

Understanding Palliative Care and the Health Workforce

Market Research Insights Report



Australian Government
Department of Health
and Aged Care



Contents

3	Executive Summary
4 – 6	Objectives and Methodology
7 – 22	Key Insights
23 – 28	Communication Preferences
29 – 30	Key Implications
31 – 33	Profile of workforce



Executive Summary

The Australian Government is committed to ensuring people living with a life limiting illness have access to quality palliative care and invests in a range of measures to support the health and aged care workforces to improve the provision of palliative care.

Market research was conducted to examine the opportunities to best support healthcare workers with knowledge and resources to enable high-quality palliative care.

The market research was undertaken by 89 Degrees East, a national data, strategy and delivery agency. Two online surveys and qualitative interviews were conducted in June and July 2022 to gather data from the health workforce who deliver palliative care and with people or carers who have lived experience with palliative care.

The research reveals that continued support for the primary and aged care workforce through education and training will enable them to feel more comfortable discussing palliative care with patients, and dispel any misconceptions or barriers surrounding it. Improving workforce understanding of holistic palliative care and how it can sit alongside and complement active treatment will lead to greater confidence and earlier conversations.

In addition, normalising the palliative care experience for less experienced workers can facilitate more frequent and productive conversations between health care professionals, patients, families, and caregivers.

Ensuring resources are accessible for a mobile workforce working across multiple settings and workplaces will be essential to building knowledge and expertise.

Project Objectives

To increase awareness and utilisation of palliative care, end-of-life care (EoC) and advance care planning (ACP) services in Australia through improved conversations and resources for patients and their support network.

Research Objectives:

- Understand the baseline knowledge that the primary care and aged care workforce have of palliative care, end of life care and advance care planning to identify knowledge and resource gaps to be addressed.
- Identify communication preferences for all communities, including channels and materials to address identified knowledge gaps.
- Inform workforce communications that will facilitate real-world learning scenarios for both the primary care and aged care workforce across all care scenarios (in-home, Residential and Aged Care Facilities [RACF], hospice and hospital).

Expected Use:

Design tailored communications for the workforce (GPs, aged care workforce, practice and community nurses) to improve knowledge and understanding amongst the primary care and aged care sectors to support patients and their support networks with information about palliative care options.

Methodology

Quantitative Research Palliative Care Workforce

- A total of **n=605** healthcare professionals across Australia who provide palliative care services participated in an online survey.
- The survey was administered to targeted participants sourced from a specialised health care professional opt-in research panel (Dynata) with quota management to reflect the workforce roles in palliative care across Australia, including GPs, nurses, aged care workers, allied health professionals and palliative care/medical specialists.
- The survey was conducted nationally between the 15th June – 3rd July 2022.

Qualitative Research Palliative Care Workforce

- A total of **n=36** one-hour interviews were conducted between Monday 4th July 2022 and Wednesday 13th July 2022 with health care professionals who deliver palliative care.
- During the interviews health care professionals were asked to expand on their experiences and challenges when providing palliative care.
- Resource and education needs were explored to help understand how to support the workforce to provide high quality palliative care.
- Findings from the interviews have supported the quantitative research findings by providing further depth and understanding to the data.

Quantitative Research Palliative Care Consumers

- A total of **n=405** consumers across Australia participated in an online survey.
- People who have been a carer, a close support person or involved with someone receiving palliative care or planning for palliative care were invited to participate in the survey.
- The survey was conducted between 20th June 2022 and 20th July 2022.
- The survey was disseminated through Palliative Care Australia's consumer network via email invitation to its database and promotion on social media channels.

Limitations and preamble

The quantitative phase of the study involved two online self completion surveys amongst 1) Healthcare professionals (clinical and non-clinical) and 2) Consumers and families who have been touched by palliative care.

Palliative Healthcare professionals (clinical and non-clinical)

In total 605 responses from health professionals were received, of which 100% answered all the questions in an average of 10 minutes. To be eligible for participation, all participants were pre-screened and qualified as currently working in a healthcare consumer-facing role, including GPs, registered nurses, aged care nurses, palliative care specialists and allied health profession. Those working in administration and support services were excluded from the sample. All participants were working in Australia and in a typical month working across a range of healthcare settings.

The sample was sourced through an accredited and ISO 20252 certified online panel provider who specialises in healthcare professionals in Australia, representing healthcare members who have opted to complete surveys and are compensated by rewards and incentives.

While a range of methods were employed to make sure the responses are representative of the Australian clinical and non-clinical health professional population involved with palliative care, it should be acknowledged that respondent participation in internet surveys is self-selecting and requires a certain degree of internet proficiency which may introduce an element of bias in the sample.

A representative sample was recruited with quotas managed by occupation, location, regional/metro area, age and gender to reflect the population of healthcare workers. Sampling errors were controlled through structuring sample quotas to be reflective of the population to reduce response bias. Survey response biases were controlled for by asking neutrally worded questions, ensuring questions were not leading, the survey was anonymous and unbranded. The sample was recruited through random sampling, in which every member of the population has an equal opportunity to be chosen in the study.

Consumers and families of patients who have experienced palliative care

In total 405 consumer responses were received, of which 100% answered all the questions in an average of 10 minutes. Consumers were pre-screened and eligibility based on the criteria of having been a carer, a close support person or involved with someone receiving palliative care or planning for palliative care. All participants were aged over 18 years old and living in Australia.

The sample was sourced through an accredited and ISO 20252 certified online panel provider with quotas managed to reflect ABS census data for gender and age location representative of population.

Margin of error for the quantitative surveys

The maximum margin of error for the total health care professional sample is +or- 3.92 percentage points and for the consumer sample it is +or- 4.82 percentage points. The response rates for both the health professionals survey and the consumer survey are above the minimum requirement for sample reliability which is reflective of the total population.

The margin of error indicates the error margin that surrounds results from the sample. For example, if the result is 50%, we can be 95% confident that if this survey was repeated, on 19 out of 20 occasions the result would fall between 47.8% and 52.2%.

Limitations of qualitative primary research

In total 36 in depth interviews were conducted with a broad range of healthcare professionals who were involved in delivering palliative care to patients. Qualitative research is not intended to be precise and definitive, but rather an exploratory method to understand perceptions and experiences, which were used to inform and support the quantitative findings. Findings from the qualitative research component should be interpreted with that constraint in mind.



Key Insights

What palliative care means to Health Care Professionals

Question: In your own words, what does palliative care mean to you?
(Coded % response, multiple overlapping categories) Base: Total n=605

30% Assistive treatment for people with life-limiting illness
"Palliative care is treatment, care, and support for patients with life-limiting illness."

29% Pain management and symptom relief
"It is a relief from pain and symptoms caused by severe illness."

16% End-of-life care
"Offers treatment and support for people who are near the end of their life."

Words mentioned 50+ times

- pain x113
- Symptom x92
- quality of life x77
- end of life x65
- relief / alleviate x63
- comfort x60
- life limiting x50

Words mentioned less than 30 times

- family x 30
- specialised x 20
- emotional x14
- mental x11
- spiritual x 6
- holistic / whole patient x5
- social x 4
- carer / caregiver x4

Quality of life improvements directly linked to symptom management, not holistic palliative care inclusive of social and emotional care.

- "Palliative care with specialised medical care that focuses on providing patients relief and improves the quality of life."
- "Palliative care helps patients relieve suffering and improve the quality of life."
- "Palliative care managing patients pain and distressing symptoms by improving the quality of life of people who are dying."
- "Palliative care controls the overall symptoms and improves the quality of life."
- "Palliative care reduces the stress and provides medications to relieve pain with the highest quality of life."

What palliative care means to Health Care Professionals (cont.)

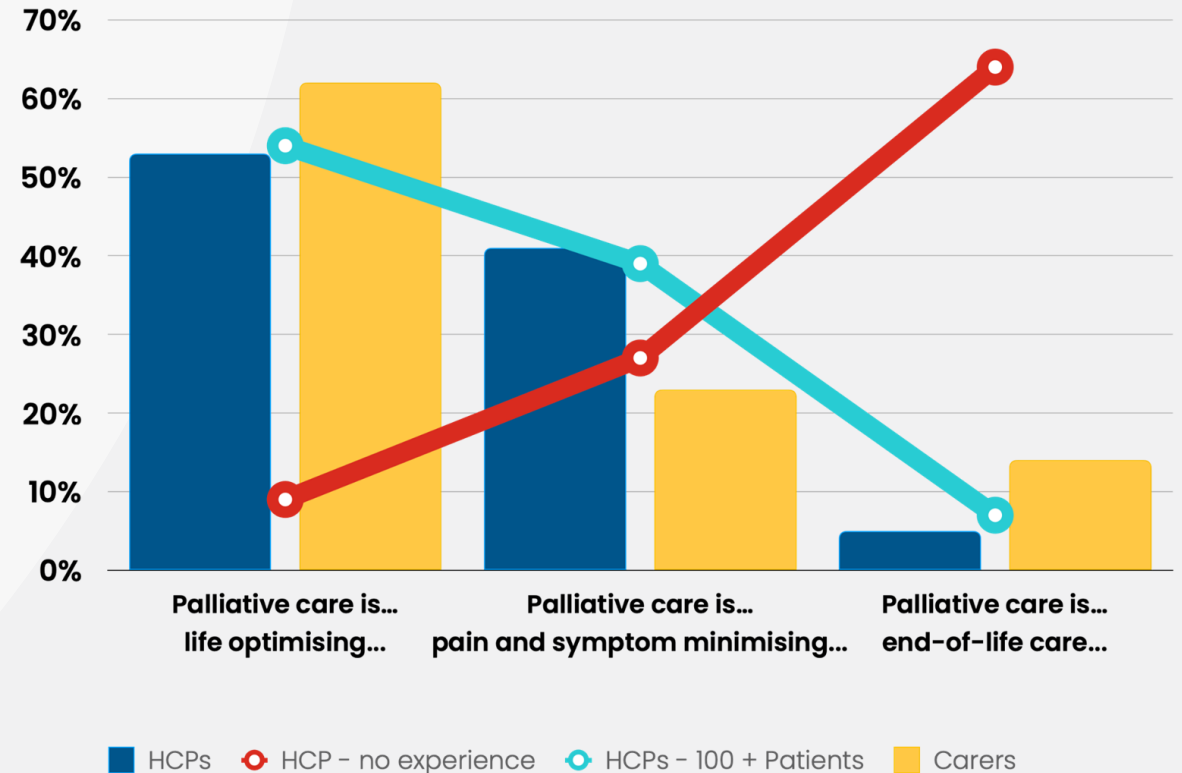
When prompted, experienced health care professionals and carers are aligned in the view that palliative care is life optimising – and inclusive of holistic physical and mental health care.

However, the unprompted responses indicate a clear and overwhelming prejudice to pain and symptom management indicating a gap between the theoretical and practical understanding.

Question: Which statement below best aligns with your understanding of palliative care ? (Select one)

Palliative care is:

- **life optimising** – health care that improves the quality of life of someone with a life-limiting condition through holistic care encompassing physical and mental health and social wellbeing.
- **pain and symptom minimising** – provides relief from pain and other distressing symptoms for a person with a terminal illness or condition approaching the end of life.
- **end-of-life care** – health care provided in the final weeks, days, and hours of a person's life.



- Experience significantly shifts perception
- Even with a lived experience of palliative care, consumers are three times more likely to see palliative care as limited to end-of-life care.

Most feel clinically capable

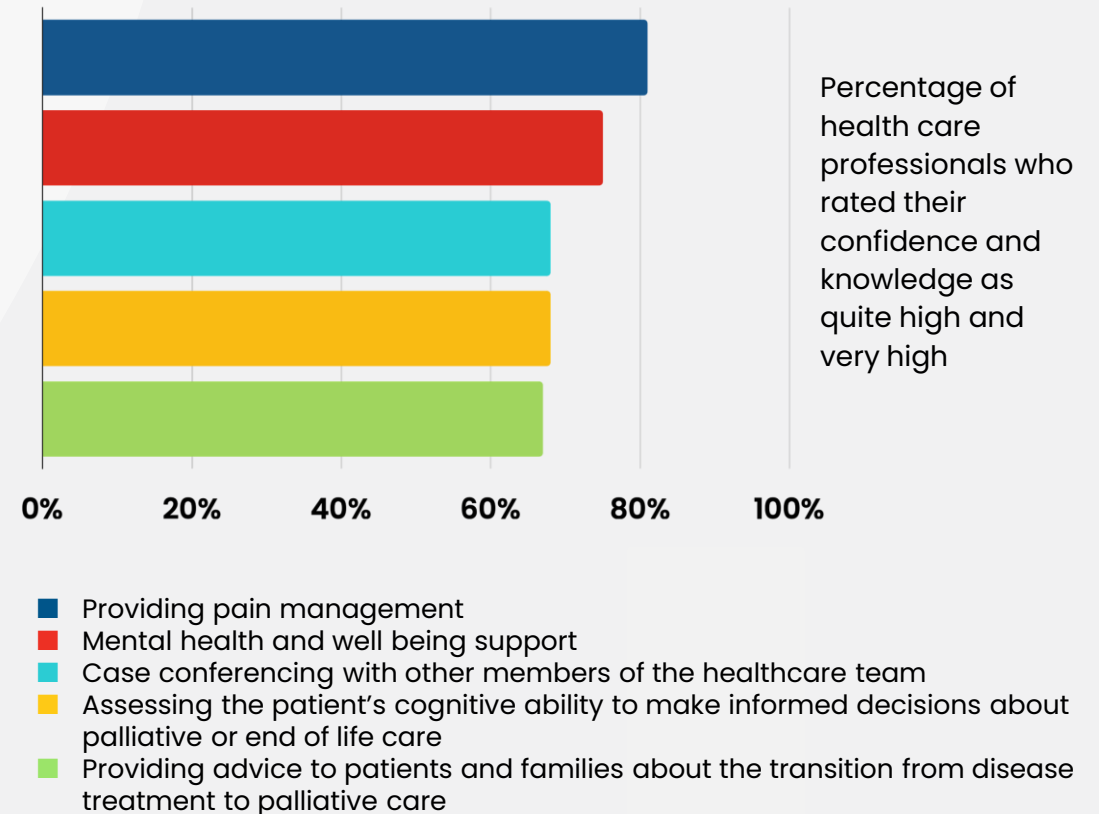
Health care professionals express high level of willingness to provide palliative care – and report high confidence in key symptom management and clinical skills.

Question: For the following statements, please indicate how much you agree or disagree? (Top 2 box – total agree) Base: Total n=605

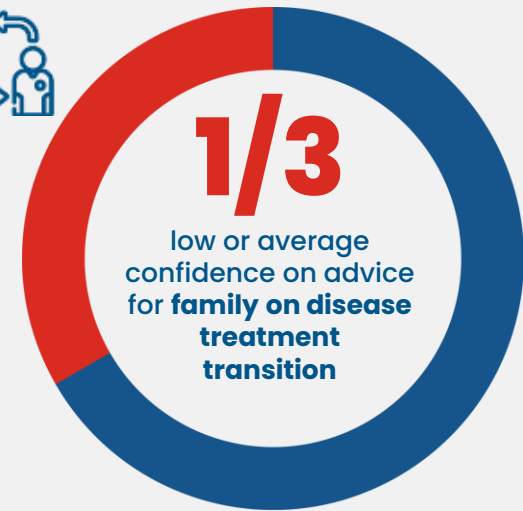
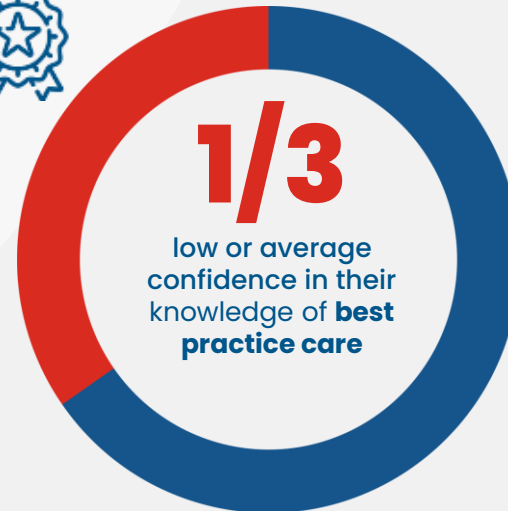
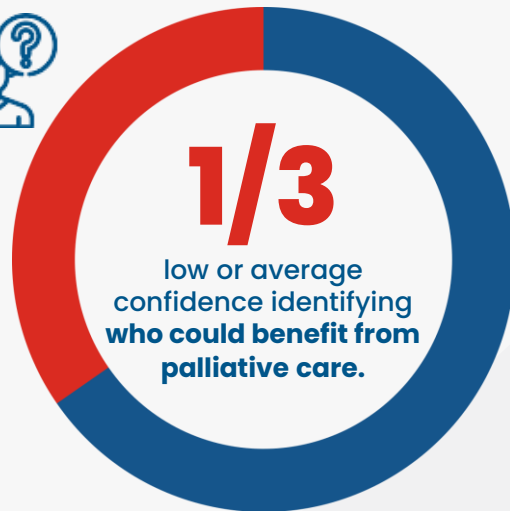
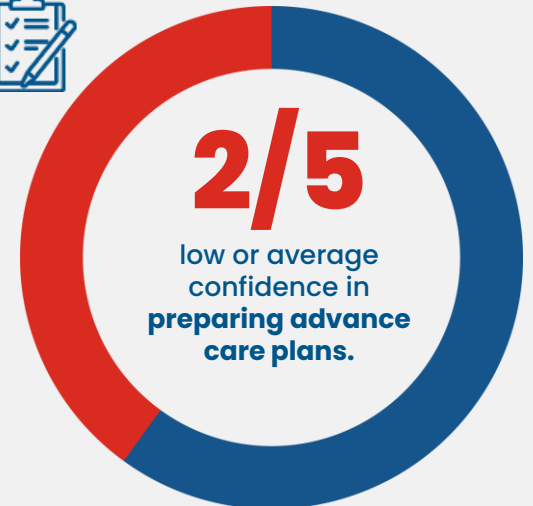
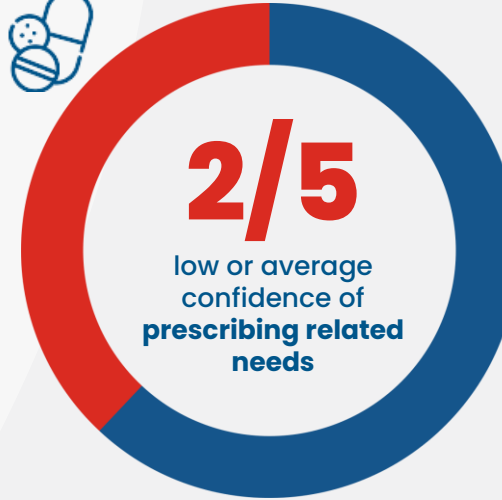
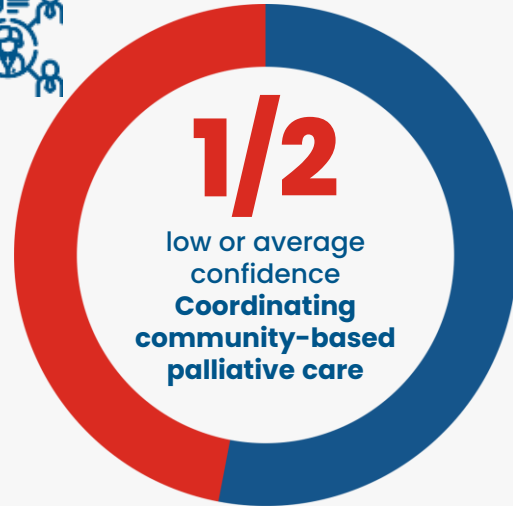


Key skills with high confidence

Question: How would you rate your confidence and knowledge for delivering the following services to palliative patients? (Top 2 box % rated high 4–5 score). Base n=605



But there are confidence gaps in clinical knowledge



High confidence



Low & average confidence

Question: How would you rate your confidence and knowledge for delivering the following services to palliative patients? Base n=605

It's hard and challenging work

3/5

Agree or strongly agree that providing quality palliative care is **challenging**

1/2

Disagree that palliative care is **personally rewarding** work

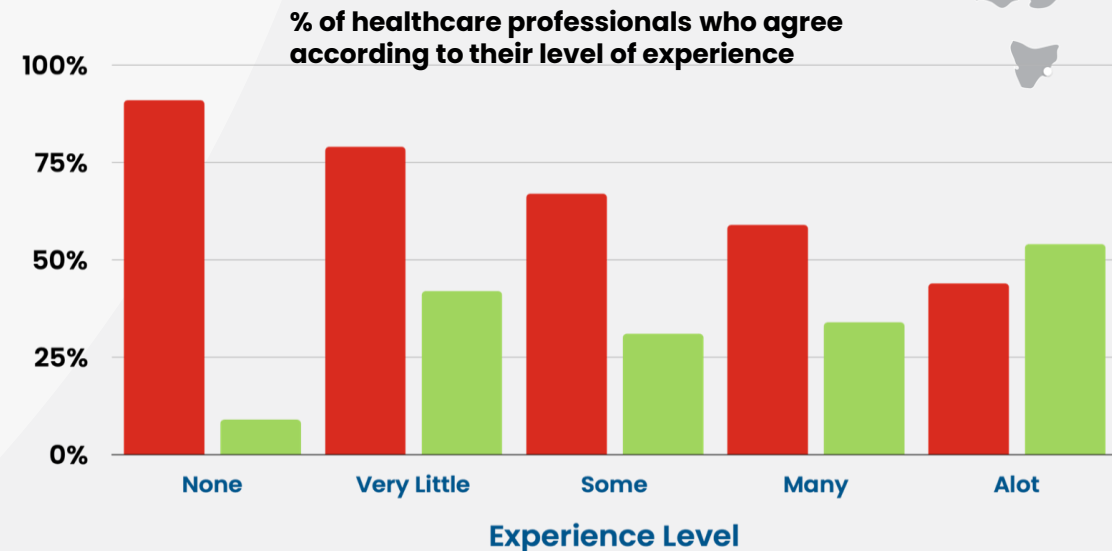
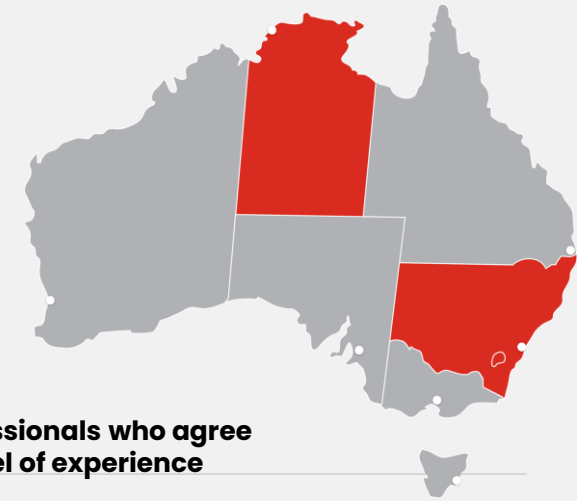
1/3

Agree or strongly agree that palliative care is **personally rewarding**.



Extensive experience eases some challenges, and increases personal reward, but it is still considered challenging by almost half the workforce who have a lot of experience.

Among those surveyed, the health workforce in NT, ACT and NSW find providing quality palliative care more **challenging**.

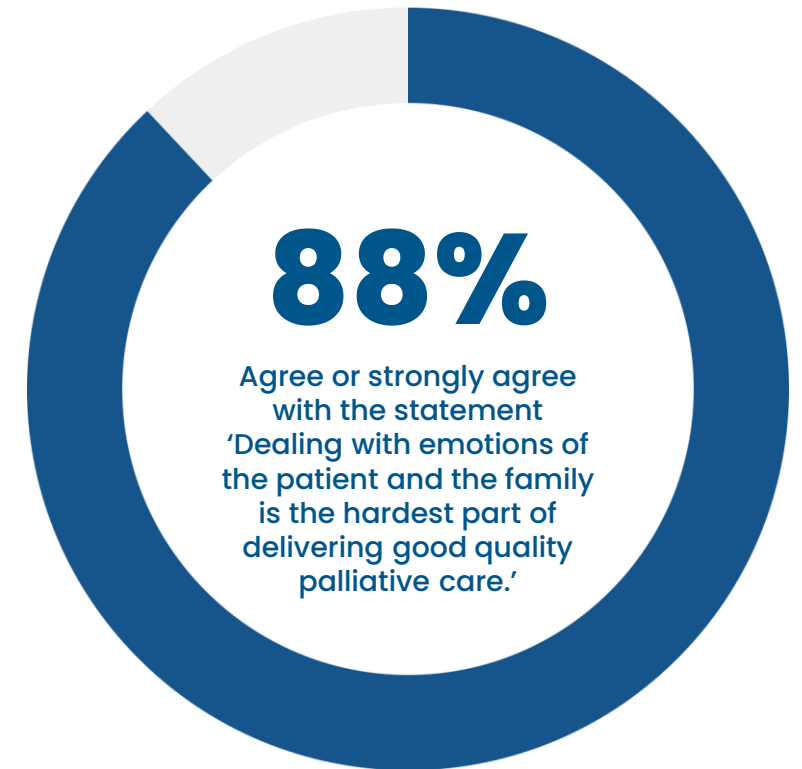


■ Providing quality palliative care is challenging.
■ Palliative care is a personally rewarding part of my work as a healthcare professional.

Emotions are a barrier to providing Palliative Care

The emotional burden of palliative care is a significant barrier.

- 88% of health care professionals are comfortable providing palliative care, but only 77% are willing to have conversations about Palliative Care, End of life and Advanced Care as part of their work.
- The gap between a healthcare professional being comfortable providing palliative care and comfortable discussing palliative care increases with experience.
- Doctors (both GP & specialists) are significantly more comfortable with conversations than all other health care professionals.



Emotional and social barriers to providing palliative care

The theme of 'families emotional stress' was prominent throughout the qualitative interview and reflects the high quantitative scores.

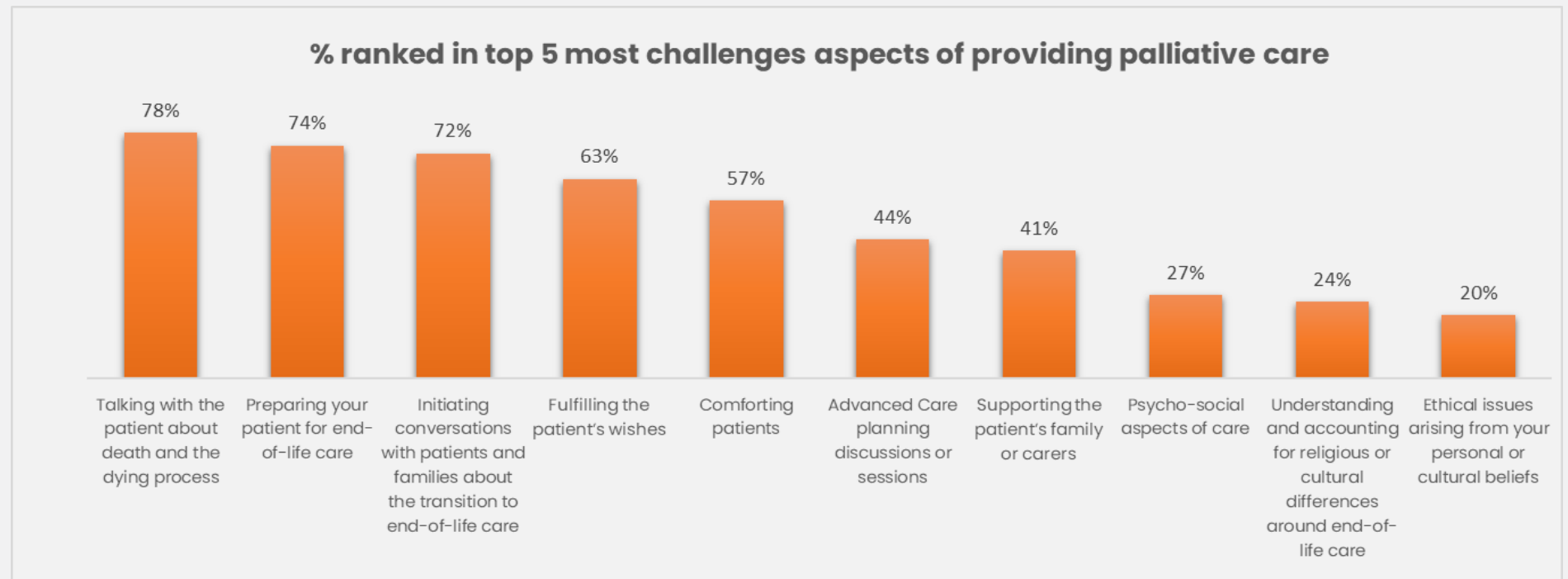
"The biggest challenge is **family** distress. More so than patients. Through our training we're taught about supportive listening, but nothing targeted towards palliative care."

"Dealing with **families** because the patient is accepting what is happening but the **families** have not and do not want their loved one to pass away and families can get angry and abusive and refuse your services as don't think that palliative care is required"

"Dealing with the **families** if they're upset, then it makes me upset, I don't like seeing people upset and it's controlling the emotions is the hardest part."

"Dealing with the **families**, no one is on the same page and trying to get consensus moving forward. Sometimes I feel myself my emotions get in the way, and I get upset about it. Accessing resources might be challenging also".

Question: Now consider for a moment the emotional and social aspects of providing palliative care and what you find the most challenging? (Rank your top 5 - reported % of all participants who ranked response in top 5) Base n=605



Normalising community perceptions of palliative care is essential to enabling the workforce

There was a clear desire among health care professionals to build community understanding of palliative care beyond end-of-life care to make the conversations easier to have without destroying patient trust.

"You can have a script, and you can introduce it. But there's so much to tell people when they're being diagnosed. There's so much to get through.

*And then to have that conversation about palliative care immediately, a patient is thinking **"I've lost hope; you're giving up on me."** Then you have lost their trust. It's because **the public perception is so far away from the reality of palliative care.**"*

*"I think there's **cultural challenges around the system**, even though we all say palliative care should start early. There's not enough conversations around the benefit for people outside of him [the patient].*

I think it's hard. That altruistic component people have of not wanting to take away a sense that there's more we can do for you. And sometimes palliative care is an afterthought as well. Someone might have nausea, and they're not thinking to refer to a palliative care team."

***"People freak out when you use the word palliative care.** We need to provide education one-on-one. When you refer to palliative care it comes with an explanation of why we're doing this."*

"We need to empower consumers to know that the definition is actually more than just the last week or two in the hospital bed."

Quotes edited for fluency.

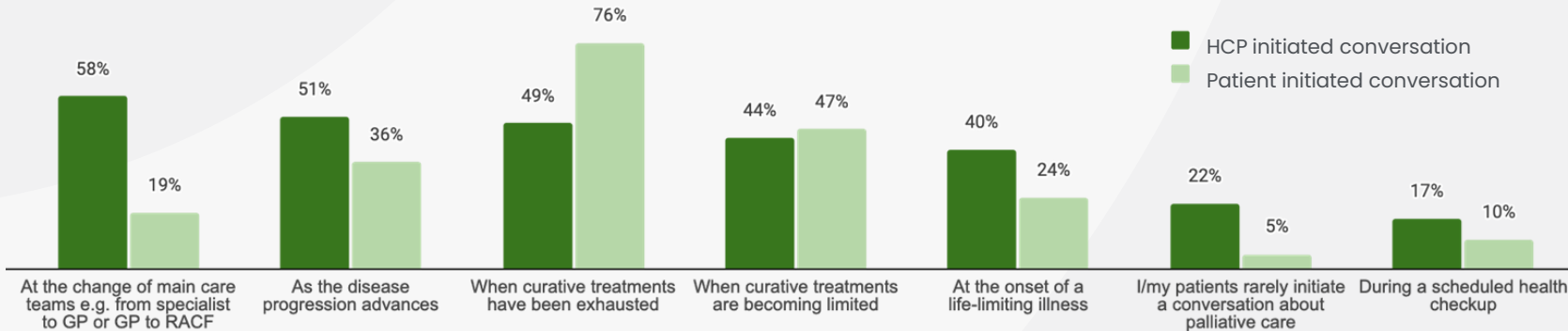
RECOMMENDATIONS:

Strengthening community perceptions and understanding of early palliative care interventions would empower the workforce in delivering quality care reducing a number of perceived barriers.

Transition of care and disease progression trigger initial palliative care conversations for health care professionals

Question: (HCP Initiated conversation) When are you most likely to initiate a conversation about palliative care with a patient who is likely to require this type of care? (You can select more than one)

Question: (Patient initiated conversation) When are your patients most likely to initiate a conversation about palliative care? Select all that apply. (You can select more than one)



3/5 initiate palliative care conversations in a transfer of care teams

1/2 initiate as the disease progression advances

1/2 initiate as the curative treatments have been exhausted

RECOMMENDATIONS:

- Build awareness of clinical skills around early referral to palliative care especially for GPs and specialist emphasising the care that should be provided before acute palliative and end of life care is required.
- Normalise early conversations about the role and value of early referral palliative care.

Conversations about palliative care

Conversations are often carer led, and late in the illness progression potentially indicating a hesitancy on behalf of health care professionals to initiate early conversations.



2/5

Carers report that either they (32%) or the patient (7%) was the first to raise palliative care, rather than a health care professional provider.

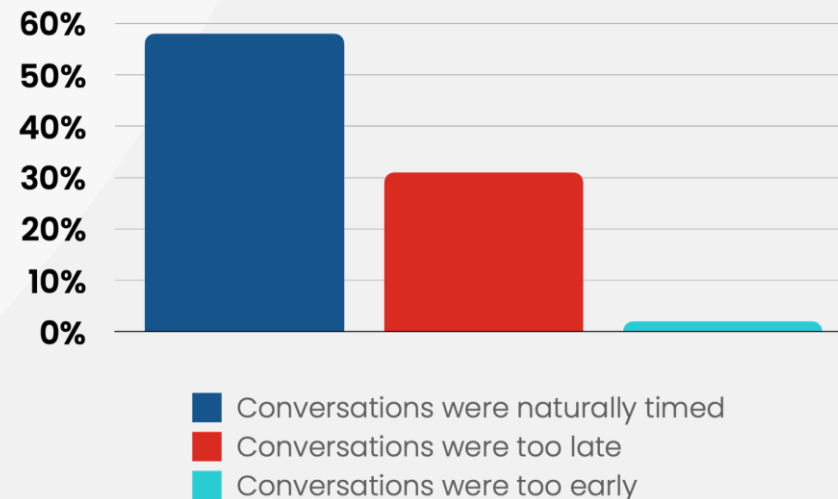
26% of conversations were initiated by the treating specialists, and only 12% by the regular GP.

17% of carers felt the person who first raised the topic of palliative care was not the right person, and largely would have preferred a palliative specialist (41%) or a GP (39%) to do so, emphasising the greater potential for GPs in early conversations.

Question: Who first raised the topic of palliative care? Select one. Base: Total n=407 (Consumer Survey)

Whilst most conversations appeared to have occurred at a naturally timed opportunity, a third occurred too late from the perspective of carers. Carers are 15 times more likely to think the conversations happened too late compared to too early.

Carer views about the timing of palliative care conversations



Question: Looking back, do you think the timing of those conversations about palliative care was appropriate? Base: Total n=407 (Consumer Survey)

Conversations about palliative care (cont.)

Health care professionals and carers report different perspectives on the initiation and timing of conversations regarding palliative care.

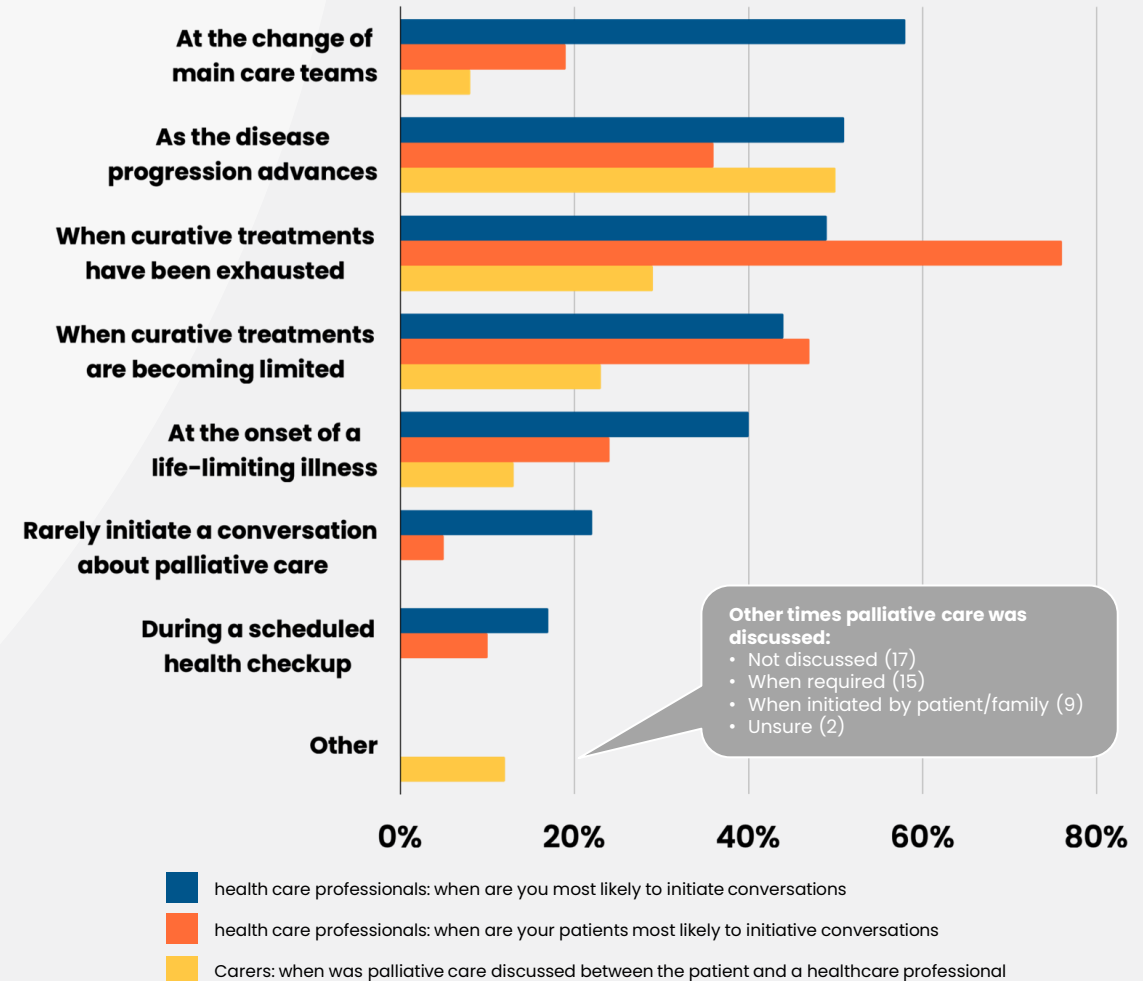
Health care professionals were most likely to indicate initiating a conversation about palliative care when care passed between care teams (58%) such as from a treating specialist to a GP or onwards to an aged care facility, but carers did not report this as when palliative care was discussed.

Health care professionals indicate that patients and carers are most likely to self-initiate the conversation when curative treatments are exhausted, but again this does not reflect the carer perspective.

Many carers reported in the 'other' category that no conversations ever occurred.

Naturally integrating palliative care as part of conversations was seen as helpful by a third of all carers (32%), but especially so when reference at first diagnosis (49%).

Initiation and timing of palliative care conversations



Common Barriers

Question: What are the most common barriers you face in providing palliative care ? (Select all that apply) base n=605



55% Time pressures



35% Legal and regulatory framework



18% Availability of local services



54% Lack of clear Advance Care Plans



26% Confusion over who is responsible



15% Availability of respite services



53% Poor communication from other healthcare professionals



24% Family emotions



14% Difficulty accessing specialist advice



49% Challenge integrating palliative care with active treatment



24% Difference in family patient opinions



13% Coordinating patient care teams



41% Late referrals



22% Patient and family cultural barriers



9% Remuneration

Who and when is unclear. It's never early enough



1/3

low or average
confidence identifying
**who could benefit from
palliative care.**

Barriers experienced in providing palliative care

1/2

Lack of clear **advance
care planning**

2/5

Late referrals and
transitions

3/10

Confusion amongst all
health care
professionals over **who
is responsible** for care

5/10

Medical Specialists:
Confusion over **who is
responsible** for care

"We often get palliative care involved too late, with poorly managed symptoms that we could have avoided with early palliative care discussions."

"Good palliative care is early, if you've got someone with a life limiting illness, as soon as they develop any sort of symptoms that would interfere with the quality of life, is when it should be discussed."

"People can't process it at the last minute, last week I was getting treatment and this week I'm dying. That's a western culture, it's a missed opportunity not to talk about it openly and what it could look like for you."

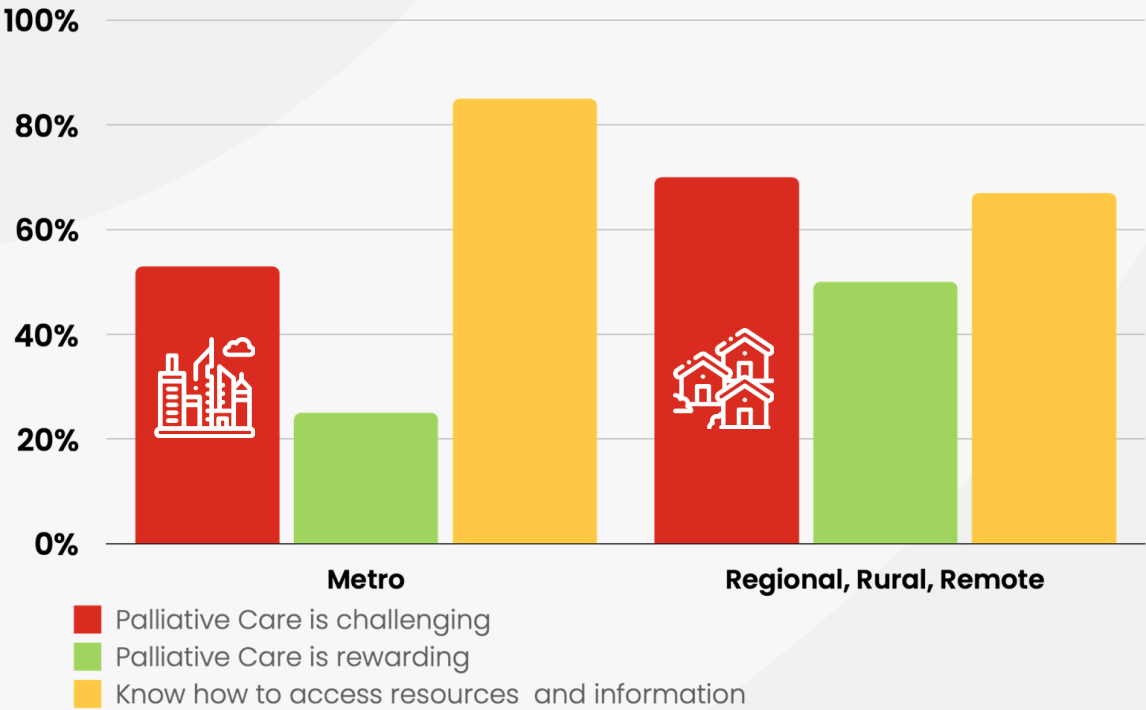
Question: What are the most common barriers you face in providing palliative care?

RECOMMENDATIONS:

- Increase awareness of case studies focused on early palliative interventions across a variety of illness and disease profiles with demonstrated integrated care.
- Increase awareness of the role of early advance care planning.

Regional, rural and remote health care professionals

Compared to metropolitan health care professionals, regional, rural and remote (RRR) health care professionals find palliative care more challenging, but conversely more rewarding. They are less likely to agree they know how and where to access appropriate information and resources to support palliative patients.



Additionally, regional, rural and remote health care professionals face additional barriers compared to metropolitan counterparts. Whilst their top challenges are consistent, they rate a number of other challenges significantly higher. However, they are less likely to report differences in family and patient opinions.

Common Barriers experienced by area working in (% of total)	Working in Metro area	Working in rural or remote
Availability of local services	13%	24%
After hours contact with patients or staff at facilities	12%	39%
Availability of respite services	11%	20%
Difficulty accessing speciality advice	10%	19%
Coordinating patient care teams	9%	18%
I am personally uncomfortable with providing palliative care	8%	6%
Remuneration	5%	16%
Difference in family / patient opinions	28%	18%
Sample base n=	364	241

*Figures in blue represent a statistically significant difference at the 95% confidence interval

Quality support for carers is essential

Whilst managing family emotions can be extremely challenging for health care professionals, providing high quality support for carers is required. Carers strongly emphasise the need to have their own needs considered as part of the palliative care experience.

81%

Total Agree: It is important for carers and family to be able to speak directly with health care teams privately from the patient

Helpful family strategies include:

- Involving family members in planning (49%);
- pre-warning family members in advance of raising with family members (18%);
- Organising a private consultation with family and carers to support the patient (17%)

1/4

Carers agreed that their role as support person was not acknowledged by health care professionals.

1/3

carers sought advice from friends and family to answer additional information needs.

The experience of current carers will drive word-of-mouth information referral for future carers and patients.



Communication Insights



Top 5 information needs



60%

**Myth-busting -
debunking
misconceptions
around palliative care**

Content to explicitly
challenge and empower
health care professionals
conversations



60%

**Conversation
Coaching**

Improve and ease
difficult conversations



52%

**Information on
Allied Health
support**

Increased awareness
of resources across
ecosystem



47%

**Best practice
palliative care
treatments**

Increased
understanding of
what care to provide.
Palliative care
professionals have the
greatest need.



44%

**Understanding
regulatory and
legal framework**

Increased confidence
they are doing the
right thing. 1/3 have
ethical issues arising
from care.

Question: Which of the following topics would you find most useful to assist you further in providing palliative care to your patients? Multi-select.
Base: Total n=605 Healthcare professionals

Workshops, webinars and websites are preferred



65%

Workshops



57%

Webinars



54%

Websites



53%

Virtual Coaching



42%

Email



41%

Online Learning



30%

Patient Case Studies



25%

Factsheets



23%

Consultation scripts

Non-metro audiences have different needs

There was significantly more demand for resources such as patient case studies, social media, factsheets, podcasts, posters and pamphlets from both younger workers (under 29) and non-metro health care professionals.

Workforce preferences

- GPs: increased preference for virtual coaching and emails.
- Aged care workers: increased preference for social media
- Palliative care workers: increased preferences for webinars and emails

Question: What is your preferred way to receive information to support you in providing palliative care to your patients? Base n=605 Healthcare professionals

Preferred way to receive information varies by location and age

Column %	Location			Age			
	Metropolit an area	Regional area	Rural or Remote area	18-29	30-39	40-49	50+
Workshops	70%	62%	47%	46%	64%	71%	54%
Webinars	60%	60%	28%	28%	61%	61%	32%
Virtual Coaching	59%	50%	22%	28%	55%	56%	39%
Websites	57%	56%	23%	26%	58%	55%	44%
Emails	48%	38%	17%	10%	51%	39%	24%
Online professional learning	40%	44%	40%	54%	42%	39%	32%
Patient case studies	21%	32%	85%	62%	24%	31%	41%
Fact sheets	17%	30%	55%	56%	20%	23%	41%
Continuing Professional Development (CPD) activities	15%	20%	57%	49%	17%	18%	37%
Consultation scripts	13%	29%	68%	46%	20%	22%	32%
Video	12%	10%	17%	31%	11%	11%	7%
Podcasts	12%	25%	47%	36%	15%	19%	27%
Social Media	11%	25%	55%	31%	26%	12%	15%
Magazines & Periodicals	8%	19%	40%	13%	11%	17%	20%
Pamphlets	5%	10%	15%	21%	5%	8%	10%
Posters	4%	10%	20%	21%	6%	6%	12%
Column n=	364	181	60	39	276	249	41

There were some differences in the preferred ways to receive information based on location and age:

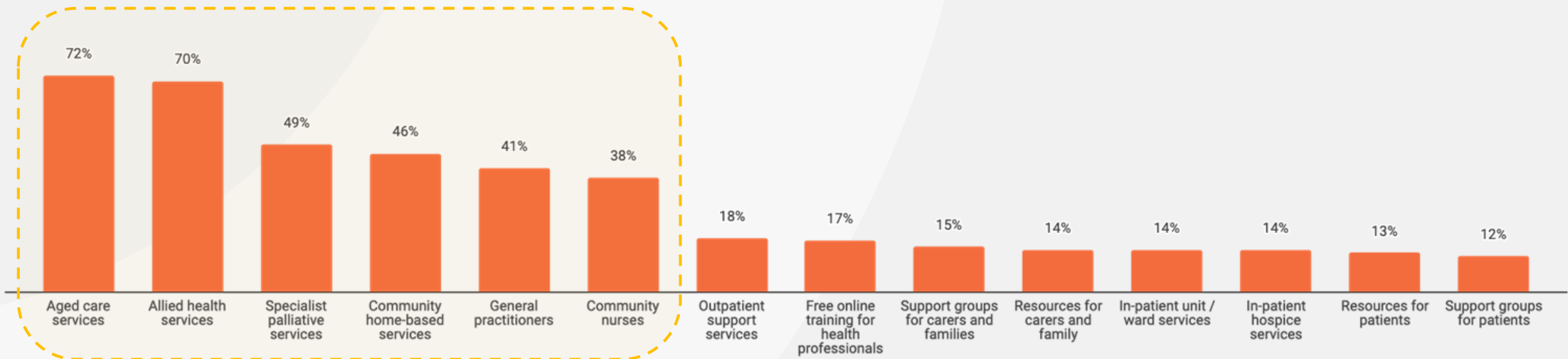
- health care professionals working in metro areas are more likely to prefer workshops (70%), virtual coaching (59%) and emails (48%).
- Those working in rural and remote areas have a higher preference for printed resources including fact sheets (55%), posters (20%), pamphlets (15%), magazines (40%) as well as online resources and case studies.
- There is a significantly higher preference amongst younger health care professionals aged 18-29 for case studies, fact sheets, CPD, videos, podcasts, pamphlets and posters.
- Older health care professionals aged over 50+ years have a preference for fact sheets (41%) and CPD activities (37%).

Question: What is your preferred way to receive information to support you in providing palliative care to your patients? Select your most preferred formats.

*Figures in blue represent a statistically significant difference at the 95% confidence interval

Aged care services and allied health services are resources accessed most regularly

Question: Which of the following services and resources do you regularly access to enable you to support patients and families? (Select up to 5) Base: Total n=605



- Over 7 in 10 access aged care services (72%) and allied health services (70%) regularly to assist in supporting patients and families going through palliative care.
- Almost half of healthcare professionals (49%) refer to specialist palliative services, and 46% regularly access home-based services.
- Just over 4 in 10 (41%) health care professionals utilise GPs to help assist support patients and families.
- Only 17% are using online training and resources for their own professionals development and 13% using resources for patients.

Health care professionals rely on service providers for support and resources.

Key sources of information for the workforce

Almost three-quarters (74%) cite their main source of information about palliative care is State or Territory health departments.

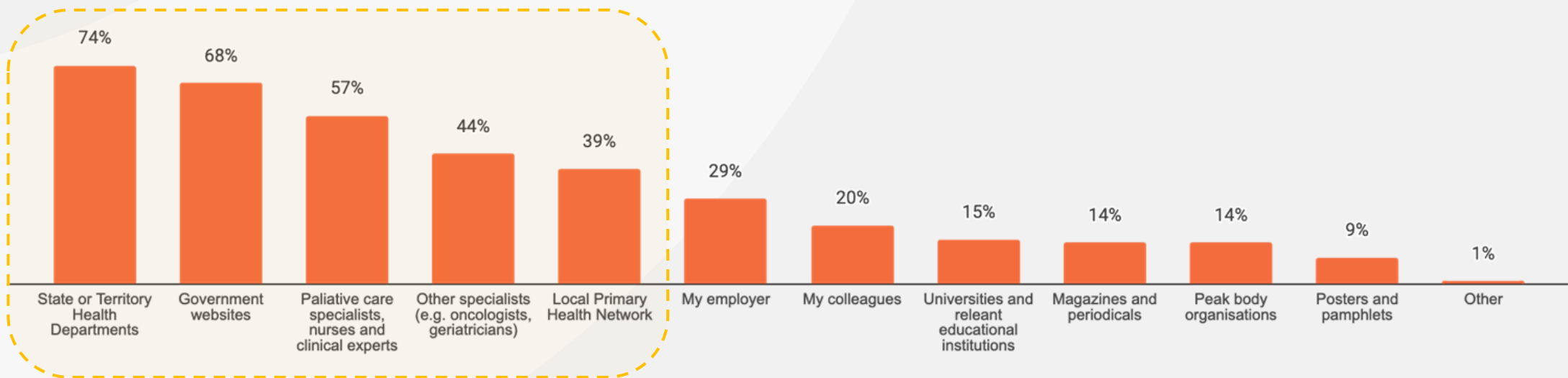
Just over two-thirds (68%) mention that Government websites are their main source of information about palliative care.

Those who report using Government websites the most are:

- Registered Nurses (90%)
- GPs (79%)

Clinical nurse specialists are more likely to use local Primary Health Network (58%) and peak body organisations (30%) as their main sources of information about palliative care.

Question: What are your main sources of information about Palliative Care?



Sample base n=605



Key Implications

Communication and education opportunities

The research insights point to a number of clear communication, education and training opportunities that will support health care professionals to deliver timely and effective palliative care. We've identified the following headline priorities:

1

Strengthen awareness and understanding within the broader community about what holistic palliative care and end-of-life care means.

2

Strengthen workforce understanding about holistic palliative care and how it can sit alongside and **complement active treatment** to encourage earlier conversations.

3

Support healthcare practitioners to have more **regular conversations** about palliative care and to feel more confident with the **social and emotional aspects** of those conversations.

4

Support less experienced healthcare workers to understand and normalise conversations about palliative care and end-of-life.

5

Build the cultural competence of the workforce to increase confidence in serving diverse communities.

6

Support the workforce to better navigate existing information and resources, particularly when 'on the job', and in non-hospital settings.



Profile of the Workforce Participating in the Research

Health Care Practitioner research participant profile

17%

(n=100)

General Practitioner (GP)



17%

(n=100)

Allied health and other professions



9%

(n=54)

Palliative Care Specialist – Physician



8%

(n=51)

Palliative Care Nurse



8%

(n=50)

Clinical Nurse Specialist



8%

(n=50)

Medical Practitioner



8%

(n=50)

Medical Specialist/Surgeon



8%

(n=50)

Aged Care Worker – Personal Support Worker



8%

(n=50)

Aged Care Nurse



8%

(n=50)

Registered Nurse

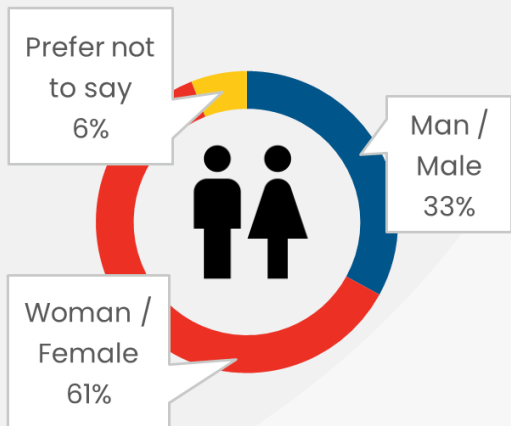


What is your profession? Select the option that best represents your everyday role.

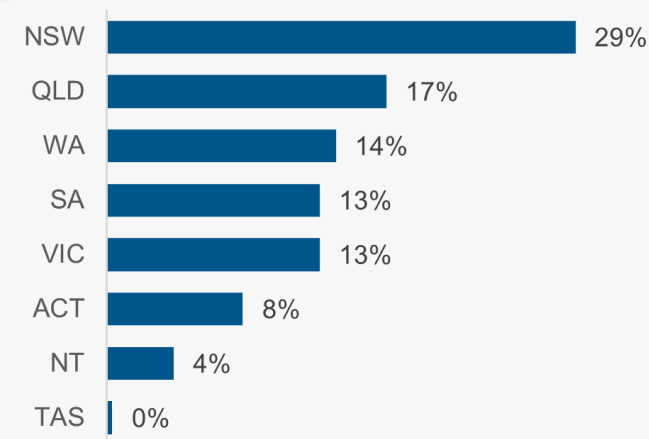
Base sample n=605

Health Care Practitioner Demographic Sample Profile

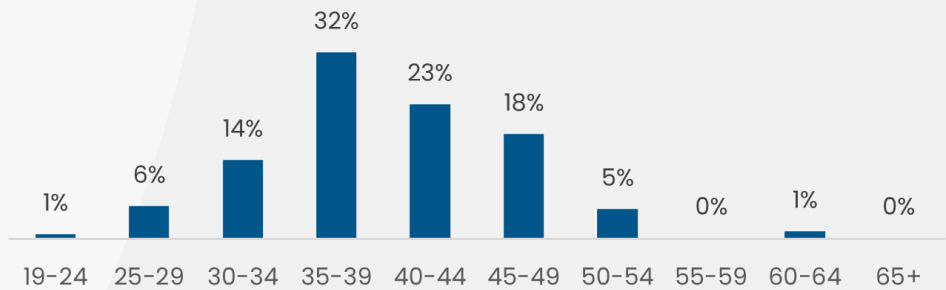
Gender



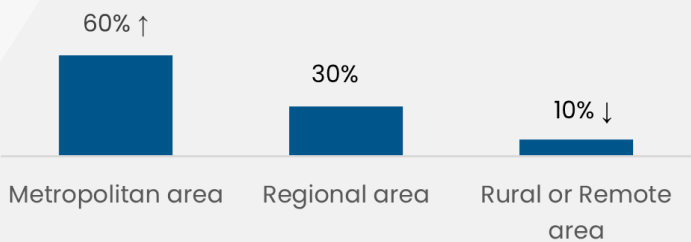
Location (State)



Age



Area live in



Are you...?
In which state or territory do you currently live?
Which of the following best describes the area you currently work in?
Which age group do you fall into?



Australian Government

Department of Health and Aged Care