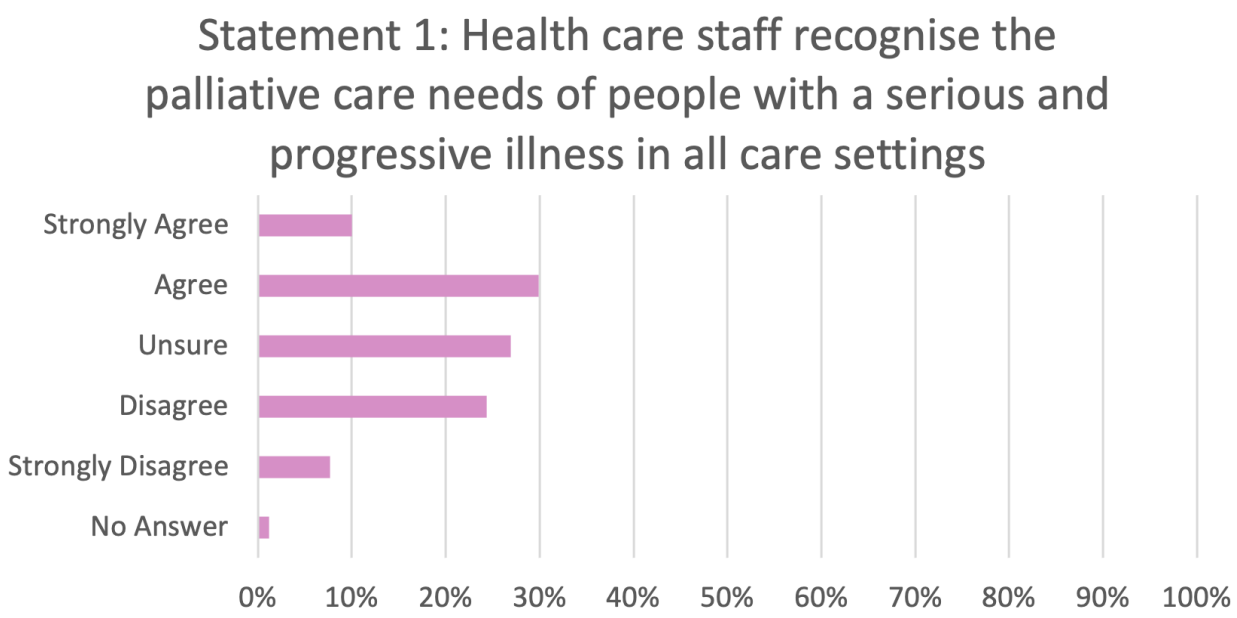
The consultation found 86% of respondents would like to plan in advance (Figure 1.9) for the type of care they receive at the end of their life. Considering that 83% of people stated they would like to receive care in their homes (Figure 2.0), it is important that measures are taken in the new policy to ensure this is possible.

2.2 Individual's Views on Current Palliative Care Services

Section three of the survey included one question which sought to understand how individuals view current palliative care services. The questions included seven different statements and asked the individuals to what extent they agreed with each statement. The possible answers were 'Strongly Agree', 'Agree', 'Unsure', 'Disagree', 'Strongly Disagree' and 'No Answer'. Replies varied but concentrated on 'Agree', 'Unsure' and 'Disagree' in similar proportions, thus reflecting less consensus from the individuals when responding about their views on current palliative care services in comparison to their understanding and awareness of palliative care services.

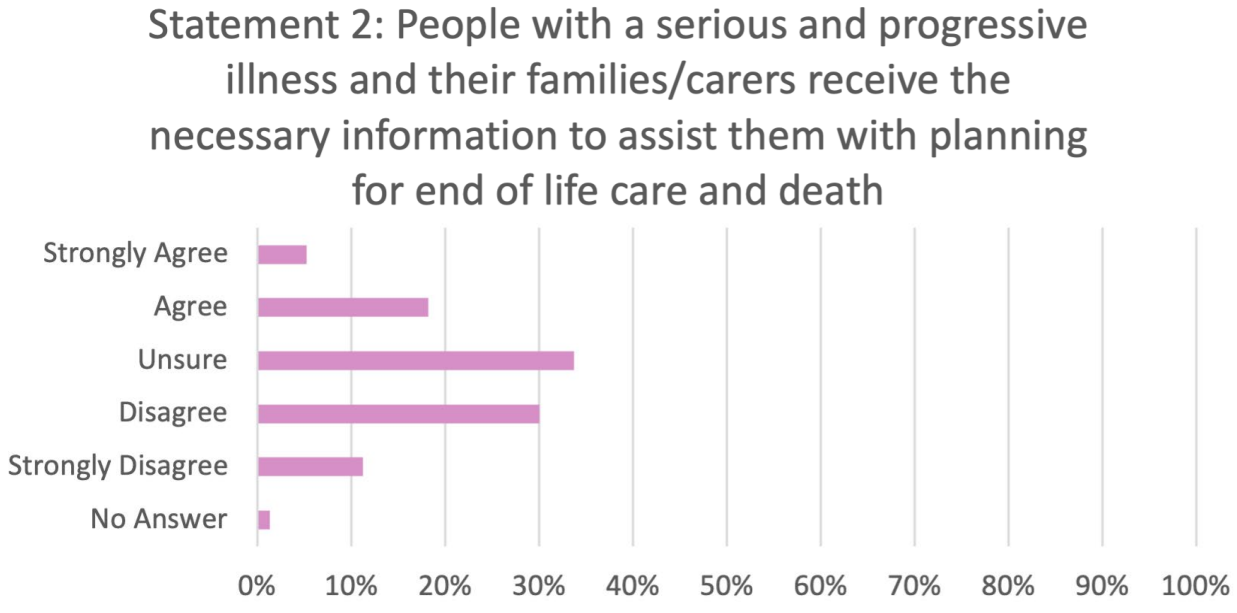
2.2 Individual's Views on Current Palliative Care Services

Figure 2.2 Response to Question 3.1 / Statement 1



Individual's responses concentrated in the middle range of the spectrum with 27% 'Unsure', 24% 'Disagree' and 30% 'Agree'.

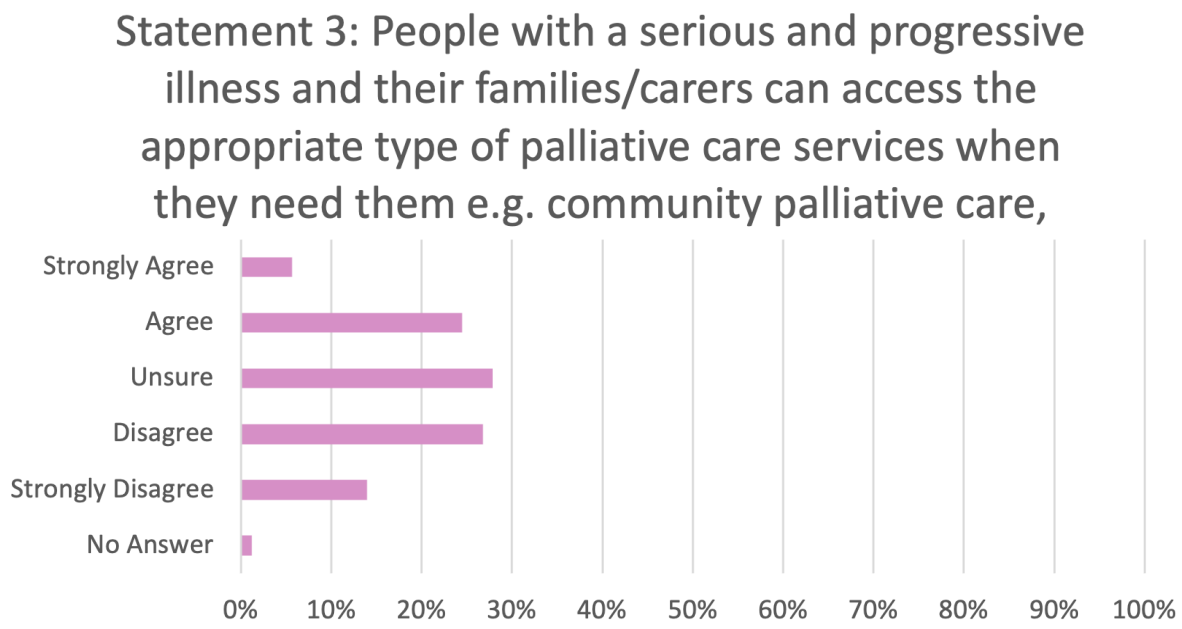
Figure 2.3 Response to Question 3.1 / Statement 2



Most respondents (33%) were 'Unsure' about Statement 2, but the majority (41%) leaned towards disagreeing with this statement.

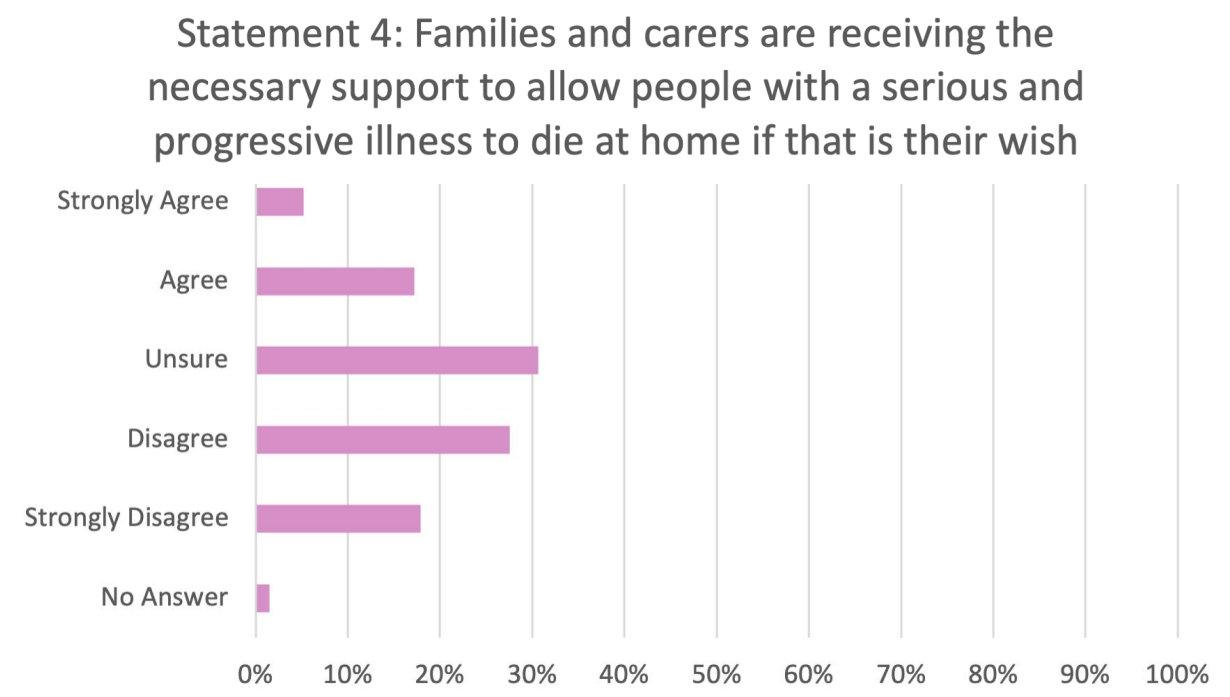
2.2 Individual's Views on Current Palliative Care Services

Figure 2.4 Response to Question 3.1 / Statement 3



A high proportion of responses (28%) were 'Unsure', but the majority (41%) leaned towards disagreement.

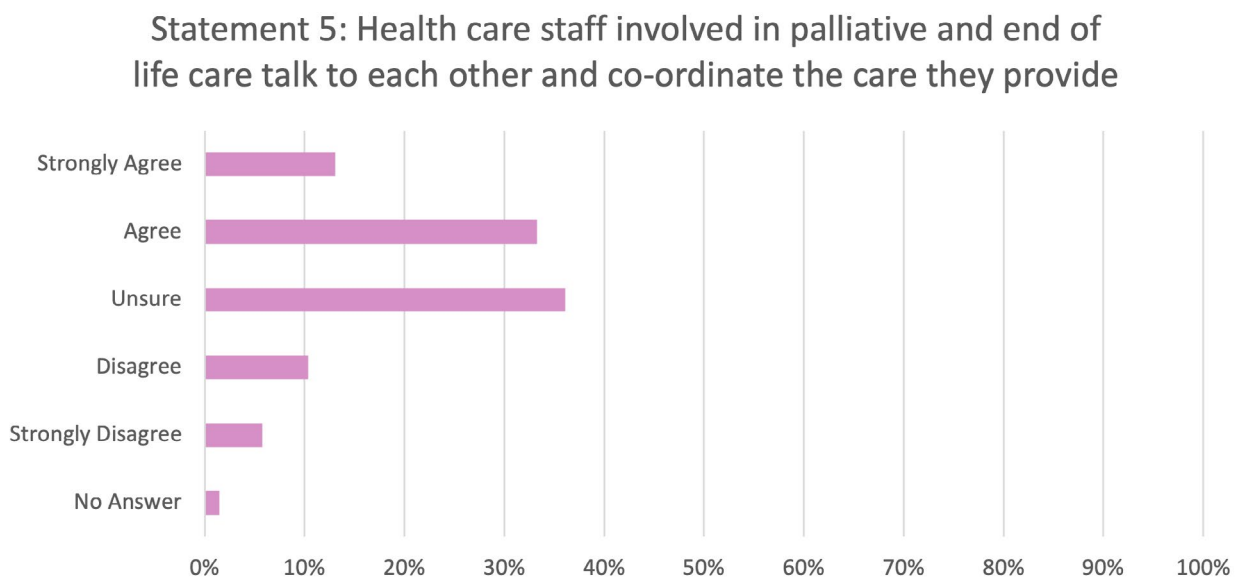
Figure 2.5 Response to Question 3.1 / Statement 4



Most people (40%) were 'Unsure' about Statement 4 but overall, most responses tended to disagree (45%).

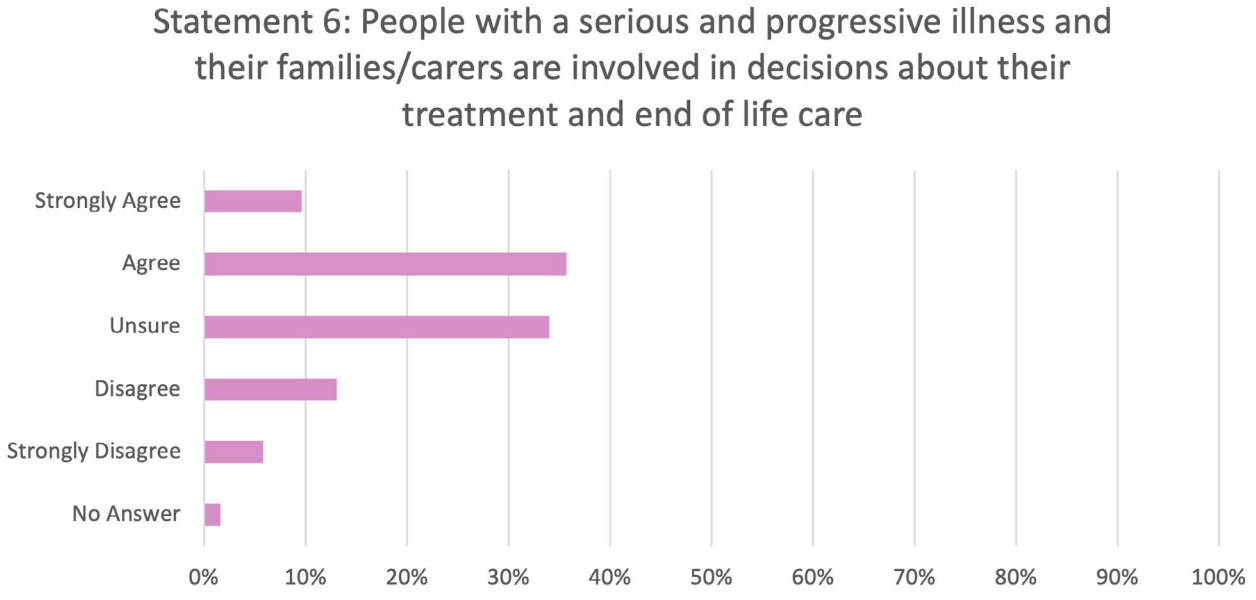
2.2 Individual's Views on Current Palliative Care Services

Figure 2.6 Response to Question 3.1 / Statement 5



The majority of individuals (36%) were 'Unsure' about Statement 5 but overall, most responses (46%) tended towards agreement.

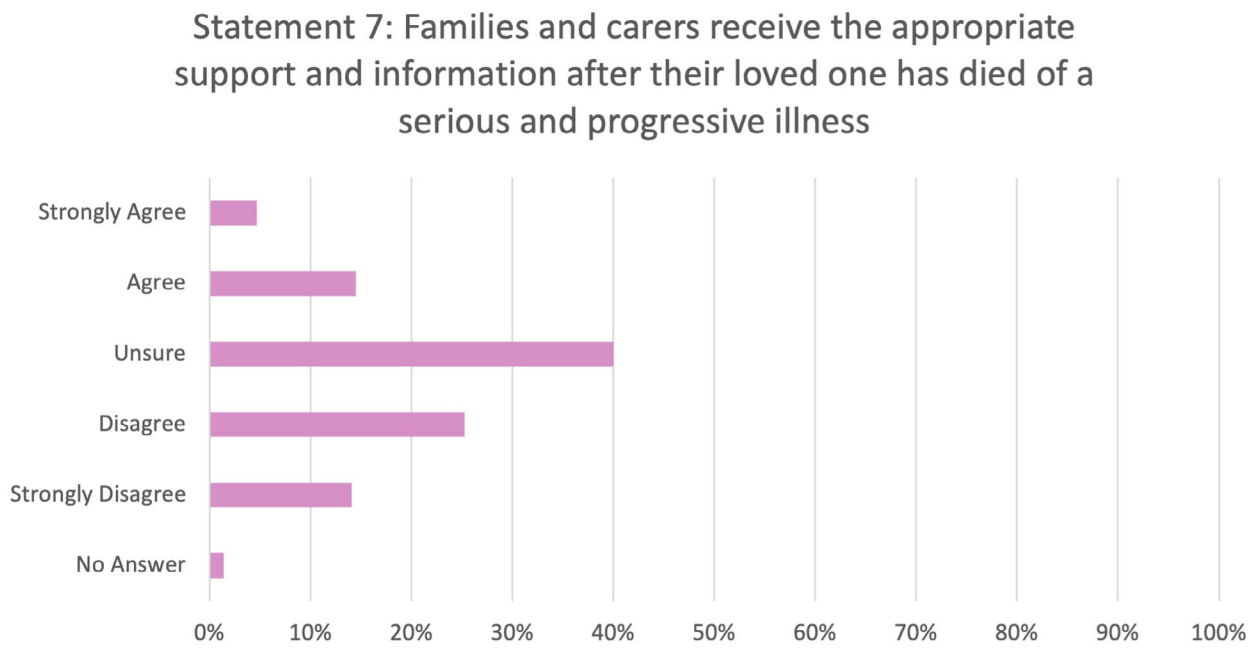
Figure 2.7 Response to Question 3.1 / Statement 6



The majority of individuals (34%) were 'Unsure' about Statement 6 but overall, most responses (45%) tended towards agreement.

2.2 Individual's Views on Current Palliative Care Services

Figure 2.8 Response to Question 3.1 / Statement 7



The majority of individuals (40%) were 'Unsure' about Statement 7 but overall, most responses (39%) tended towards disagreement.

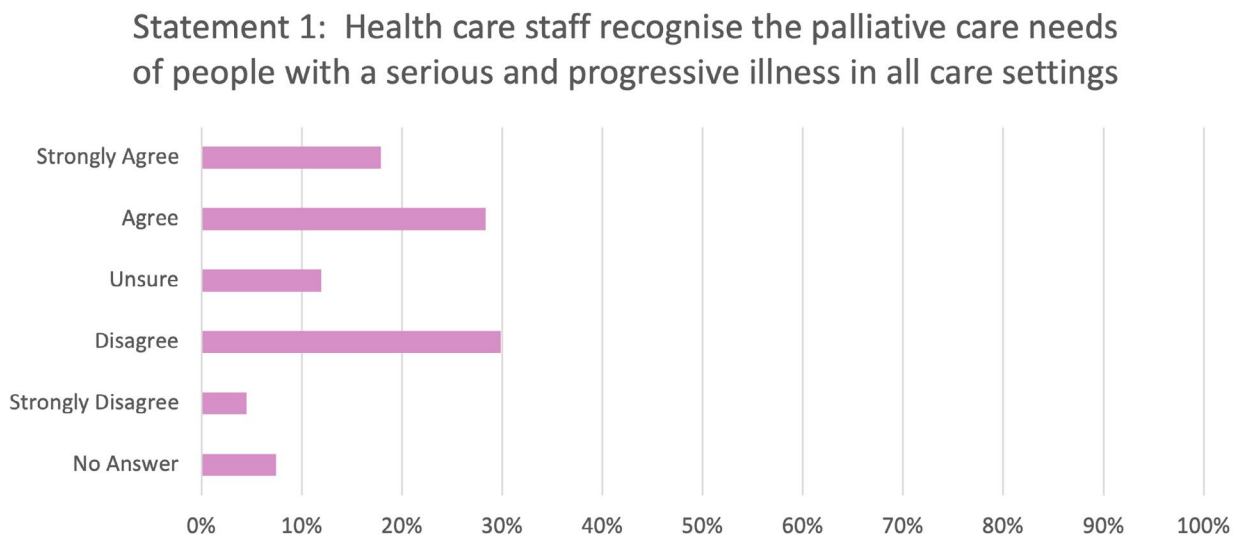
2.2.1 Key Findings of Section 2.2

If we look at each possible answer on its own, in five out of seven statements the most popular answer was 'Unsure'. This suggests individuals are less certain about palliative care services in comparison to their understanding and awareness about palliative care. This may be because many respondents may not have had exposure to palliative care services. Although individuals reported having a good understanding and awareness of the concept of palliative care, there is more uncertainty about the extent to which palliative care services and supports are available, such as bereavement support, shared decision making and support for those who wish to die at home. Respondents highlighted potential gaps in relation to people with a serious and progressive illness and their families/ carers receiving the necessary information, accessing the appropriate type of palliative care services when they need them and receiving the necessary support to allow people to die at home if that is their wish.

2.3 Organisation's Views on Current Palliative Care Services

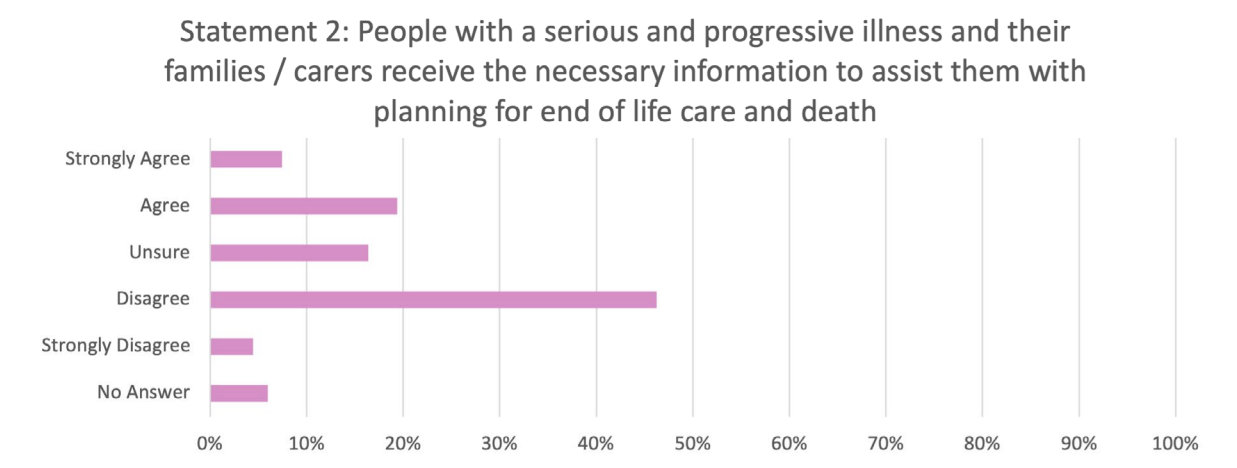
Section two of the organisational survey sought to understand organisations' views on current palliative care services through three different questions. The first question included the same seven different statements that individuals were asked. The possible answers were 'Strongly Agree', 'Agree', 'Unsure', 'Disagree', 'Strongly Disagree' and 'No Answer'. In general, responses were much more categorical in comparison to individual responses; with organisations either agreeing or disagreeing but rarely being unsure, although, just like individuals, end of the spectrum answers ('Strongly Agree' or 'Strongly Disagree') were chosen less often.

Figure 2.9 Response to Question 2.1 / Statement 1



Organisations were divided about Statement 1 with 30% 'Disagreeing' and 28% 'Agreeing'. However overall, most responses tended towards agreement.

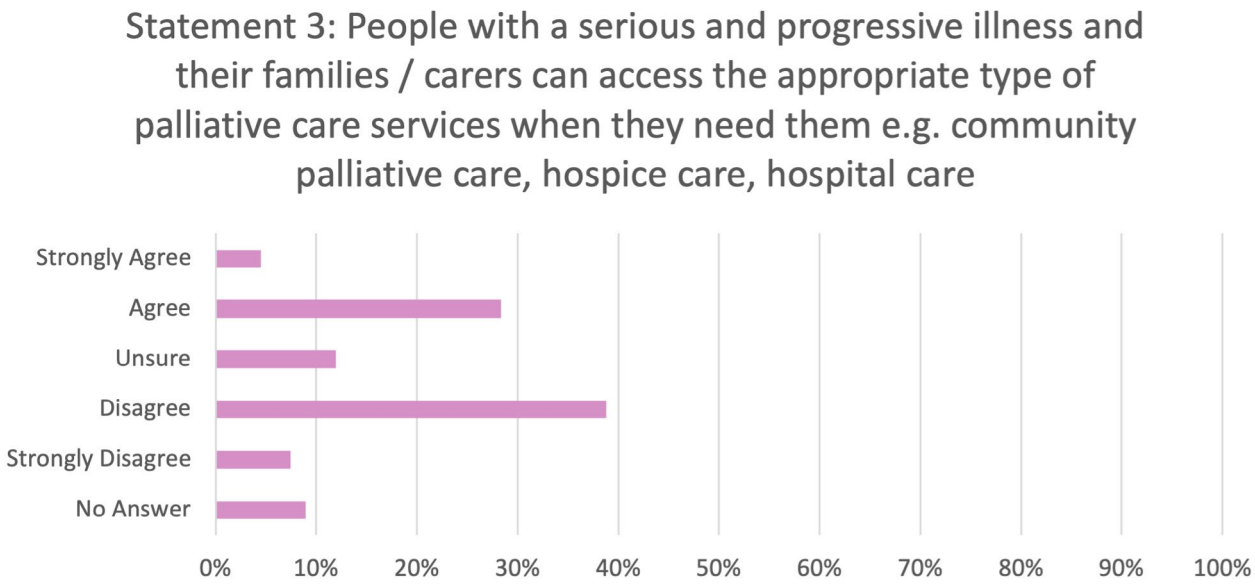
Figure 3.0 Response to Question 2.1 / Statement 2



Most organisations (46%) 'Disagreed' with Statement 2 while only 19% 'Agreed'.

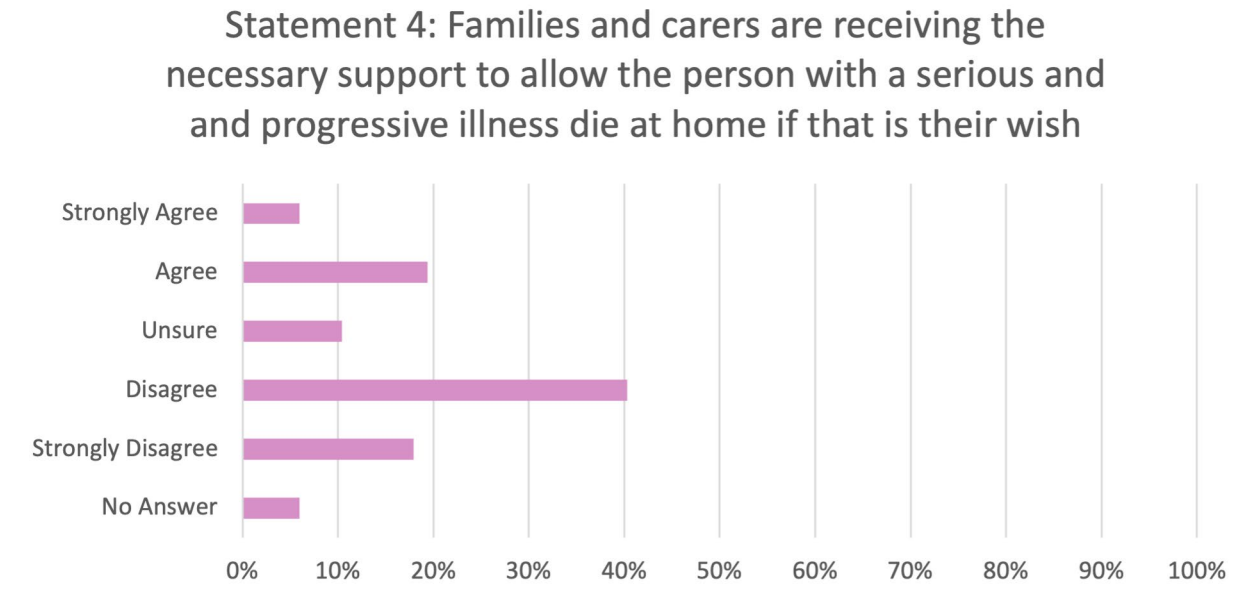
2.3 Organisation's Views on Current Palliative Care Services

Figure 3.1 Response to Question 2.1 / Statement 3



The majority of organisations (39%) 'Disagreed' and 28% 'Agreed'.

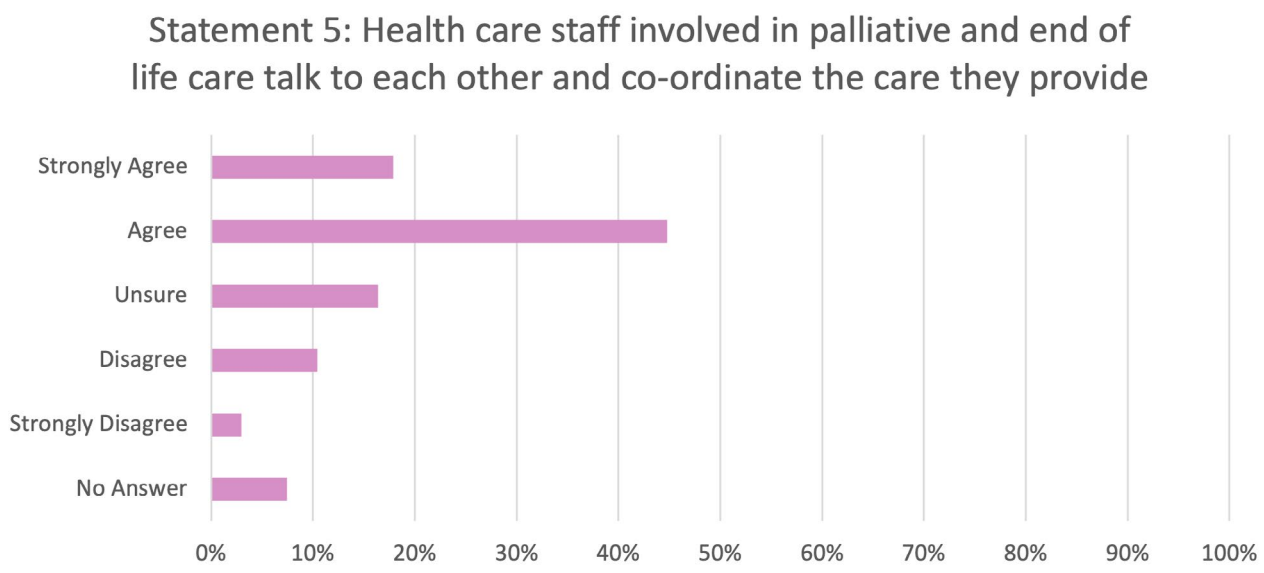
Figure 3.2 Response to Question 2.1 / Statement 4



Organisations mainly (58%) leaned towards disagreement, while only 25% generally agreed.

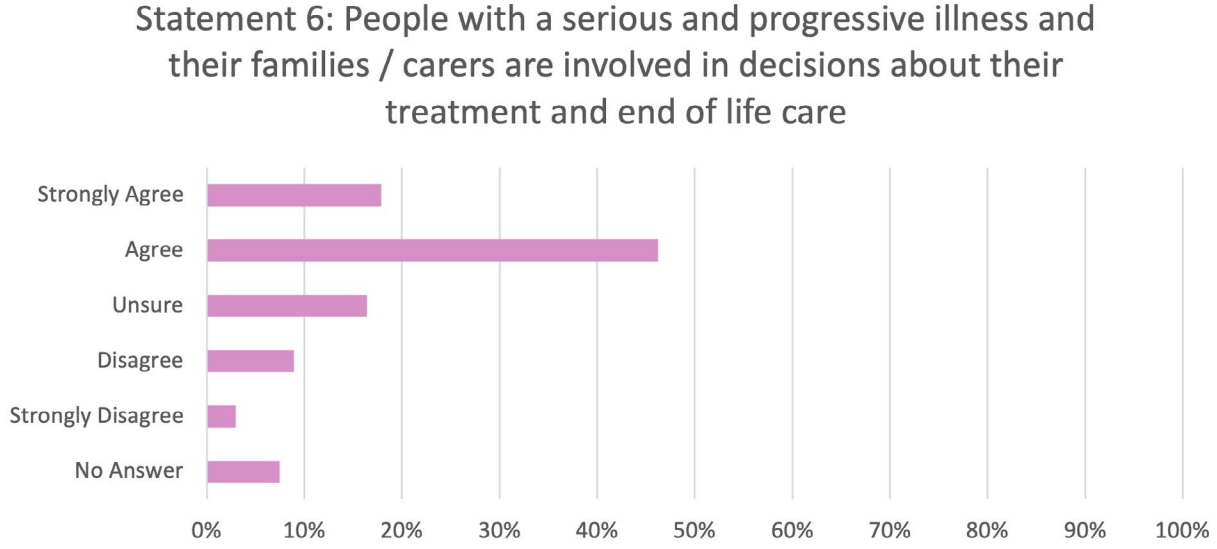
2.3 Organisation's Views on Current Palliative Care Services

Figure 3.3 Response to Question 2.1 / Statement 5



Most organisations (63%) agreed with Statement 5.

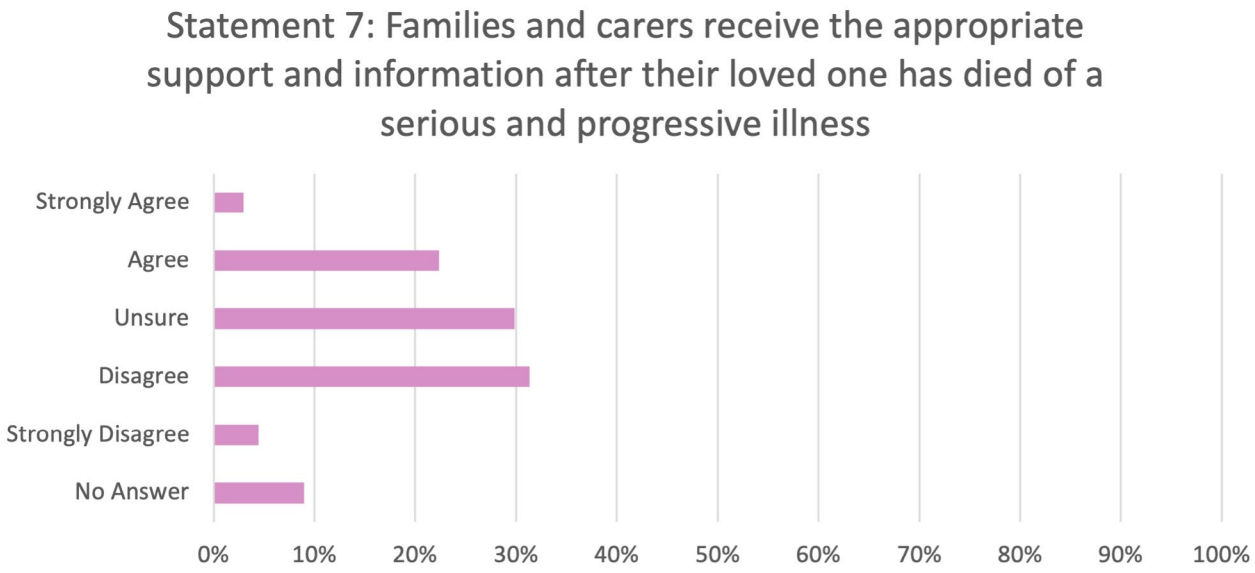
Figure 3.4 Response to Question 2.1 / Statement 6



Again, most organisations agreed with Statement 6, with 64% leaning towards agreement.

2.3 Organisation's Views on Current Palliative Care Services

Figure 3.5 Response to Question 2.1 / Statement 7



Finally, organisations were divided by Statement 7 as 31% 'Disagreed', 30% were 'Unsure' and 22% 'Agreed'. However, overall, the responses leaned towards disagreement with 36%.

2.3.1 Key Findings of Section 2.3

As per the profile of respondent organisations, the key findings of Section 2.3 mainly represent the voices of organisations that identified as health service providers, charity/NGO or community/voluntary groups.

In general, organisations were clear whether they agreed or not with a statement, except in two cases: Statement 1 and 7. The first refers to health care staff recognising the palliative care needs of people with a serious and progressive illness in all care settings; 28% agreed while 30% disagreed. Statement 7 refers to families and carers receiving the appropriate support and information after their loved one has died. Answers reflect a lack of consensus among organisations with 31% disagreeing, 30% being unsure and 22% agreeing.

Most organisations disagreed with statements that, relating to people with a serious illness, family or carers received the appropriate support/access/information (Statements 2, 3 and 4). On average 54% of organisations disagreed and a fair proportion (average of 13%) were unsure.

Finally, organisations were in general agreement regarding health care staff working well together (Statement 5). There was also strong agreement with Statement 6 that refers to involving people with a serious illness, their families and carers in the decisions of their treatment and end of life care.

2.3.2 Cross-cutting Themes Between Individuals and Organisations

If we compare the answers individuals and organisations provided, we note there are a few areas where organisations and individuals share the same views.

- The majority of individual respondents and organisations disagreed with the statements that people with a serious and progressive illness, their family and carers are receiving the necessary information/access/support (Statements 2, 3, 4 and 7).
- The majority of organisations and individuals agreed that health care workers work well together and include people with a serious illness as well as their families in the treatment and end of life care discussions (Statements 5 and 6).

2.4 Strengths of the Current Provision of Palliative Care Services

The second question of section two was an open-ended question that asked organisations: What is working well in the current provision of palliative care services in Ireland (i.e., what are the strengths)? A total of 58 organisations replied to this question and five main themes emerged: dedicated and skilled staff, a multidisciplinary team approach to patient care, integration of specialist palliative care across different care settings, physical infrastructure, and training and education. The responses commended best practices currently taking place in palliative care services, and specific examples were provided to illustrate where work was being done well and producing effective results.

2.4.1 Dedicated and Skilled Staff

A dedicated and skilled workforce was the most frequently referenced strength of current palliative care services, mentioned by 44% of organisations. Staff skills and their dedication is seen as being palliative care services' greatest strength. The specialist palliative care teams are commended due to their kind, supportive and holistic approach to care:

> *'dedicated staff who work tirelessly to care for clients'*
> *'great skills, compassion, support and care to all families and patients'*

A range of different organisations, including other representative bodies and health service providers, particularly acknowledged the important role of nurses in achieving integration across different services and beyond what is expected of them. A charity organisation described public health nurses as an excellent resource to minority groups including the Traveller community as they are a source of clinical information and act as a bridge with other health care teams.

Finally, organisations also reflected on the recent challenges palliative care services (and the healthcare system in general) have experienced due to the COVID-19 pandemic. They highlighted the contribution of front-line staff who have continued to provide an excellent level of service to patients and their families during the pandemic.

2.4.2 Multidisciplinary Team Approach to Patient Care

A multidisciplinary team approach to patient care was referenced by 28% of organisations as an aspect of the palliative care area which is working well in current services. It was highlighted by a number of organisations that there is a strong culture of a multidisciplinary team approach to patient care within palliative care services.

Health service providers and union/staff representative bodies noted that a multidisciplinary approach to care provides patients with individualised, holistic and person-centred care that considers their palliative care needs. Respondents also mentioned that members of the multidisciplinary team benefit from consulting with other disciplines to discuss and plan care. This benefits patients as they receive a holistic assessment of their palliative care needs and a well-developed care plan. A particular area that was highlighted as working well were the rehabilitative palliative care programs that have been collaborating with multidisciplinary teams to meet patient goals. Another positive example resulting in enhanced palliative care services were the primary care teams working alongside the specialist palliative care multidisciplinary team. Finally, a few organisations mentioned that a multidisciplinary team approach to specialist palliative care is recognised in different policy/framework documents such as the HSE Role Delineation Framework for Adult Palliative Care Services (HSE, 2015), Report of the National Advisory Committee on Palliative Care, 2001 and HSE Adult Palliative Care Services, Model of Care for Ireland, thus validating its role.

2.4.3 Integration of Specialist Palliative Care

26% of organisations consider the integration of specialist palliative care services across different types of care settings to be working well. Organisations consider that integration of palliative care across sectors is still developing and acknowledge that the National Clinical Program for Palliative Care is an important structure that has supported the development of integrated services.

'The Adult Palliative Care Services, Model of Care for Ireland provides an excellent framework for the provision of specialist palliative care services and for the integration of the palliative care approach into hospital, community and primary care services. Over the last number of years, substantial progress has been made in expanding the best-practice model of palliative care from hospice setting to the acute hospital setting and into the community.'

Moreover, organisations recognised that specialist palliative care services have expanded to other areas of healthcare beyond the provision of cancer care.

Organisations also reflected that healthcare professionals outside specialist palliative care have developed additional skills and are now recognising their role in meeting some of the palliative care needs of their patients.

Examples of effective integration described in the responses include:

- Palliative care teams and public health nurses working closely to provide a shared care approach to support individuals to remain at home.
- Increased collaboration between palliative care teams and HSE primary care and social care services.
- Consultants working across the acute hospital, local hospice and in homes in the community supports continuity of care, collaboration, communication and building trust in services for the patient and family.
- AIIHPC promoting and supporting best palliative care practice, research and driving public engagement and information from an all-island perspective.
- Good synergies and teamwork between adult palliative care services, paediatric palliative care services and the voluntary sector, ensuring the child remains in their own community.
- Occupational therapists have assisted in creating a more seamless transition for patients between specialist palliative care services, acute settings, community and social care services. They have developed care and communication pathways between occupational therapy services.

2.4.4 Physical Infrastructure

24% of organisations considered palliative care services to have good physical infrastructure and to have greatly developed since 2001. Health service providers particularly noted that there are acute hospital and community palliative care services across the country, albeit with differing levels of resourcing. Capital investment in the development of more inpatient hospice beds nationwide has also been commended, including:

'specialist palliative care units with excellent inpatient infrastructures', and 'co-located sites for inpatient and outpatient services on hospital sites leading to improved integration and the breakdown of organisational boundaries.'

A respondent highlighted that in one area of the country there is improved access to medicines for patients with palliative care needs thanks to the community pharmacy scheme where pharmacies hold a small stock of commonly used medicines for palliative care, funded by the HSE. It was recommended that this should be available nationally. An increase in palliative care support beds has also been highlighted as an essential resource that has given respite to families who are caring for an individual at home.

Finally, two specific programmes were noted for contributing towards the improvement and transformation of hospital care and the physical environment: Hospice Friendly Hospitals and the Design and Dignity Programme led by the Irish Hospice Foundation and working in partnership with the HSE.

2.4.5 Training and Education

22% of the organisations mentioned training and education as a positive aspect of current palliative care services. It was noted that further programmes have become available at both specialist and non-specialist palliative care levels. The following are some of the programmes that were highlighted in the responses:

- The palliative care education programme for nurses and healthcare staff that is being delivered by the Centre of Children's Nurse Education at Children's Health Ireland in Crumlin;
- Master/Postgraduate Diploma in Health Sciences (Children's Palliative / Complex Care) facilitated by both the teaching teams at NUI Galway and UCD;
- Palliative Care Certificate for GPs being delivered by the Irish College of General Practitioners and funded by the ICGP, Irish Hospice Foundation and the HSE;
- Palliative Specialist Registrar Training Scheme being delivered by the Royal College of Physicians of Ireland.

Online courses and resources were recognised as improving the overall access to palliative care education. The Palliative Meds Info service, operated by Our Lady's Hospice, and AIIHPC's Palliative Hub websites were highlighted as examples.

Multidisciplinary learning and training were also acknowledged as a strength of palliative care services. In this regard, organisations highlighted the importance of the Palliative Care Competence Framework which has the potential to improve staff recruitment, training, and development.

Health service providers commended the training and education that is currently provided to undergraduate and postgraduate health care staff about principles of palliative care. Other representative bodies also highlighted the benefit of specialist palliative care professionals such as pharmacist and dietitian teaching on health-related undergraduate and postgraduate courses in third-level institutions to ensure the programmes provide a solid base of palliative care education. Bespoke training provided by specialist palliative care teams to other health care providers was also noted as a valuable practice.

2.5 Weaknesses of the Current Provision of Palliative Care Services and How to Improve Them

The third and fourth questions of the public consultation were open-ended questions that asked organisations: (1) What is not working well in the current provision of palliative care services in Ireland (i.e., what are the weaknesses)? and (2) What changes or improvements do you suggest for inclusion in the update to the Adult Palliative Care Policy?

The responses to these questions were closely connected as organisations tended to suggest solutions/improvements to the weaknesses they had highlighted. Therefore, they have been presented together in the present section.

The following themes emerged:

- Staff shortages and the need for enhanced palliative care education
- Inadequate support for family carers
- Barriers to integration
- Inconsistent staffing of multidisciplinary teams
- Lack of infrastructure
- Lack of public awareness
- Lack of adequate key performance indicators
- Lack of equity in service provision

Two sub-themes, funding and the need to honour people's wish to die at home, were cross-cutting themes which will be referred to accordingly.

2.5.1 Staff Shortages and Staff Education

This theme was highlighted by 66% of organisations as a current weakness of palliative care services. It encompasses several sub-themes: shortages, recruitment and retention, emotional and psychological support, training & education, lack of staff support and carer support.

SHORTAGES

In general, the current staffing levels were identified as being insufficient to meet the increasing needs of patients and changing demographics. Several organisations highlighted that minimum staffing levels as per current policies are not being met. The following roles in particular were highlighted as being under stress and needing attention:

Nurses

Organisations mentioned the critical shortage of nurses at all levels but a need for night nurses was especially noted and even more so in rural areas. There were also issues with the recruitment and retention of nurses, particularly those with experience and specialist training in palliative care.

'Current requirements are based on 15-year-old data, therefore there is an urgent need to review the staffing and skill mix requirements in keeping with Framework for Nurse Staffing and future demographic projections when planning services'

Palliative Medicine Consultants

Organisations highlighted the need for more Palliative Medicine Consultants across all care settings. Health service providers, as well as community/voluntary organisations, recommended an increase in consultants in acute hospitals including outpatient clinics and emergency departments. This would ensure early identification, intervention, and access to palliative care services.

Home Carers

The need for home care support to assist family carers was highlighted in a number of submissions. It was noted that there are a number of barriers to the provision of home care services for people with palliative care needs and their families, including difficulty sourcing staff to provide the home care hours, particularly overnight and at weekends, and a lack of consistency with carers.

'A shortage of professional carers (homecare packages) to support patients and caregivers negatively impacts the ability for patients to remain at home if wished, contributes to caregiver fatigue and delays discharges of patients from hospital to home.'

Health and Social Care Professions

A number of respondents highlighted the shortages of Health and Social Care Professions. For example, a health service provider highlighted the role of specialist palliative care occupational therapists in providing a holistic service incorporating equipment when it is needed, providing advice to family carers around safe manual handling techniques, and education about fatigue management and energy conservation. Another organisation highlighted that not all hospices are able to offer speech and language therapy sessions, as recommended in the 2001 policy.

Bereavement Support

Several respondents said that bereavement services are underdeveloped and need to be enhanced across the board. Some responses indicated that staffing shortages limited the ability to provide adequate bereavement support. Furthermore,

'provision of bereavement support remains extremely inconsistent, particularly in the community setting [as well as acute hospitals], where it is often non-existent.'

Most organisations felt that further resources are required to provide the necessary level of bereavement support.

HOW TO ADDRESS STAFF SHORTAGES

Several organisations believe a comprehensive assessment of workforce requirements needs to be carried out. This assessment needs to consider the broader clinical scope of palliative care and the increasing complexity of patients' needs.

'Where specialist palliative care teams provide care to a large geographical area, this should inform workforce planning in determining the number of nurses, doctors and allied health professionals required as travel time impacts on service delivery.'

A union/staff representative body suggested that 'The National Framework on Staffing and Skill Mix for

2.5.1 Staff Shortages and Staff Education

Nursing' should be referenced to ensure optimal nursing staffing and skill mix for all palliative care services across community and acute settings. Also, an annually funded workforce plan was suggested, which should include educational opportunities for staff.

A health service provider suggested there should be dedicated state funding for bereavement support services for the families of people who die at home or unexpectedly. The Framework for Adult Bereavement Care (2020) was referenced as relevant guidance to ensure support is carried out in a consistent and systematic manner. In line with this suggestion, an organisation mentioned a tiered approach was necessary, such as peer or trained supervised volunteers and Medical Social Workers to meet the needs of bereaved individuals/ families and ensure appropriate referrals into mental health services if required.

Recruitment and Retention

'Recruitment and retention of specialist palliative care healthcare workers has become more challenging in all settings, limiting the provision of palliative care.'

The difficulty with staffing is shared by a number of organisations. It was said that incentives for professionals to upskill and incorporate palliative care into practice are minimal which contributes to a deficit of skilled workers. Also, health service providers and charities/NGOs mentioned that the differentiation between HSE and Section 38 versus Section 39 organisations has exacerbated these issues; recruiting outside the HSE has become increasingly difficult because employers cannot offer the same benefits as a public servant post.

Need for Increased Staff Support

'Community palliative care nurses are at burn out; more community palliative care nurses are needed as the number of patients wishing to die at home is increasing rapidly, our public health colleagues are required to take on other roles, therefore medication management at end of life requires a daily visit from palliative care nurse.'

Although the above quote refers to community palliative care nurses, other responses also recognised the importance of health care staff being supported across all care settings. Respondents identified that currently, staff support is limited and it varies between hospitals and disciplines. It was highlighted that staff are under an enormous amount of pressure which is leading to burnout and exodus. It was highlighted that there is a need to ensure strong supportive management structures and sufficient administrative supports available to alleviate the pressure on staff working in palliative care.

Psychological and emotional support for staff was also suggested for those working in long-term care settings in which staff build strong bonds with residents and their families prior to the resident's death, such as residential care settings.

Training and Education

Insufficient training and education of staff is seen as a general weakness by 29% of organisations. There is a need for increased palliative care knowledge among all healthcare staff including General Practitioners, staff in nursing homes and ambulance services.

'Palliative care may not be fully recognised by non-specialist staff as an essential part of care plans with early intervention in a disease trajectory beneficial. Without adequate planning identified within policy, patients might not receive sufficient palliative care input.'

Furthermore, respondents reported healthcare professionals may lack the understanding of palliative care as an approach rather than a stage at end of life. It was suggested that many healthcare staff are not fully aware of the value of advance care planning with patients, thus referrals are often delayed or simply not made.

'Disconnect between acute services and palliative care services, poor understanding of what palliative care has to offer through all stages of disease trajectory, not just 'end of life care'.'

2.5.1 Staff Shortages and Staff Education

It is suggested that the aforementioned is underpinned by the fact that palliative care education is not universally available to undergraduates and even more limited for postgraduates wanting to upskill in this area. A number of respondents expressed the view that existing postgraduate programmes may not always meet the higher-level education needs of the specialist palliative care Health and Social Care Professions and they therefore may need to be expanded in order to meet these needs going forward.

A health service provider suggested that palliative care training should be part of the Higher Specialty Training curriculum for all doctors. This would ensure that all doctors can undertake a palliative care needs assessment and utilise a palliative care approach.

Respondents also highlighted that there is insufficient expertise in quality improvement, change management and knowledge transfer. Further training for staff on sensitive issues like breaking bad news, bereavement support, anti-racism and cultural awareness were also noted as necessary and would assist with the current shortcomings around equitable palliative care. Furthermore, a health service provider mentioned a lack of access to HSE Management Training Programmes and HSE Nurse Education/Training for Section 39 agencies.

It was also highlighted by a couple of health service providers that there is a lack of a career pathway for specialist palliative care Health and Social Care Professions. It was recommended that consideration be given to the need for postgraduate education opportunities, supervision, mentoring and grade progression. Respondents felt that this would lead to sustainable clinical leadership in the area of specialist palliative care.

'All medical training schools and intern training posts should review their curricula and training content to ensure that all interns have achieved the required palliative care approach competencies by end of intern training year.'

2.5.2 Inadequate Support for Family Carers

Support for family carers was highlighted as being inadequate by a number of respondents. For example, respondents identified gaps in palliative and end of life care training and education for family carers who may be caring for patients at home and recommended that funding be made available to develop such resources.

A charity/NGO and other representative bodies also highlighted that there should be a focus on increasing cooperation between family carers, health care staff and those in receipt of palliative care. A charity/NGO recommended the benefits of using the Carers Needs Assessment Tool as an effective tool to identify carer's needs and enable them to care for their family member or friend and to preserve their own health and well-being within their caregiving role. A longer 'sit in' service provided by paid carers, which would enable family carers to have a respite away from home, was also recommended.

One organisation also suggested that a map of palliative care services in the community should be available in order to support people with palliative care needs and their family carers to smoothly navigate the health system.

2.5.3 Barriers to Integration

As previously reported, 26% of organisations thought that integration of specialist palliative care services was working well. Although progress in this area is acknowledged by respondents, 41% consider further work is required to integrate and consolidate palliative care across all care settings and services.

'An appropriate governance model must be designed and implemented that recognises and supports the integrated nature of specialist palliative care delivery across all care settings – inpatient hospice, community (including community hospitals and nursing homes) and acute hospital settings.'

Poor integration was also attributed to staff shortages. For example, hospitals with specialist palliative care services were highlighted as not having opportunities to integrate with chronic disease teams such as respiratory or cardiology due to staffing deficits. An organisation also mentioned that the failure to develop new roles, such as Advanced Nurse Practitioners who can work across different settings, represented a missed opportunity for service integration.

A health service provider as well as another representative body expressed their concern that persistent misconceptions by healthcare professionals exist regarding the concept of palliative care. It was further noted by community and voluntary groups as well as other representative bodies that early intervention in palliative care may not be fully recognised by all health care staff as a key and beneficial part of care plans. Respondents noted that specialist palliative care has a role at all stages of life from the perinatal period through to centenarians. Integration could be further improved if the HSE ensures cohesion among the various strands of care provision at a local and national level.

'Re-establishment of the national council for palliative care, along with regional bodies overseeing palliative care development that are fully integrated with representation from all relevant HSE and charitable bodies in the region, will help ensure maximum efficiency and transparency.'

A health service provider also highlighted that palliative care should be integrated into relevant National Clinical Programmes models of care and the National Integrated Care Programmes in order to ensure that focus on palliative care is maintained. Some organisations believe further integration can be achieved if ties are fostered between palliative care and universities to promote education and research, both nationally and internationally.

Finally, lack of integration was also associated with funding. Currently, there are separate budgets for acute care and community care which are not jointly allocated. A health service provider argues that if closely linked, HSE management would be more incentivised to support integrated planning across both settings.

2.5.4 Lack of Infrastructure

Although 24% of organisations commended the overall physical infrastructure of palliative care services, a further 31% believe other areas of infrastructure still need to be developed: IT infrastructure, palliative care support beds and more resources for home care.

IT infrastructure was highlighted by a number of different organisations as a barrier to services. Respondents felt that the lack of an efficient IT system across all care settings inhibits collaboration across teams. A community/voluntary group mentioned that the limited electronic access to test results (blood, scans, etc) makes the overall system very inefficient, duplicating efforts and resources. A number of health service providers as well as other representative bodies highlighted the urgent need for an electronic healthcare record which would enable information to be available across all care settings and services. Related to this issue, a couple of charity/NGO organisations mentioned the absence of a unique patient identifier which exacerbates the challenges around communication, integration of services and data analysis.

In relation to palliative care support beds, although many organisations welcomed the increase of this resource in Section 3.4.4, some believe:

'the use of palliative care support beds needs to be reviewed and improved. The effectiveness of this resource should be reconsidered, and resources invested more appropriately in the community.'

Respondents stated that at times people's wish to die at home is not being met because there is limited availability and timely availability of resources i.e., home care packages, night nurses, equipment and medical cards.

How to Improve Infrastructure

In order to improve the current infrastructure of palliative care services, 28% of respondents submitted ideas to be considered in the new policy. Organisations believe capital investment is required in the following areas:

- A number of specialist palliative care inpatient units need to be upgraded to provide single room accommodation to allow privacy and meet infection control requirements, as well as increase the number of single rooms in acute and long-stay settings.
- Increase in the number of palliative care inpatient beds within cancer centres and having specific regard to infrastructure for adolescents and young adults.
- Increase provision of hospice beds and community hospital beds to enable discharge from acute settings.
- A dedicated capital estates fund be created for adapting the physical care environment.

Investment is also required to develop an integrated IT and communication system between voluntary organisations providing palliative care and the HSE. As previously mentioned in Section 3.5.4 there is a need to create a national electronic patient record to facilitate care of patients across different sites. This will assist with integration and communication across all services in all care settings.

2.5.5 Inconsistent Multidisciplinary Team Provision

As previously noted, a multidisciplinary team approach to patient care is identified as a strength by a fair proportion (28%) of organisations. However, a similar proportion (26%) believe that not all health disciplines are being included in a consistent and comprehensive manner throughout palliative care services. Other specialists, like dietitians, believe they are underrepresented within specialist palliative care due to the lack of a manager role which can lead to the development of enhanced dietetic services within palliative care. Also, pharmacists consider their involvement in clinical governance at times is limited within services. It was reported that staffing deficits have resulted in several care settings being unable to provide a multidisciplinary team approach to care.

'Service provision is uneven across the country, and in some areas there are limited multidisciplinary teams (nurses only, or nurses and doctors) rather than comprehensive teams.'

In order to improve the current inconsistencies in multidisciplinary teams, organisations believe further resources need to be allocated to this area, particularly for hospitals, communities and cancer institutes/centres that do not have full multidisciplinary teams. Full multidisciplinary teams are necessary to support individuals with palliative care needs at home.

'community-oriented multidisciplinary teams need to be developed to provide complex in-home interventions that allow patients to be rehabilitated and continue to live in their preferred setting.'

Most organisations considered a full multidisciplinary team should include doctors, nurses, physiotherapists, occupational therapists, social workers, speech and language therapists, pharmacists, dietitians, health care assistants, chaplains, social workers, and adequate administrative support. Some organisations also suggested psychologists, librarians, music, art, and complementary therapists should be included in all specialist palliative care inpatient units. Responses from professional organisations including speech and language therapy and dietetics highlighted the need for the new policy to explicitly mention the requirement for these disciplines to be an integral part of the specialist palliative care multidisciplinary team.

Overall, organisations acknowledge the considerable benefits of a multidisciplinary team approach and the potential for the new policy to build on the existing team culture.

2.5.6 Lack of Public Awareness

19% of organisations discussed the lack of public awareness of palliative care and they emphasised the lack of understanding about palliative care availability and its scope.

'There is not enough information on the palliative care services available in various parts of the country out there among the general public. Consequently, people are not aware in advance of the options, if any, available to them if a family member needs palliative care, or has a progressive illness but wishes to remain in their own home.'

Health service providers, NGOs and community and voluntary groups believe the public should be further educated regarding symptom management, respite, rehabilitation, and the role of palliative care outside of cancer. They also highlighted general misconceptions that need to be challenged such as believing palliative care is only for the terminal phase of an illness. More accessible information with details on local palliative care services would assist families and patients to know what is available, its value and how to access it.

Likewise, organisations said further awareness and education is needed around advance care planning and living wills. It was suggested that it is not always clear how to access this type of information and this needs to be improved. Organisations agreed that provision of advance care planning is limited in healthcare settings as it requires substantial practitioner time and resources. Health care service providers felt that healthcare staff lack the expertise and confidence to discuss this with patients.

Moreover, there was concern expressed about the lack of information regarding bereavement support and how to access it, including greater access to bereavement support for children and young people who are impacted by the death or the anticipated death of a person receiving palliative care. In addition, bereavement information should be tailored for this audience. Bibliotherapy and specific reading material were named as important resources that can assist with provision of bereavement support to clients and their families.

How to Increase Public Awareness

An array of organisations, including health service providers, community/voluntary groups and other representative bodies, submitted ideas on how public awareness of palliative care services could be improved.

'A Public Awareness Campaign should be set up and updated regularly to ensure the public know of their options well before illness strikes, as rushed decisions made under stressful conditions are to no one's benefit.'

One organisation mentioned that special support plans or resources should be created for families to expand their awareness and understanding of the services available. An organisation noted that palliative care librarians could play a special role by improving digital and information literacy, as well as educating the public, patients, and service providers, supporting engagement with the community, patient and general public.

Overall, a number of health service providers, NGOs and other representative bodies believe the content of the campaigns and resources need to be accessible to all and include information about access to palliative care, its scope beyond cancer, advance care planning, treatment choices, living wills, bereavement support, and management of symptoms (including physical and psychological).

2.5.7 Lack of Adequate Key Performance Indicators

15% of organisations consider current KPIs are not adequate nor conducive to improvements.

A health service provider noted that the current minimum data set against which specialist palliative care services are being assessed are not fit for purpose and current KPIs are not comprehensive in scope. The latter does not capture the role of palliative care in reducing length of hospital stay, reducing hospital readmission or supporting individuals to be discharged from hospital for end of life care. Furthermore, it was highlighted that

'in order to develop meaningful KPIs for specialist palliative care services, measurable definitions of complexity in palliative care that include patient ratings need to be implemented.'

In order to improve the existing KPIs, a health service provider suggested that data needs to be shared and in a format that allows benchmarking, learning and comparison to drive continuous improvement. A health service provider suggested that to have a consistent and reliable system, a national approach must be taken.

'We need to move beyond service activity data to include outcome measures. Consider incorporation of palliative care outcome measures with appropriate infrastructural support at a local and national level.'

A charity/NGO mentioned that investment in a nationally mandated integrated quality improvement programme for the residential care sector to improve palliative care services would be beneficial.

Respondents also suggest including routine service user evaluations and incorporating audit and quality KPIs in all palliative care services. Moreover, to create meaningful KPIs, a health service provider mentioned that measurable definitions of complexity in palliative care need to be implemented at HSE level. It was also suggested that ongoing engagement with international colleagues with national-level support would be beneficial in identifying the most appropriate model for the Irish context at any given time, to build a metric system that will reflect the contribution of health and social care workers working in palliative care.

Another representative body proposed that progress of the implementation of the new policy should be assessed. The process for reviewing the new policy should include input from patients and families with lived experience as well as front-line staff.

2.5.8 Lack of Equity

28% of organisations believe palliative care services currently lacks equity and that access to services can be determined by location, age, and diagnosis.

Several organisations cited specific regions of the country where they believed there were significant gaps in the provision of specialist palliative care services inpatient services, for example, in the North East and Midlands. Respondents also referenced disparity in access to out of hours services in different regions of the country.

'vast variance in availability among the available services, with variance in areas where some are available on a 24-hour basis, and others are only available during office hours.'

Health service providers and other representative bodies also recommended the provision of a nationwide, comprehensive and standardised out of hours palliative care service.

Likewise, health service providers and charities/NGOs mentioned gaps in services which support the transition of children and young adults to adult palliative care services. They highlighted a lack of information, clarity and consistency regarding the transition process for patients and their families.

To ensure a smooth transition is provided to children with life-limiting conditions and/or young adults, health service providers and charity/NGOs recommended establishing direct links between the paediatric, young adult, and adult palliative care services; clear transition pathways that consider the unique needs of each individual group should be implemented in a comprehensive integrated system. On this note, a health service provider mentioned the possibility of developing transition clinics to assist with this process.

Several organisations consider the new policy needs to take special consideration of minority groups in order to ensure they have appropriate access to palliative care services.

'Policy must include a focus on marginalised groups in society (e.g., homeless, prisoners, asylum seekers, LGBT community, people with disabilities, etc.) and meet their palliative care needs.'

A union/staff representative body mentioned Registered Intellectual Disability Nurses playing a key role in caring for people with disabilities and thus their role should be emphasised in the new policy.

'More emphasis is required around planning to meet the palliative care needs of people within specific groups e.g. intellectual disability, physical disability etc.'

Organisations also noted that although palliative care services have expanded beyond oncology, further work is still required to ensure appropriate referrals to specialist palliative care services are taking place and thus ensuring equitable access to all patients regardless of diagnosis. Furthermore, a health service provider as well as other representative bodies believe most patients with non-cancer conditions are currently more likely to receive palliative care at the end of life rather than appropriate early referral and access to specialist palliative care services, as recommended.

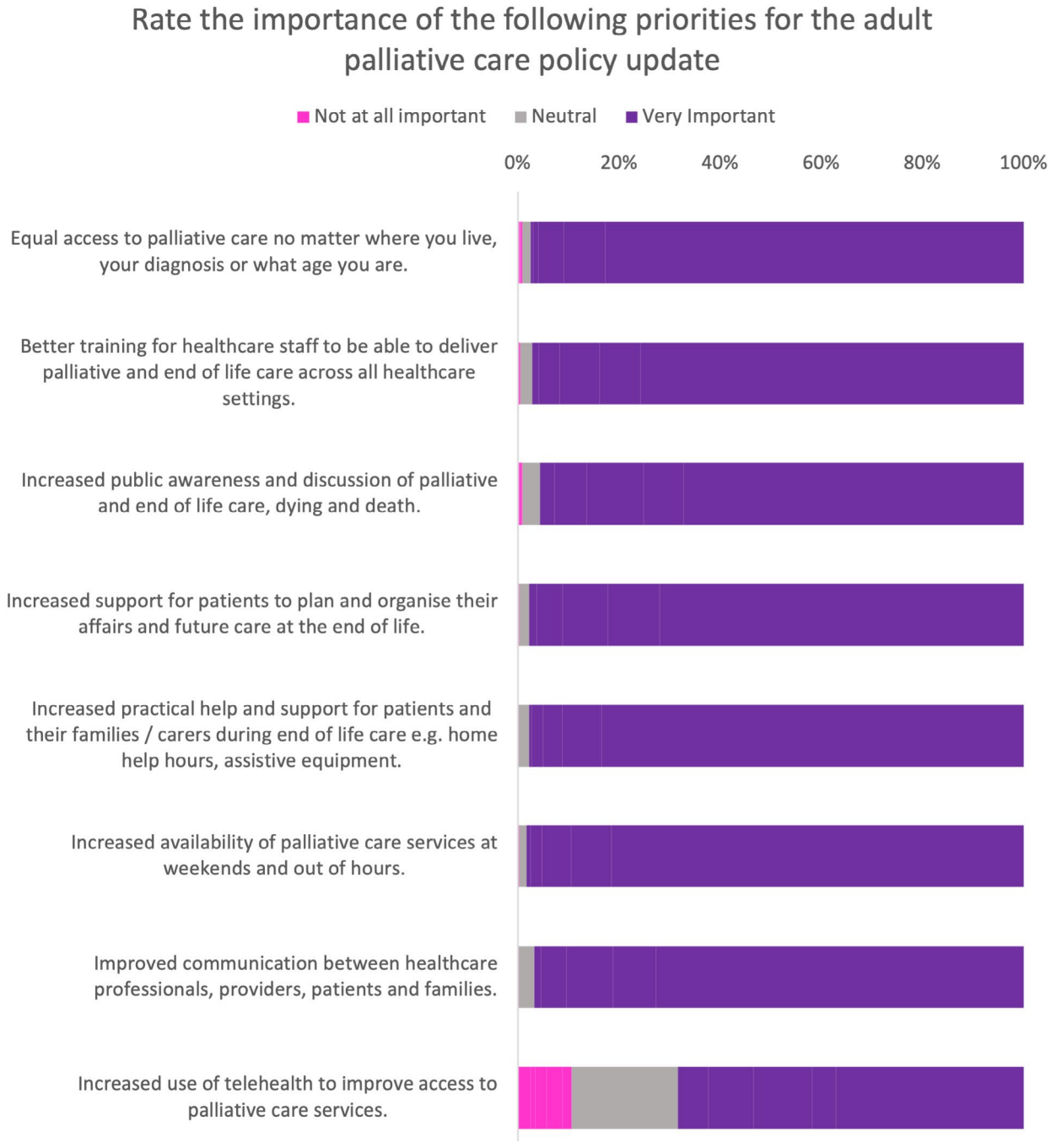
'Pathways outlined in the model of care may not fully translate to people with non-cancer conditions in the community e.g. people with dementia, chronic obstructive pulmonary disease, heart failure.'

2.6 Views on the Future of Palliative Care Services

INDIVIDUALS AND ORGANISATIONS

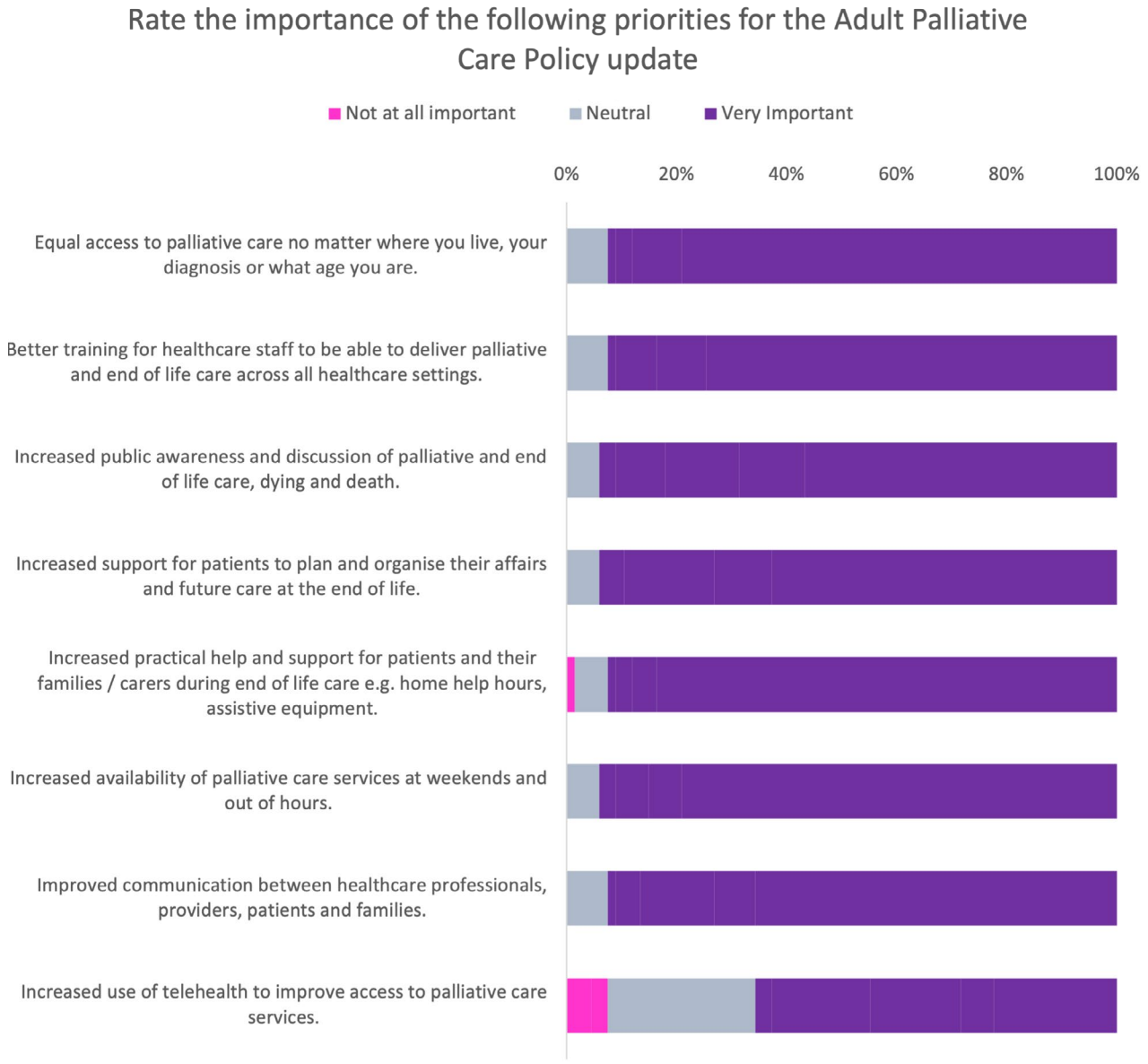
The last section of the individual and organisational survey wanted to understand the priorities for the new Adult Palliative Care Policy. Eight statements had to be ranked from 0 being not at all important to 10 being very important. For the purpose of analysis and representation of results, responses from 0-4 were combined under 'not at all important' and responses from 6-10 were combined under 'very important'. Responses that were ranked '5' were classified as neutral.

Table 3.6 Individual's priorities for the new policy



2.6 Views on the Future of Palliative Care Services

Table 3.7 Organisation's priorities for the new policy



Tables 3.6 and 3.7 illustrate individuals' and organisations' priorities for the new Adult Palliative Care Policy. Clearly there is consensus that all eight priorities are important and must be considered when drafting the new policy. Even in the few answers where some respondents selected 'Not at all important' it accounts for less than 1% of the submissions.

The only slightly more contentious priority relates to the increased use of telehealth to improve access to palliative care services. Although no further information was requested from individuals, this priority was highlighted by two organisations when speaking about the strengths of the current palliative care services. Telehealth was referenced in relation to service adaptations that were necessary due to the COVID-19 pandemic including remote appointments between health professionals and patients.

Section 3. Conclusion

The responses to the public consultation highlighted a range of issues for consideration when developing the new Adult Palliative Care Policy.

The consultation responses indicated that individuals have heard about palliative care and would like to plan in advance for the type of care they receive at the end of their life. It is noteworthy that most individuals have indicated that they would prefer to receive care in their own homes at the end of their life.

There were mixed and contrasting views from individuals and organisations regarding current palliative care services. There was a lack of consensus on whether people with a serious and progressive illness, and their families and carers, are receiving the necessary information to assist them with planning for end of life care and death. Furthermore, there was a lack of consensus on whether they are accessing the appropriate type of palliative care services and whether healthcare staff recognise the palliative care needs of people with a serious and progressive illness in all care settings. Some of these issues resonate with key themes that the organisational responses highlighted and that have been described in Section 2.

Individuals and organisations agree that all priority options presented in the survey should be the focus of the new policy. Equal access and availability of palliative care services are important, but this means the education and training needs of all healthcare staff will need to meet future demand. Fundamentally though, if palliative care is to improve the quality of life of patients and their families who are facing problems associated with life-threatening illness, then palliative care cannot depend on location, age or diagnosis. Indeed, equity of service is highlighted as the top issue for the new policy to address.

Lack of appropriate funding for palliative care was considered one of the main underlying challenges, with the reliance on charity fundraising to fund capital and revenue costs repeatedly highlighted. It was also suggested that specialist palliative care services will require additional funding to meet the future growing need for their services. Additional resources will also be required to provide care for people with life-limiting conditions in non-specialist palliative care services, such as within primary care.

Staff were praised by organisations for their skills, hard work and commitment. However, the theme of staff shortages was highlighted repeatedly as a barrier for palliative care services development. It was reported that there are gaps for certain disciplines within specialist palliative care services when compared to the workforce requirement recommendations included in the 2001 policy. Although specific roles have been highlighted as important, the overall conclusion is that a comprehensive workforce plan across all areas is needed going forward. Recommendations on staffing in the new policy will need to be informed by current research and workforce reports, as well as emerging approaches to population projection, segmentation and modelling being adopted by Sláintecare. These will recognise population densities and dispersal, socio-economic status, increasing longevity and the burden of chronic disease. Workforce planning is required to ensure that future palliative care services have the staffing to meet the projected needs of the population, both at a national and regional level.

The need to increase the level of palliative care knowledge and awareness among healthcare staff working outside specialist palliative care settings was also highlighted by organisations. The provision of additional education and training across all healthcare disciplines will improve the confidence and competence of non-specialist palliative care staff to care for people with life-limiting conditions and ensure timely and appropriate referrals to specialist services.

Section 3. Conclusion

It is also necessary to increase public awareness regarding palliative care including signposting to palliative care services to inform the public and to reduce misconceptions about palliative care.

Once the new policy is published, it will be important to assess its short-term and long-term impact. If the appropriate key performance indicators are implemented and monitored systematically then progress can be measured, insights can be gained, and the necessary adjustments to ensure targets are achieved can be made.

The responses to the public consultation reflect the commitment of the wider sector to the continued development of palliative care services which should be embraced. The new policy should take cognisance of the strengths within current services, learn from them and replicate them where possible, while also identifying and understanding the weaknesses to be addressed.

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Appendices

Appendix 1: Public Consultation Questionnaire – Individuals

An Roinn Sláinte
Department of Health

Public Consultation on Adult Palliative Care Policy Update

Survey for Individual Respondents

Introduction

The Department of Health plans to update the Palliative Care Policy for Adults in 2022 and is seeking the views of the public on palliative care services in Ireland and the public's priorities for the update. The public consultation will allow the Department of Health to hear the views from a wide range of stakeholders and the findings will inform the policy update. We are asking individuals to participate in the public consultation by completing the online survey below. If you are completing the survey on behalf of an organisation or representative body then click here. The survey is best viewed on a larger screen (computer, tablet, large smartphone). If you are using a smartphone with a small screen, you may need to rotate your screen to landscape view.

Any personal information which you volunteer to this public consultation will be treated with the highest standards of security and confidentiality, strictly in accordance with the General Data Protection Regulation 2016/67 and the Data Protection Act 2018. The Department's Privacy Policy can be viewed here.

Section 1: Respondent's Profile

This section asks questions about yourself, so we can look at the submissions received from different points of view. This is the only reason for collecting this information.

1.1 Gender

- ○ Male
- ○ Female
- ○ Other
- ○ Prefer not to say

1.2 Your Age

1

Appendices

Appendix 1: Public Consultation Questionnaire – Individuals

- Under 18
- 18 - 24
- 25 - 34
- 35 - 44
- 45 - 54
- 55 - 64
- 65 - 74
- 75 or older
- Prefer not to say

1.3 About You

Of the list below, which best describes you. (You can select more than one.)

- Person with a serious and progressive illness
- Family member, friend or carer of someone living with a serious or progressive illness
- Family member, friend or carer of someone who died following a serious and progressive illness
- Health care worker
- Member of the public
- Other
- Prefer not to say

You selected other, please specify:

50 character(s) maximum

1.4 Your Location

- Connaught
- Leinster
- Munster
- Ulster

Which Ulster county do you live in?

- Antrim
- Armagh
- Cavan
- Derry
- Donegal
- Down

2

- Fermanagh
- Monaghan
- Tyrone

Section 2: Understanding and Awareness of Palliative Care.

This section asks questions on your understanding and awareness of Palliative Care.

2.1 To what extent do you agree with the following statements.

Statement	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
I have heard about palliative care.					
I understand how palliative care can benefit people who need it and their families.					
I know where to access information about palliative care and end of life care services.					
I feel comfortable talking about end of life care, dying, death and bereavement.					
I would like to plan in advance for the type of care I receive at the end of my life.					

2.2 Where would you like to receive care at the end of your life? (You can select more than one.)

- Home
- Hospice
- Hospital
- Nursing Home / Residential Care Facility
- Other
- Don't know

You selected other, please specify:

50 character(s) maximum

3

2.3 If you wanted more information about palliative care and end of life care, where would you access it from? (You can select more than one)

- ☐ G.P.
- ☐ Other healthcare professionals
- ☐ Family and friends
- ☐ Religious organisation
- ☐ Voluntary organisation
- ☐ Citizens Information
- ☐ Other online sources
- ☐ Other
- ☐ Don't know

You selected other, please specify:

50 character(s) maximum

Section 3: Views on Current Palliative Care Services

This section asks about your views on current palliative care services in Ireland for people with serious and progressive illnesses and their families / carers.

3.1 To what extent do you agree with the following statements in relation to current palliative care services in Ireland.

Statement	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Health care staff recognise the palliative care needs of people with a serious and progressive illness in all care settings.	○	○	○	○	○
People with a serious and progessive illness and their families / carers receive the necessary information to assist them with planning for end of life care and death.	○	○	○	○	○

4

Appendix 1: Public Consultation Questionnaire – Individuals

People with a serious and progressive illness and their families / carers can access the appropriate type of palliative care services when they need them e. g. community palliative care, hospice care, hospital care.					
Families and carers are receiving the necessary support to allow people with a serious and progressive illness die at home if that is their wish.					
Health care staff involved in palliative and end of life care talk to each other and co-ordinate the care they provide.					
People with a serious and progressive illness and their families / carers are involved in decisions about their treatment and end of life care.					
Families and carers receive the appropriate support and information after their loved one has died of a serious and progressive illness.					

Section 4. Views on the Future of Palliative Care Services.

This section asks for your views on the future of palliative care service in Ireland.

4.1 On a scale of 0 to 10 (Number Slider) where 0 is not at all important and 10 is very important, please rate the importance of the following priorities for the adult palliative care policy update.

Equal access to palliative care no matter where you live, your diagnosis or what age you are.

5

Appendices

Appendix 1: Public Consultation Questionnaire – Individuals

Better training for healthcare staff to be able to deliver palliative and end of life care across all healthcare settings.

Increased public awareness and discussion of palliative and end of life care, dying and death.

Increased support for patients to plan and organise their affairs and future care at the end of life.

Increased practical help and support for patients and their families / carers during end of life care e.g. home help hours, assistive equipment.

Increased availability of palliative care services at weekends and out of hours.

Improved communication between healthcare professionals, providers, patients and families.

Increased use of telehealth to improve access to palliative care services.

6

Appendices

Appendix 2: Public Consultation Questionnaire – Organisations

An Roinn Sláinte
Department of Health

Public Consultation Adult Palliative Care Policy Update

Survey for Organisations

Fields marked with * are mandatory.

Introduction

The Department of Health plans to update the Palliative Care Policy for Adults in 2022 and is seeking the views of the public on palliative care services in Ireland and the public's priorities for the update. The public consultation will allow the Department of Health to hear the views from a wide range of stakeholders and the findings will inform the policy update. We are asking organisations to participate in the public consultation by completing the online survey below. If you are not representing an organisation / representative body and want to complete the survey as an individual, then click here.

This survey is best viewed on a larger screen (desktop, tablet, larger smartphone). If you are using a smartphone with a small screen, you may need to rotate your screen to landscape view.

Any personal information which you volunteer to this public consultation will be treated with the highest standards of security and confidentiality, strictly in accordance with the General Data Protection Regulation 2016/67 and the Data Protection Act 2018. The Department's Privacy Policy can be viewed here.

Please fill in the details below on behalf of your organisation / representative body:

☐ I confirm I am the authorised representative on behalf of an organisation/representative body.

* First name

1

Appendices

Appendix 2: Public Consultation Questionnaire – Organisations

* Last name

* Job Title

* Name of Organisation

* Address of Organisation

Section 1: Organisation's Profile

This section asks questions about your organisation, so we can look at the submissions received from different points of view. This is the only reason for collecting this information.

1.1 Please select the category that best describes your organisation.

- Health service provider
- Union/Staff representative body
- Other representative body
- Academic institution
- Charity / NGO
- Community / Voluntary group
- Advocacy body
- Other

You selected other, please specify:

50 character(s) maximum

Section 2: Views on Current Palliative Care Services

This section asks about your organisation's views on current palliative care services in Ireland for people with serious and progressive illnesses and their families / carers.

2

Appendix 2: Public Consultation Questionnaire – Organisations

2.1 To what extent do you agree with the following statements in relation to current palliative care services in Ireland.

Statement	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Health care staff recognise the palliative care needs of people with a serious and progressive illness in all care settings.	○	○	○	○	○
People with a serious and progressive illness and their families / carers receive the necessary information to assist them with planning for end of life care and death.	○	○	○	○	○
People with a serious and progressive illness and their families / carers can access the appropriate type of palliative care services when they need them e. g. community palliative care, hospice care, hospital care.	○	○	○	○	○
Families and carers are receiving the necessary support to allow the person with a serious and progressive illness die at home if that is their wish.	○	○	○	○	○
Health care staff involved in palliative and end of life care talk to each other and co-ordinate the care they provide.	○	○	○	○	○
People with a serious and progressive illness and their families / carers are involved in decisions about their treatment and end of life care.	○	○	○	○	○

3

Families and carers receive the appropriate support and information after their loved one has died of a serious and progressive illness.					

2.2 What is working well in the current provision of palliative care in Ireland? i.e. What are the strengths?

2500 character(s) maximum

2.3 What is not working well in the current provision of palliative care in Ireland? i.e. What are the weaknesses?

2500 character(s) maximum

Section 3. Views on the Future of Palliative Care Services

This section asks for your organisation's views on the future of palliative care service in Ireland.

3.1 On a scale of 0 to 10 (Number Slider) where 0 is not at all important and 10 is very important, please rate the importance of the following priorities for the adult palliative care policy update.

Equal access to palliative care no matter where you live, your diagnosis or what age you are.

Better training for healthcare staff to be able to deliver palliative and end of life care across all healthcare settings.

Increased public awareness and discussion of palliative and end of life care, dying and death.

Increased support for patients to plan and organise their affairs and future care at the end of life.

4

Increased practical help and support for patients and their families / carers during end of life care e.g. home help hours, assistive equipment.

Increased availability of palliative care services at weekends and out of hours.

Improved communication between healthcare professionals, providers, patients and families.

Increased use of telehealth to improve access to palliative care services.

3.2 What changes or improvements do you suggest for inclusion in the update to the adult palliative care policy?

2500 character(s) maximum

5

Appendices

Appendix 3: List of Respondent Organisations

Association of Occupational Therapists of Ireland (AOTI)
Cairdeas Centre, Co. Carlow
Camross Active Retirement Group, Co. Laois
Care Alliance Ireland
Caredoc, Carlow
Centre for Economic and Social Research on Dementia, NUI Galway
Children's Health Ireland
Cleas ctr, Oileáin Árann,
Comhar Chuigeal (Leitir Meallain) Teoranta, Co. na Gaillimhe
Connolly Hospital, Blanchardstown
COPD Tipperary
Cork University Hospital
Department of Paediatric Palliative Medicine, Children's Health Ireland
End of Life Ireland
Galway Hospice
Great Ormond Street
Hope Ireland
HSE National Clinical Programme for Palliative Care
HSE Primary Care, Sligo
HSE Primary Care, Churchtown
HSE Johnstown Health centre, Kildare
HSE Cavan Monaghan Mental Health Services
HSE Clare Mental Health Services
HSE Kilmallock primary care centre
HSE Carlow primary care centre
HSE Regional Hospital, Mullingar
HSE Public Health Nursing, Crumlin
HSE Midlands Palliative care
IAPC Pharmacists Group
Irish Association for Palliative Care
Irish Association of Speech and Language Therapists
Irish Hospice Foundation
Irish Hospital Consultants Association

Appendices

Appendix 3: List of Respondent Organisations

Irish Medical Organisation
Irish Nurses and Midwives Organisation (INMO)
Irish Nutrition & Dietetic Institute (INDI)
Irish Palliative Medicine Consultants Association
Irish Society of Chartered Physiotherapists
Jack and Jill foundation
Kiln lane Residents Association, Co. Laois
Knockeen Nursing Home, Wexford
Laois Open Door Theatre
Longford Westmeath Community Palliative Care Team
Latton Social Services and Development CLG, Co. Monaghan
Marymount University Hospital and Hospice
Mater Misericordiae University Hospital
Milford Care Centre
National Cancer Screening
National Hospice Friendly Hospital Programme Coordinator Network Group
Nursing Homes Ireland
Our Lady's Hospice & Care Services
Pavee Point Traveller & Roma Centre
Primary Palliative Care Steering Committee hosted by Irish Hospice Foundation (IHF)
Pro Life Campaign
Progressive Supranuclear Palsy Association of Ireland
Royal College of Physicians of Ireland
Southeast Palliative Care, Waterford
St Luke's Radiation and Oncology Centre, St James's hospital
St James's Hospital
St John of God Northeast Community Services
St Michael's House
St. Francis Hospice
Tallaght University Hospital

AIIHPC

All Ireland Institute of
Hospice and Palliative Care

A Report By All Ireland Institute Of Hospice And Palliative Care For The Department Of Health